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Original Paper

Technology-Based Psychological Interventions for Young Adults With Early Psychosis and Cannabis Use Disorder: Qualitative Study of Patient and Clinician Perspectives

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Abstract

Background: The persistence of cannabis use disorder (CUD) in young adults with first-episode psychosis (FEP) is associated with poor clinical and functional outcomes. Face-to-face psychological interventions are effective in treating CUD. However, their use in early intervention services (EISs) for psychosis is inconsistent because of barriers, including high workload and heterogeneity in training of clinicians and lack of motivation for treatment among patients. Tailoring new technology-based psychological interventions (TBPIs) to overcome these barriers is necessary to ensure their optimal acceptability.

Objective: The aim of this study is twofold: to explore psychological intervention practices and intervention targets that are relevant for treating CUD in individuals with early psychosis and to explore factors related to the development and implementation of a technology-assisted psychological intervention.

Methods: A total of 10 patients undergoing treatment for FEP and CUD in EISs participated in a focus group in June 2019. Semistructured individual interviews were conducted with 10 clinicians working in first-episode clinics in the province of Québec, Canada. A hybrid inductive-deductive approach was used to analyze data. For the deductive analysis, we used categories of promoting strategies found in the literature shown to increase adherence to web-based interventions for substance use (ie, tailoring, reminders, delivery strategies, social support, and incentives). For the inductive analysis, we identified new themes through an iterative process of reviewing the data multiple times by two independent reviewers.

Results: Data were synthesized into five categories of factors that emerged from data collection, and a narrative synthesis of commonalities and differences between patient and clinician perspectives was produced. The categories included attitudes and beliefs related to psychological interventions (eg, behavioral stage of change), strategies for psychological interventions (eg, motivational interviewing, cognitive behavioral therapy, psychoeducation, stress management), incentives (eg, contingency management), general interest in TBPIs (eg, facilitators and barriers of TBPIs), and tailoring of TBPIs (eg, application needs and preferences, outcome measures of interest for clinicians).

Conclusions: This study provides a comprehensive portrait of the multifaceted needs and preferences of patients and clinicians related to TBPIs. Our results can inform the development of smartphone- or web-based psychological interventions for CUD in young adults with early psychosis.

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KEYWORDS

psychology; intervention; cannabis misuse; cannabis use disorder; young adult; clinician; psychosis; schizophrenia; dual diagnosis; qualitative; acceptability; technology-based; telemedicine; mHealth; digital health; eHealth; application; smartphone; mobile phone

Introduction

Background

Cannabis is one of the most commonly used substances worldwide, with an estimated annual use of 2.5% in the global population [1]. In Canada, cannabis was legalized for recreational use in 2018, and a population survey in the province of Québec one year after legalization showed that cannabis use in the previous 12 months was highest among individuals aged 18 to 24 years (38%), approximately 50% of whom had moderate or high risk of developing problematic cannabis use, especially among those reporting psychological distress [2]. Mental health is a key modulator of the risk of harms associated with this substance, as illustrated by the high prevalence of cannabis use disorder (CUD) in young adults with first-episode psychosis (FEP; 42%-53%) [3,4]. In this population, persistent cannabis misuse is associated with a longer duration of untreated psychosis [4], increased severity of psychotic and affective symptoms [3,5,6], higher rates of psychotic relapses and hospitalizations [3,7-9], poor psychosocial functioning [3,5,6], lower medication adherence [8,10,11], and lower housing stability [3].

Face-to-face psychological interventions that employ cognitive behavioral therapy (CBT) and motivational enhancement therapy (MET) are effective in decreasing the frequency of cannabis use and severity of dependence in individuals with CUD [12]. A survey of Canadian early intervention services (EISs) for psychosis showed that only 12% offered formal services to address cannabis misuse. This study also highlighted many barriers to adequate implementation of face-to-face psychological interventions for cannabis addiction, including low motivation of patients to change their cannabis use, heterogeneity in staff training and treatment goals (eg, harm reduction [HR] vs lower cannabis consumption), and limited access to treatment because of transportation barriers and restricted clinic hours [13].

Using internet-based psychological interventions can circumvent some of these barriers and pave the way toward more homogenous cannabis misuse–focused programs that can be accessed via EISs. In their systematic review and meta-analysis, which included 2963 participants *without psychosis*, Olmos et al [14] found that internet-based psychological interventions comprising CBT and motivational interviewing (MI) were effective in decreasing the frequency of cannabis consumption. To improve their efficacy in treating CUD, the design of web-based interventions (eg, type of psychotherapeutic techniques used, number of modules, intervention length) must be optimized and solutions to address low engagement of users (eg, high attrition, small number of logins) must be implemented [15-18]. A systematic review of technology-based psychological interventions (TBPIs) to address problematic cannabis use in people *with psychosis* found that none of the included studies used internet-based psychological interventions for these patients and that CBT was not incorporated in any of the TBPIs [19], despite existing evidence at the time the review was conducted that CBT was effective in decreasing the quantity of cannabis used in this population [20]. Nevertheless, the review highlighted that using qualitative methodologies to elicit patient and clinician treatment preferences could help improve the content of psychoeducational videos, engagement in the interventions, and cannabis use–related outcomes [19].

The available body of evidence underlines the importance of promptly addressing cannabis misuse in people with psychosis, the potential of TBPIs (eg, internet-based technologies, text messages) in decreasing cannabis use in this population, and the paucity of studies investigating barriers and facilitators of TBPIs for decreasing cannabis consumption in EISs for psychosis.

Objectives

The objectives of this study are to explore the perspectives of clinicians and patients on (1) psychological intervention practices and intervention targets that are relevant for treating CUD in individuals with early psychosis and (2) factors related to the development and implementation of a TBPI for CUD.

Methods

Study Design

We used a qualitative study design and qualitative description methodology to collect, analyze, synthesize, and interpret data [21,22]. This study was approved by the Research Ethical Committee of the Centre hospitalier de l'Université de Montréal (University of Montreal Health Centre, CHUM; 19.067).

Participants and Study Setting

We explored the perspectives of 2 distinct groups of participants: 10 patients and 10 clinicians. For patients, we used purposeful homogenous sampling [23] and used the following eligibility criteria: (1) age range of 18 to 35 years; (2) diagnosed with psychotic disorders and CUD based on the Diagnostic and Statistical Manual of Mental Disorders-V criteria; (3) willingness to access interventions to stop or reduce cannabis use; (4) receiving treatment at CHUM's EIS for psychosis (the jeune adultes souffrant de psychose [JAP] clinic); (5) able to consent to participate in the study; and (6) fluent in French. Clinicians working in first-episode clinics in Québec were eligible to participate. The JAP clinic, located in downtown Montreal with a catchment area of approximately 230,000 inhabitants, offers a range of biopsychosocial interventions for psychosis, including pharmacotherapy, family interventions, psychoeducation, CBT, and interventions for comorbid substance use disorders (SUDs), both in individual and group

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formats. The clinic follows the provincial guidelines for Québec EIS for psychosis [24]. Currently, TBPIs are not offered as part of EISs for psychosis in Québec.

To recruit clinicians, we used a hybrid purposeful sampling strategy to account for *similarities* (ie, all clinicians were active in clinics in Québec offering EISs for psychosis, including the JAP clinic) and *variations* pertaining to specialty (eg, physicians, nurses, social workers) and location of the clinic (ie, metropolitan or urban), as these factors result in different challenges in offering services [23].

Study Procedure and Data Collection

Clinicians at the JAP clinic identified eligible patients and made the first approach to seek their interest in participating in the study. Then, a research assistant (VL), who was not involved in clinical care, contacted interested patients, explained the study, obtained their written consent, and invited them to the focus group (June 2019). For patients, we used the focus group method that facilitates the collection of rich data by enabling a dynamic exchange of opinions between participants with similar lived experiences. The research project was presented to clinicians working at the JAP clinic, and the research assistant scheduled face-to-face interviews and provided additional information about the study. We collected data from clinicians using individual interviews because of the heterogeneity of these participants in terms of professional background (eg, physicians, social workers), experience, and responsibilities in EISs for psychosis. The clinicians signed a consent form on the day of the interview. Selected clinicians from the Québec Programs Association for First Psychotic Episodes were invited by email, and the research assistant contacted those interested in participating over phone and provided consent electronically.

Patients and clinicians completed an anonymous sociodemographic questionnaire at the beginning of the focus group or interviews. A moderator (NA) with a background in anthropology and extensive experience in qualitative research in the field of mental health and addiction facilitated the focus group using a semistructured interview guide with open-ended questions developed a priori by the authors based on their review of the literature and consultations with experts (Multimedia Appendix 1). To minimize possible bias during data collection, we invited a moderator affiliated with another institution. The moderator was not involved in participant recruitment and did not know the participants. The focus group was held in French and audio recorded. Participants’ opinions were summarized by the research assistant, presented back to participants by the moderator, and validated by the participants at the end of the focus group. We assessed participants’ involvement in the focus group discussions and concluded that we had sufficient data to answer our research question.

From July to September 2019, semistructured individual interviews were conducted with clinicians by the focus group moderator and were audio recorded. Interviews were conducted in person with clinicians at the JAP clinic and via Skype videoconferencing with clinicians in other locations. The recruitment of clinicians was discontinued once the amount of new information collected during the interviews decreased significantly, indicating data saturation. An interview guide was developed a priori by the authors (Multimedia Appendix 2).

Data were collected in French, audio recorded, and transcribed by a specialized transcription firm, and quotations from transcripts used to substantiate results were translated into English by a professional translator. The transcripts were reviewed for accuracy by the research team before data analysis. Patients were compensated Can $50 (US $38) in the form of supermarket gift cards and clinicians were compensated Can $100 (US $76) for their time and participation in the study.

Data Analysis

We used a hybrid deductive-inductive approach to analyze data [25,26]. For the deductive analysis, we developed an analytic framework that combines the main topics of the interview guides with the categories of promoting strategies (ie, tailoring, reminders, delivery strategies, social support, and incentives), which were identified by Milward et al [27] in their systematic review as the most important strategies for increasing participation in web-based interventions for substance use. For the inductive analysis, we generated new themes and subthemes through an iterative process that involved multiple reviews of qualitative data. We used a sequential approach for data analysis: in phase 1, we organized the patient focus group data into themes and subthemes. In phase 2, the results of the first phase were used to inform the deductive analysis of the semistructured individual interviews with clinicians and new themes were created inductively. In phase 3, we integrated the results of the first 2 phases into a common thematic structure and synthesized and interpreted data by comparing the opinions of patients and clinicians. Trustworthiness, rigor, and verification of the data were established through intercoder agreement. Researchers with different backgrounds (family medicine [OT], psychiatry [CT], and nursing [VM]) and a patient partner (CA) independently coded the raw data, and discrepancies were resolved through discussions between coders. OT was involved in coding all the data with additional contributions from CT, VM, and CA. The results of each phase were validated by senior researchers (DJ, AA, and NK). The use of NVivo software (V.11; QSR International) facilitated data management and analysis. Relevant patient (P) and clinician (C) quotes are provided.

Results

Overview

A total of 11 patients and 10 clinicians were invited to participate in the study; all, except one patient, agreed to participate and signed the consent form. The duration of the focus group was 75 minutes, and the mean duration of the individual interviews was 37.2 (SD 6.8) minutes (range 25-51 min). The participants’ characteristics are presented in Tables 1 and 2. Thematic analysis yielded five main themes (Figure 1).

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Table 1. Sociodemographic characteristics of patients (n=10).

Category	Value, n (%)
Age group (years)	
20-29	8 (80)
30-39	2 (20)
Born in Canada	
Yes	8 (80)
No	2 (20)
Years lived in Canada	
Less than 10	0 (0)
More than 10	10 (100)
Biological sex	
Male	7 (70)
Female	3 (30)
Gender	
Man	6 (60)
Woman	2 (20)
Transgender man	2 (20)
Race or ethnicity	
White	7 (70)
Asian	1 (10)
Metis	1 (10)
Black	1 (10)
Marital status	
Single	9 (90)
Stable relationship	1 (10)
Educational attainment	
Primary school	1 (10)
Secondary school—not graduated	3 (30)
Secondary school diploma	4 (40)
Professional school	1 (10)
University undergraduate	1 (10)
Employment status	
Full time	2 (20)
Part time	1 (10)
Student	3 (30)
Sick leave or invalidity	2 (20)
Other	2 (20)
Income per year, Can $ (US $)	
<10,000 (<7692)	2 (20)
10,000-20,000 (7692-15385)	4 (40)
Do not know	3 (30)
Prefer not to answer	1 (10)

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Table 2. Sociodemographic and professional characteristics of clinicians (n=10).

Category	Value, n (%)
Clinic location	
Metropolitan	6 (60)
Urban	4 (40)
Age group (years)	
20-29	1 (10)
30-39	4 (40)
40-49	5 (50)
Gender	
Man	2 (20)
Woman	8 (80)
Professional occupation	
Nurse	2 (20)
Case manager (sexologist)	1 (10)
Case manager (occupational therapist)	3 (30)
Case manager (social worker)	1 (10)
Psychiatrist	3 (30)
Clinical experience (years)	
4-5	2 (20)
6-10	4 (40)
11-20	3 (30)
>20	1 (10)
Clinical experience in treating psychosis and CUD[a] (years)	
<5	2 (20)
6-10	5 (50)
11-20	3 (30)
New patients with psychosis and CUD per month	
1 to 5	9 (90)
6 to 10	1 (10)
Total patients with psychosis and CUD per month	
1-5	1 (10)
6-10	2 (20)
11-20	6 (60)
21-30	1 (10)

[a] CUD: cannabis use disorder.

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Figure 1. Integration of patient and clinician perspectives related to technology-based psychological interventions. TBPIs: technology-based psychological interventions.

Attitudes and Beliefs Related to Psychological Interventions

Challenges and Facilitators of Psychological Interventions

Cognitive Functioning

Clinicians considered cognitive impairment as an important determinant of the efficacy of psychological interventions. In patients' opinion, new skills acquired during psychological interventions facilitate long-lasting effects of the intervention on cannabis consumption. Meanwhile, clinicians were concerned about patients' ability to use new acquired skills:

> *Patients often don't take in the information and then they can't correctly identify the factors of relapse, you know, and among other things because of the damn cognitive issues....* [C7]

Although patients felt that psychological interventions provided a simulation instead of an accurate reflection of real life:

> *Why do I think psychotherapy doesn't really work the way it should? Because it doesn't reproduce the right environment like...what the person is naturally confronted with, like in their daily life. Like, it tries to create a simulation.* [P7]

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clinicians surmised that these impressions may be attributed to patients' limited ability to process information. Clinicians acknowledged that poor and fluctuating cognitive functioning represented an important barrier to psychological interventions by limiting patients' capacity to engage in introspection, understand information, plan activities, and attend scheduled therapy sessions. In addition, reduced verbal communication abilities in patients represented a challenge for psychological interventions:

> *Me, I think that the patients have a hard time expressing their emotions. They struggle with putting their thoughts into words. They still have problems associated with schizophrenia...with mental health.* [C3]

As a result, to achieve optimal effects, the length and intensity of treatment often needed to be increased, which added a significant financial burden associated with treatment.

Patient Engagement in Psychological Interventions

Achieving optimal control of psychotic symptoms with antipsychotics was considered by clinicians an essential part of treatment. They stated that prompt psychotherapeutic interventions were needed if patients' desire to consume cannabis increased as their psychotic symptoms became less intense. Clinicians believed that peer pressure to use cannabis—combined with patients' diminished self-awareness related to the effects of cannabis on their mental health—represented a significant challenge for psychological interventions, especially in the more permissive social context related to cannabis use postlegalization in Canada:

> *Ever since pot was legalized, I've noticed a phenomenon for different individuals. It's that the patients tend to play down how cannabis use can impact their lives.* [C3]

Certain drug use patterns were a barrier to psychological interventions because arriving intoxicated at clinical visits impeded patient-clinician communication, whereas concurrent drug use (eg, using cannabis to antagonize the effects of *speed*) required a reassessment of psychological intervention targets. Patients viewed engagement in the treatment as an important determinant of achieving optimal results:

> *...you know, you can also cheat in psychotherapy. You can... I mean there's... if you're really determined, you can do it.* [P1]

Patients' precarious socioeconomic situations (eg, homelessness) had a negative impact on their engagement in psychological interventions:

> *Well, it also depends on Maslow's pyramid...what I mean is that they're homeless... um...they don't have any income, what I mean is that, even though you will work on your use...they may not be there yet, you know?* [C2]

Clinicians were confident that psychological interventions could interrupt the vicious cycle where cannabis misuse contributed to unemployment, low educational attainment, low income, and poor social interactions, all of which could in turn contribute to increased cannabis consumption.

Clinicians' Skills and Experience With Psychological Interventions

Depending on clinicians' training background, skills, and experience, the type and intensity of face-to-face psychological interventions varied. In clinicians who attended only short-term (1 to 2 days) formal training in psychological interventions, engagement and competency in using psychotherapeutic interventions (eg, CBT, motivational interviewing [MI]) was facilitated by working with highly skilled clinicians in EISs for psychosis. An understanding of and a compassionate attitude toward cannabis consumption habits facilitated a strong therapeutic bond that was viewed as essential in improving cannabis use outcomes. Psychological interventions for CUD were viewed as a component of the comprehensive treatment approach needed by young adults with FEP:

> *We try to talk about cannabis as well, but we are not there to treat cannabis based on our plans. I think that it's an integrated approach.* [C3]

Clinicians used CBT, MI, HR, or psychoeducation as single therapies or in combination and as individual or group therapy, for example, life balance group therapy.

Patients received varying intensity of psychological interventions for CUD, depending on the treatment priorities of the clinician and clinic:

> *But I don't do it systematically - because I don't think about it in a systematic way - and not every time either. But I think that I might do it more than I think...but without even realizing it.* [C2]
>
> *We are, of course, in a clinic, where the priority, at first, is still to make sure that we are treating acute psychotic symptoms.* [C10]

Clinicians who had experience with treatment protocols for SUDs acknowledged the value of these protocols in providing guidance and facilitating discussions with patients about cannabis consumption. Some barriers to implementing treatment protocols included low patient adherence to treatment and insufficient tailoring of the protocol to individual needs. Good communication within and between intervention teams related to treatment goals was considered of key importance for improving cannabis-related outcomes:

> *Well, there's a team (community-based) that does what they want. And then someone else will say, "well, you can use but be careful of this and that." It makes it so that the teenager never talks about their use issues with their psychiatric team because they're afraid.* [C3]

Clinicians frequently lacked the time to deliver well-structured psychotherapeutic interventions. In addition, staff turnover interrupted the continuity of interventions. In clinicians' opinion, an interdisciplinary approach that included specialists in addiction psychiatry and psychologists could overcome some of these barriers.

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Behavioral Stage of Change

Patients stated that adequate motivation to change cannabis consumption was a prerequisite for optimal engagement in interventions and achieving cannabis abstinence:

> *...it could never, even with traditional psychotherapy, it could never do the whole job, and it's up to you... it's always like 80/20. You have to put in the majority of the effort and that's it.* [P1]
>
> *Because for me, they always asked me to stop, stop, stop. But it wasn't coming from me. So, I don't stop.* [P3]

To identify patients' personal treatment goals, it was important to proactively assess their behavioral stage of change that reflected their motivation to decrease cannabis use:

> *It's rarely them that will come and ask for help saying, "hey, I'm here because I have a problem so big that I have to make drastic changes to my life."* [C3]

For example, both clinicians and patients explained cannabis abstinence relapse when coercive measures (eg, court order) were implemented by patients' lack of motivation to change their cannabis use.

Interestingly, clinicians' and patients' experience with motivational group therapy shows that patients who are in precontemplation (ie, do not want to change their cannabis consumption) could benefit from low-intensity motivational interventions to help them progress toward more advanced stages of change:

> *Whereas otherwise, one week, two weeks can go by, and I won't think about it at all. And then, having to go every week, it's like... I have more and more now when I smoke outside, I think about it.* [P6]

Clinicians considered patients who progressed to more advanced stages of behavioral change, including contemplation (ie, ambivalent), preparation, or action stages, as good candidates for higher intensity MI and/or CBT (ie, more frequent and regular sessions). Notably, clinicians agreed that the greatest barrier to psychological interventions was patient unwillingness to decrease cannabis use.

Strategies for Psychological Interventions

Cognitive Behavioral Therapy

CBT was considered an appropriate psychotherapeutic approach for patients with a relatively high functional status (ie, with a full-time job and stable housing) and for those who developed some degree of motivation for changing their cannabis use:

> *Yes, it's because they are in precontemplation and when you come up with a CBT approach... it makes um... they look at you... and it's as if they don't hear you.* [C9]

By modifying cognitions (ie, thoughts), clinicians stated that CBT could enable patients to make better decisions about cannabis consumption and to improve their social interactions:

> *What they enjoy most in life is chilling out. They don't have any other interests, and my job is to help encourage them to try other things.* [C9]

This view was echoed by patients who expected psychological interventions to teach them techniques useful for replacing the rewarding effects of cannabis with other activities and for facilitating positive thinking:

> *I think that we're just looking for the effect of the substance. That effect would have to be reproduced by something less dangerous or something like that. Because I think if... we're always looking for the effect. It's the effect of the drug that a user looks for and that's why they use.* [P5]
>
> *If you are addicted to it, then, of course, you see the negative in everything all the time, so, of course, you want to smoke all the time, and then you will relapse, you know?* [P10]

Useful behavioral distraction strategies included encouraging patients to discover interests and passions, engaging in activities (eg, talking to friends, watching movies, playing games, or listening to music), and congratulating them on being persistent in their choice. Patients were aware of the importance of engaging in occupations that divert their attention away from consuming cannabis to achieve personal cannabis use goals and better manage cravings:

> *There's like playing sports um... like when you want to use, well you watch a TV show or a movie instead. You occupy yourself... you fill your head with other things.* [P8]

MI and HR

Clinicians used MI to encourage patients to examine their thoughts and feelings and increase their awareness of problems triggered by cannabis abuse, for example, anxiety. They considered MI effective in lowering patients' mental health stigma and increasing their acceptance of and adherence to specialized treatments. Patients stated that psychological interventions helped them conceptualize the effects of cannabis on their mental and functional status, identify personal reasons for reducing cannabis use, and understand their consumption habits:

> *The more I use, the less creative and focused I become. And I did it a lot when I was making music. So then, I was just like... it's one more reason to stop.* [P3]
>
> *For me, like you said, playing sports um... because for me it's... Me too, when I actually quit smoking, because it's like cyclic. It seems like sometimes I smoke and sometimes I just can't help myself from smoking.* [P9]

Although clinicians perceived MI to be less effective in addressing CUD in patients unwilling to change their cannabis use (ie, lack of motivation), they continued with low-intensity MI until the patient became more receptive to change. Typical MI questions were centered around the influence of cannabis

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on patients' functional status and increasing their perception of self-efficacy corresponding to their short-term achievements:

> *...how does it impact your studies, your social relationships, in what way? Do you notice a difference in how you feel when you're using versus when you're not using? Are you satisfied with that?* [C2]
>
> *What are your achievements? What were you proud of this week? What did you accomplish?* [C2]

In patients who achieved abstinence, clinicians avoided questions related to cannabis use and focused instead on long-term objectives (eg, employment or school).

For patients who did not want to decrease their cannabis consumption, some clinicians considered that the right approach is to start with HR interventions (eg, buying cannabis with low tetrahydrocannabinol [THC] content or purchasing from legal sources). HR interventions can help severely functionally impaired patients control their cannabis use, which is essential for securing basic life necessities (eg, housing) and avoiding coercive measures (court orders) that were considered less effective and last-resort measures. Encouraging patients to smoke later in the day and after school or work could increase their satisfaction with life, self-confidence, and self-efficacy related to controlling cannabis use:

> *And they redefine themselves differently than just as a user, it makes them say, "I'm also a worker, that's what I do in life."* [C2]

The HR approach was acceptable for patients because of its emphasis on controlling cannabis use rather than achieving abstinence:

> *Well, I think that in life you always have to find a balance. It can't be all black. It can't be all white. There's always a little bit of one in the other, kind of like yin and yang.* [P2]

Psychoeducation

Easy access to information related to available cannabis products was valued by patients:

> *... I was really looking forward to pot being legalized so that I'd have more information. Since it was legalized, I've started smoking pot that's a lot lower in THC. And I have less... I don't have as many psychotic symptoms as before.* [P9]

Clinicians stated that psychoeducation (eg, information about the effects of THC and cannabidiol [CBD]) could act synergistically with HR toward achieving cannabis consumption goals. They reported that providing information about the effects of cannabis on mental and physical health facilitated patient reflections about cannabis-related lived experiences and helped develop their motivation for treatment. Emphasizing the clinical benefits of cannabis abstinence was considered important as it prepared patients to better deal with more permissive social norms related to cannabis use postlegalization:

> *And also considering that it's legal now, there's a trivialization—even before and after cannabis was legalized—that's very present socially in Quebec. It means that we have to talk about the effects of the substance.* [C7]

Clinicians stated that psychoeducation delivered in both individual and group therapy could have complementary effects and that information should cover a broad range of health-related aspects associated with cannabis use without assuming that patients have basic knowledge.

Stress Management

Patients expected psychological interventions to help them gain control of their cannabis use by acquiring skills (eg, mindfulness meditation) to deal with general life stressors and cannabis use–related stress (eg, cravings):

> *That would be one of my goals, in psychotherapy, to deal with the stress I would normally take away with ... by smoking a joint.* [P3]

Clinicians believed that integrating stress management approaches in the long-term treatment plan could help patients reduce the amount of cannabis used and maintain therapeutic gains:

> *...once there is a reduction, I make sure that it is always anchored in factors of stress and how to manage them - before starting the next step - you know, we take it step by step.* [C6]

Addressing Concomitant Substance Use

Clinicians stated that in their experience, the most prevalent substances used by young adults with psychosis are cannabis and tobacco, followed by alcohol and amphetamines. Clinicians addressed multidrug use differently: some preferred a global approach to addiction (ie, not drug specific), whereas others used drug-specific psychological interventions and prioritized the most problematic substance for the patient:

> *Of course, we always ask the person: what's your biggest issue? Because often trying to work on everything... it scares them. If we say "well, you know what, we will work on your addiction in general." They're going to say, "well, hang on then"... you know? So that's it, you have to work with them.* [C8]

There was ambivalence among clinicians regarding interventions simultaneously targeting cannabis and tobacco abuse. Motivated by the fragile mental status of some patients, clinicians generally recommended a sequential approach that starts with addressing cannabis misuse; in their opinion, patients could be overwhelmed by simultaneously reflecting about 2 substances and handling distinct objectives related to substance misuse. Despite acknowledging the negative long-term health consequences of tobacco smoking, clinicians did not view tobacco use disorder as a treatment priority because patients often request support for quitting smoking after achieving treatment milestones related to cannabis use and significantly improve functionally.

Addressing Psychosocial Determinants and Global Functioning

Clinicians described the unfavorable psychosocial context of many young adults with FEP: disruption of normal life

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trajectories, difficulties in social interactions, unmet basic life needs, and inability to pursue personal goals. Consequently, clinicians adopted a holistic treatment approach and simultaneously addressed CUD and patients' poor functional status:

> *But... because I, I...I just can't separate quitting from what he does in life.* [C2]

They felt that a multidisciplinary intervention strategy could help patients slowly regain control of their lives and increase their adherence and confidence in long-term CUD treatment.

Incentives

Promoting Engagement With Peers and Sense of Achievement

With regard to internet-based psychological interventions, patients suggested that an incentive algorithm contingent on participation in the intervention (eg, completing modules, participating in group discussions) could act as a catalyst for patient engagement in treatment. A reward system could help patients get recognition from their peers and satisfy their personal need for achievement:

> *...because there are people like me, the "completionist". As soon as "achievements" come into play, I have no choice but to reach them.* [P1]

Contingency Management

Clinicians valued contingency management (CM), as it facilitated patient reflections about cannabis use habits and allowed them to eventually develop motivation to engage in behavioral change. Some clinicians offered rewards contingent on participating in treatment sessions (eg, group therapies) to patients who initially lacked motivation to change their cannabis use. These clinicians reported that some of these patients changed from precontemplation to contemplation:

> *In our balance group, well we still do it, you know, they're in precontemplation and don't have a desire to change, and the worst thing is that they come just to eat pizza... but they're there for an hour and we talk about use. It makes it so... in the end, they don't only come for that.* [C9]

In contrast, for patients who were motivated but had not yet stopped using cannabis, clinicians advocated against using CM:

> *And then there are some patients that don't need it. For the type of people that are already self-motivated. I find that giving them money to come and reflect, it puts them into the position of a patient that needs the clinic to function, you know?* [C3]

In cannabis-abstinent patients, providing grocery coupons contingent on cannabis-free urine samples was considered effective in maintaining abstinence. A major barrier toward including CM in standard services offered in EISs for psychosis is the absence of funding dedicated to such *intervention*; in this context, offering financial incentives from patients' own budget (applies to a subgroup of vulnerable patients that benefit from budget management at the clinic) contingent on cannabis abstinence was considered a viable alternative to achieve long-lasting treatment benefits because it actively stimulates them to change their cannabis use behavior:

> *But I think what's important is that the person is able to satisfy themselves, on their own, so that they can develop that confidence: "OK, I will allow myself to go to the movies" for example, or "go out with friends", you know, it's finding the right way to reward themselves.* [C2]

Notwithstanding its putative efficacy in increasing patient adherence to scheduled psychological intervention visits or maintaining abstinence, clinicians advised against using CM over long periods to enable patients to develop independence in managing their cannabis consumption before they graduate from the 3-year intensive follow-up program offered in EISs for psychosis.

General Interest in TBPIs

Facilitators of and Barriers to TBPIs

Clinicians mentioned that TBPIs could be considered by patients as less formal than face-to-face interventions, facilitate shared decision making around the therapeutic plan, decrease the probability of confrontational situations triggered by patients' reluctance to disclose their cannabis use patterns, and offer patients more time to reflect on their cannabis use. Clinicians believed that TBPIs would enable patients' rapid access to support when in urgent need, for example, when craving cannabis. Although using TBPIs could circumvent some patient-clinician communication barriers (eg, commuting time for appointments), clinicians were concerned that in patients with pronounced avoidant behavior, the use of TBPIs could exacerbate their isolation and social anxiety. Clinicians feared that in some patients, TBPIs could weaken the clinician-patient therapeutic bond that was an important determinant of adherence to treatment:

> *So, I would explain to them that the possibility exists, but again, it doesn't take away the meetings, the importance of the meetings and that we will continue to put in the work. But that we could use this tool that could help make things easier to access. I would present it to them kind of like that.* [C10]

Moreover, both clinicians and patients mentioned that TBPIs could more easily lead to *cheating on the treatment plan* when patient engagement was low; therefore, maintaining human contact was viewed as important to ensure treatment success:

> *Yes, face-to-face human contact may not be a priority - but there has to be some form of human contact and that someone, somewhere, sees progress.* [C6]

Patients mentioned that their engagement in using TBPIs could be influenced by the level of social support for treatment (eg, family, friends) and subjective norms (ie, opinion of peers that could regard TBPIs as less reliable than face-to-face interventions):

> *Well, I think they'd take me less seriously than if it was real therapy.* [P8]

In the context of psychosis, patients' poor cognitive abilities could impede their ability to use TBPIs and delusions (eg, being

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spied on via the internet) could decrease their willingness to use TBPIs. Clinicians believed that TBPIs could increase access to psychological interventions in remote areas and in individuals with subthreshold psychosis who misused cannabis and who were not treated in specialized mental health services. Patients described TBPIs as a comfortable and accessible alternative to face-to-face psychological interventions but expressed concerns about costs associated with using their personal data plan.

The acceptability of TBPIs for clinicians was dependent on their readiness to integrate internet-based applications in the traditional model of clinical work, their general skills in using technology, and their training in using new applications. Some clinicians who were familiar with telepsychiatry (eg, for patients with anxiety or depression) saw the value of TBPIs in providing visual interactions with patients and considered them an option for group therapies. Clinicians highlighted that developing an application to address cannabis misuse in young adults with psychosis is timely in the context of uncertainties related to the long-term impact of legalization of cannabis consumption. They mentioned that such an application could increase the intensity of psychological interventions, decrease clinician workload, and help less formally trained clinicians deliver psychological interventions for cannabis misuse in a consistent way. To achieve these goals, clinicians suggested that the application should be tailored to patient treatment goals and be offered to all patients. In addition, clinicians requested adequate training on how to use the application and suggested the presence of a clinician promoter of the application on site. To facilitate its implementation into practice, they would use an informal, nondirective approach in promoting the application, especially in patients that are unmotivated to change their cannabis consumption:

> *But we can say, listen, there's this new thing that we can try together if that's okay with you? You will see, you know, if you like it or not, it's really your choice. This is just one more thing that we're offering you. You don't force it on them and explain it more clearly by saying, "I think that it could help."* [C2]

Other suggestions to facilitate a successful implementation provided by clinicians included walking the patient through the functionalities of the application, providing assistance as needed, and using a demo version to advertise the application in the waiting room.

Technology-Related Attitudes and Beliefs

Clinicians acknowledged the widespread use of technology (eg, smartphones and apps) among young adults for whom it is an integral part of their social life:

> *And our patients will be less and less... I think teenagers are becoming less and less able to express themselves verbally. And more and more able to do everything using technology - both their social skills and their connections to each other or to others and all that.* [C3]

Clinicians highlighted that the poor socioeconomic status of some patients explained their lack of familiarity with newest technologies, use of outdated devices, and reliance on free wireless networks for internet access and on free text messaging services to communicate with peers. In their opinion, inconsistent access to technology was sometimes a consequence of pawning their devices to buy substances. Nevertheless, clinicians considered it important to capitalize on the high rate of technology use among young adults and implement TBPIs for young people with psychosis who abuse cannabis. For some patients, barriers to using TBPIs included inadequate protection of confidentiality and personal data over the internet, potential health harms of technology (eg, cell phone radiation), and preference for in-person interactions:

> *I'll tell you what, secure technology is impossible.* [P10]
>
> *I'm becoming a bit scared of new technology... I stay away from using it. And I like to sleep far away from my phone.* [P3]
>
> *Um ... it would be if you weren't talking to a robot. I think that's the most important thing. It's that you have human contact ... that there's like human interaction.* [P8]

Clinicians also questioned the confidentiality of personal data when using internet-based applications and platforms and ethical implications of using TBPIs in acutely distressed patients.

Tailoring of TBPIs

Outcome Measures of Interest for Clinicians

Frequently, outcomes of interventions for SUDs were defined and prioritized jointly by clinicians and patients and were reassessed on a regular basis. Apart from outcome measures directly related to cannabis use (ie, frequency of use, quantity, abstinence, and relapse), clinicians were interested in patients' motivation (ie, stage of change), their confidence in achieving and maintaining cannabis reduction goals, and their perception of their own ability to resist the temptation to use. In addition to cannabis, clinicians monitored the type, number, and frequency of use of other substances, for example, alcohol, amphetamines, and tobacco. They regularly assessed patients' compliance with the recommended daily occupational schedule (eg, eating, working, studying, or sleeping), with the goal of assisting them in achieving personal long-term life objectives, for example, graduating from school or finding a permanent job. Clinicians were also interested in assessing patients' mental health status, quality of life, and quality of relationships with family and friends. Clinicians preferred that TBPIs collect data about how often it helps patients resist the urge to consume cannabis and the locations or contexts in which the application is accessed (eg, at home or while being bored or stressed) to better understand the triggers of cannabis use. Finally, they were interested in patient satisfaction with the application, frequency of application use, and patient rating of the helpfulness of the application in increasing their reflection on cannabis use and achieving consumption goals.

Strategies for Delivering TBPIs

Communication and Support

Patients and clinicians agreed that TBPIs must align with the multifaceted support needs of young adults with psychosis and

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CUD. Often individuals with early psychosis experience a state of social isolation, and their main pillar of support is their therapist. Patients and clinicians emphasized the need to facilitate interactions with family, friends who do not consume cannabis, other patients with psychosis and CUD (eg, group therapies), and community services for people with mental health problems. For patients with poor family support, working in synchrony with intervention workers from community organizations, including partners from supervised housing facilities, shelters, and residential treatment facilities, was considered critical:

> *PortageTSTM [a drug addiction rehabilitation center], they really do wonders. They're more into creating therapeutic communities where everyone helps each other, and you can build yourself up as a new person in a community that accepts you - unlike communities on the street that aren't as healthy - to heal you.* [C7]

Both patients and clinicians suggested that TBPIs could broaden patients' support systems by providing information about available community resources and integrating static communication channels (eg, text based, where a significant time lag exists between exchange of ideas) and live communication channels (eg, text, audio, or audio video) that enable real-time exchange of information. Clinicians and patients favored a balanced human-technology psychotherapeutic approach and highlighted that TBPIs should not be limited to static content (eg, therapy modules) or robot-like interactions (eg, automated answers) but also include live interactions to enable immediate support from health professionals and patients' social circles.

Format and Structure of the TBPIs

With regard to the format of TBPIs, patients suggested that static information could be offered in text, audio (for situations when reading is not convenient), or video format (eg, motivational videos). They suggested a regular update of information to maintain a high level of interest in the intervention. Patients would appreciate an interactive application that allows discussions with their clinician and personalization of the content (eg, based on individual answers to questions during the intervention). Divergent opinions were expressed by young adults with regard to accessing TBPI modules, as some were against the idea of having free access to all modules from the beginning and others deferred to individual preference and suggested having the option of selecting the frequency at which the modules would be unlocked. In terms of the TBPI structure, patients preferred to have the option of both individual and group interactions. Some preferred to participate in a TBPI about 2 times per week for approximately 10 minutes per session. Reminders in the form of weekly notifications were considered useful to maintain active participation in the intervention; however, too frequent notifications were considered intrusive by patients.

Clinicians highlighted the importance of tailoring the format, content, and structure of the TBPI to patients' motivation to change cannabis use, to their cognitive difficulties, and to the presence of psychotic symptoms. They recommended MI, CBT, and psychoeducation modules to be delivered in a simple and friendly language combined with graphics or images to facilitate patients' reflection of cannabis use. An example of easy-to-understand content included testimonials of young people about the lived experiences of psychosis and CUD. To maintain an adequate intensity of the intervention, completion of at least one module per week (not exceeding 30 min) was recommended. Some clinicians were concerned that a TBPI would not be effective in decreasing cannabis use for patients in the precontemplation stage, independent of the intensity of the intervention. For patients who are ambivalent, clinicians estimated that TBPIs lasting 2 to 4 months would facilitate a clinically significant reduction in cannabis use; if a patient's objective is abstinence, a longer duration (3-6 months) was recommended. Clinicians emphasized that, at the end of TBPIs, patients should be offered booster modules every 2 to 3 weeks (to follow up on patients' objectives) for a minimum duration of 3 months to maintain cannabis use therapeutic gains. Throughout the TBPI period, clinicians recommended the use of reminders to stimulate patient reflections about cannabis use and ensure adequate participation in the intervention and optimal adherence to standard of care treatments. In their opinion, patients with control of psychotic symptoms (eg, paranoia) would benefit most from TBPIs. Some clinicians hesitated to provide recommendations for the length of TBPIs and follow-up because of variability in the efficacy of psychological interventions among patients.

Application Needs and Preferences

Clinicians agreed with patients that the application hosting the psychological intervention should offer a dedicated space for accessing information about the different types of cannabis (eg, Sativa or Indica), effects of consumption (eg, addiction potential or impact on psychosis), or effects of THC and CBD:

> *...you know like the type of users, because you know, sometimes the people that use Indica are not going to be the same type of people that are going to use Sativa.* [P4]

Providing up-to-date information could correct misconceptions and facilitate patients' reflections about cannabis use. Recording the quantity of cannabis used was of interest to patients, as it could help them monitor associated costs; however, some had reservations about providing this information daily or disclosing it to clinicians. On the other hand, clinicians considered the data recorded by the application to be more reliable than patients' estimates of cannabis use provided during face-to-face visits. Patients preferred the application to be multifunctional beyond simply hosting the psychological intervention modules:

> *You know that apps can do a lot now... like Amazon it's not just for buying stuff. There are so many other things you can do.* [P6]

Additional functionalities suggested by patients included monitoring physical exercise and budget, providing up-to-date information about activities available in their area, and suggesting stress relief methods (eg, meditation techniques). Clinicians and patients suggested that the application could be helpful in planning daily activities (eg, eating or sleeping) and

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achieving a balanced lifestyle, including improved control of cannabis use:

> *But it's... maybe it has another use, that it makes you more aware, there's something that you want to do about it. And it goes beyond just stopping smoking and it will improve your quality of life.* [P6]

Technology Needs and Preferences

Aligned with their application needs, patients and clinicians suggested the following technological solutions: internet links to reliable sources of information about cannabis, informational and motivational videos, and add-on applications and widgets (eg, fitness, budget management, logbook for cannabis consumption, network games, daily planner, and scoreboard for reward points accumulated based on progress in the intervention and goals achieved). Patients suggested that customization and personalization features (eg, avatars, questionnaires about personal interests, and hobbies) could increase their interest in using the application. Reminders (eg, to participate in the intervention or to attend scheduled visits) could take the form of alarms or text notifications. The application could have various embedded communication tools, such as simple text messaging, chat, forum, and video sharing. Through the application, patients preferred to have rapid access to contact details of key resources, such as their therapist, mental health and addiction facilities in the community, and public services for nonurgent health issues (ie, Info Santé in Québec). Finally, both categories of participants emphasized that using a design that appeals to young people (eg, colors, images, or interactivity) and ensuring flawless functionality on multiple platforms (eg, iPhone or Android) are necessary to maintain optimal application use and retention in the psychological intervention.

Discussion

Principal Findings

Our findings advance the qualitative literature by exploring and comparing the views of patients with early psychosis and clinicians related to the use of psychological intervention to treat CUD and their needs and preferences for TBPIs in the context of EIS for psychosis. Our results showed that the type and intensity of face-to-face psychological interventions for CUD were variable and depended on clinicians' training background, skills, and experience. Similar to previous studies, we found that structural factors (ie, lack of time and staff turnover) represent barriers to psychological interventions [13,28]. Clinicians viewed TBPIs as a useful addition to their toolbox of interventions and as a way to circumvent some of these barriers and increase the consistency of services offered in FEP clinics.

We found that patients' motivation to change cannabis use was a central psychological intervention target and an important determinant of the type of psychological intervention used. Clinicians often relied on the Transtheoretical Model [29] as a framework to assess patients' motivation and jointly decide on treatment goals, select the type of psychological intervention, and monitor treatment efficacy. Similar to the results of a previous survey of Canadian EIS for psychosis [13], we found that patients' lack of motivation (ie, precontemplation) represented a major barrier to psychological interventions for CUD. Despite clinical evidence showing that brief MI interventions are effective when used in synchrony with HR in individuals with SUD [30], for patients in the precontemplation stage, clinicians preferred HR. In these patients, normal life was disrupted (with serious implications on housing, finances, and social interactions) and improving their functional status was a priority intervention target for clinicians. Clinicians combined HR with psychoeducation (to correct misconceptions and facilitate patients' reflection about cannabis use) and concentrated more on MI, once patients started building self-motivation. As the theoretical underpinning of both approaches is to engage individuals in discussion to activate motivation for achieving long-term cannabis use–related goals, it may at first sight appear surprising that clinicians used mostly HR alone in patients in precontemplation. Possible explanations include inconsistent use of standardized protocols in EISs for psychosis, heterogeneity in staff psychological intervention training, and other treatment priorities, for example, treating acute psychotic symptoms.

The use of CM was restricted to patients in precontemplation (contingent on attending scheduled group therapy) and maintenance (contingent on providing cannabis-free urine specimens) stages. Clinicians emphasized the importance of developing and maintaining intrinsic motivation and patient autonomy in controlling cannabis use to achieve long-lasting cannabis consumption goals. Therefore, using CM only in conjunction with other psychological interventions (eg, MI, CBT, or psychoeducation) was considered potentially beneficial in achieving long-term reductions in cannabis use. This opinion is empirically supported by recently published data from the Contingency Intervention for Reduction of Cannabis in Early Psychosis randomized controlled trial (RCT), which showed that cannabis use and abstinence rates were not statistically different between the CM and computer-based psychoeducation intervention arms at 3- and 18-month follow-ups [28,31]. Our results suggest that offering nonfinancial incentives as part of the TBPIs could be considered a strategy to increase patient engagement in the intervention, are social reinforcement techniques (eg, certificates for achieving treatment milestones), and are generally appreciated by individuals receiving interventions for SUD [32,33].

We highlighted that social isolation among young adults with psychosis could explain their perceived need for regular communication with clinicians, family, friends, peers with similar lived experiences, and community mental health services. In their study, Fortuna et al [34] described social isolation as a hallmark of people with serious mental health illness, with approximately 60% reporting feeling lonely; the authors identified addressing loneliness as the primary unmet need in these individuals. In our study, patients and clinicians opted for a balanced therapeutic approach that used both technology-based and face-to-face communication. Informed by Roger's model of diffusion of innovation adapted for eHealth interventions, Eysenbach [35] highlighted that increased personal contact with clinicians, receiving positive feedback from health care

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professionals, and facilitating peer-to-peer communications could decrease the nonusage attrition rate of TBPIs. Our results align with those of Byrne et al [36], who reviewed qualitative research studies to explore priorities in treatment outcomes for individuals with psychosis and highlighted the need to improve social and functional abilities and satisfaction among these patients. In our study, participants mentioned that smartphones are frequently used to engage in social communications, which aligns with the findings of Schlosser et al [37,38], who used an RCT and a smartphone-based intervention to improve motivation and quality of life in people with recent onset schizophrenia spectrum disorders. In their feasibility study, 75% of participants owned a smartphone and 96% reported using a social media platform [37]. Importantly, Schlosser et al [37,38] used qualitative research methods to elicit participant preferences and tailored the intervention to their most important values: to have a sense of control over their future and deepened relationships with family and friends.

Our synthesis of clinicians' and patients' preferences related to the functionalities and design of a TBPI aligned with the results of other studies using qualitative and quantitative methods. In their systematic review of studies using mobile application-based interventions in individuals aged 13 to 26 years with prodromal and FEP, Camacho et al [39] showed that live communication platforms (eg, chat or forum) were widely used and responded to patients' need for rapid support by enabling the sharing of lived experiences and information. In their survey of young adults with FEP related to their preferences of using technology to deliver specialized psychiatric services conducted in Québec before cannabis legalization, Lal et al [40] found that 91% of young adults with psychosis would like to receive information related to mental health, psychosis, and recovery in general. Results of a population-based survey [2] conducted in Québec postlegalization (2019) showed that approximately 25% of adults aged 18 to 34 years considered regular cannabis consumption to be minimally related to health risks and approximately 75% of the same age group believed that recreational use of cannabis was acceptable. In this context, providing accurate information about the effects of cannabis on mental health could prepare youth with psychosis to better cope with permissive social norms. Consistent with our results, Bucci et al [41] and Schlosser et al [37] highlighted the importance of using a casual, friendly, and nonstigmatizing approach and using an appealing design that could resemble a social media application rather than a clinical tool. The authors highlighted the importance of personalizing the application with individual therapy goals and features of interest (eg, communicating and sharing photos with peers), minimizing repetition of content, and adapting the frequency of reminders (ie, notifications) to their preferences [37,41]. Taken together, these measures could facilitate the assimilation of TBPI into patients' daily routines and increase their participation in the intervention.

This study had several limitations. First, although we used a purposeful sampling approach to maximize the representation of the diversity of young patients with FEP, we recruited only patients treated at the JAP clinic located in the large metropolitan Montréal area and their opinions could be different from the opinions of patients followed up at clinics located in semiurban or rural areas in Québec or other jurisdictions. Second, because of the predominance of male patients in EISs for psychosis, we recruited more males and the voice of females was underrepresented. Third, we did not capture the perspectives of other persons that play a crucial role in the care of individuals with early psychosis and CUD, such as family members and community mental health workers. Finally, from a reflexive standpoint, we acknowledge the probable influence of our global research aims on data collection and analysis, specifically our goal of developing innovative interventions for the treatment of CUD in young adults with psychosis.

Conclusions

As it stands, research on smartphone-based psychological interventions for young adults with psychosis is limited but increasing [39]. Research into the effects of internet-based interventions on decreasing cannabis consumption in young adults with psychosis is in its incipient stage [19] but is gaining momentum [42,43], with increasing demand for eHealth interventions and the number of jurisdictions that are legalizing the recreational use of cannabis. This qualitative study fills an important research gap related to patients' and clinicians' perceptions of psychological interventions and the use of technology to include these interventions in the clinical toolbox for patients with CUD and FEP. We synthesized and compared patient and clinician views and experiences and provided categories of factors that could guide the development of internet-based psychological interventions tailored to their preferences. Future research using quantitative methods to evaluate patient preference with regard to TBPI for CUD in youth with psychosis is needed to validate our findings.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Focus group topic guide.
[DOCX File , 27 KB - formative_v5i4e26562_app1.docx]

Multimedia Appendix 2
Interview guide for clinicians.
[DOCX File , 23 KB - formative_v5i4e26562_app2.docx]

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Abbreviations

CBD: cannabidiol
CBT: cognitive behavioral therapy
CHUM: Centre hospitalier de l'Université de Montréal (University of Montreal Health Centre)
CIHR: Canadian Institutes of Health Research
CM: contingency management
CUD: cannabis use disorder
EIS: early intervention service
FEP: first-episode psychosis
HR: harm reduction
JAP: jeune adultes souffrant de psychose (young adults with psychosis)
MET: motivational enhancement therapy
MI: motivational interviewing
RCT: randomized controlled trial
SUD: substance use disorder
TBPI: technology-based psychological intervention
THC: tetrahydrocannabinol

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Original Paper

Perceived Impacts, Acceptability, and Recommendations for Ecological Momentary Assessment Among Youth Experiencing Homelessness: Qualitative Study

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Abstract

Background: The use of ecological momentary assessment (EMA) to study youth experiencing homelessness (YEH) behaviors is an emerging area of research. Despite high rates of participation and potential clinical utility, few studies have investigated the acceptability and recommendations for EMA from the YEH perspective.

Objective: This study aimed to describe the perceived benefits, usability, acceptability, and barriers to the use of EMA from the homeless youth perspective.

Methods: YEH were recruited from a larger EMA study. Semistructured exit interviews were performed using an interview guide that focused on the YEH experience with the EMA app, and included perceived barriers and recommendations for future studies. Data analyses used an inductive approach with thematic analysis to identify major themes and subthemes.

Results: A total of 18 YEH aged 19-24 years participated in individual and group exit interviews. The EMA was highly acceptable to YEH and they found the app and EMA surveys easy to navigate. Perceived benefits included increased behavioral and emotional awareness with some YEH reporting a decrease in their high-risk behaviors as a result of participation. Another significant perceived benefit was the ability to use the phones for social support and make connections to family, friends, and potential employers. Barriers were primarily survey and technology related. Survey-related barriers included the redundancy of questions, the lack of customizable responses, and the timing of survey prompts. Technology-related barriers included the “freezing” of the app, battery charge, and connectivity issues. Recommendations for future studies included the need to provide real-time mental health support for symptomatic youth, to create individually customized questions, and to test the use of personalized motivational messages that respond to the EMA data in real time.

Conclusions: YEH are highly receptive to the use of EMA in studies. Further studies are warranted to understand the impact of EMA on YEH behaviors. Incorporating the YEH perspective into the design and implementation of EMA studies may help minimize barriers, increase acceptability, and improve participation rates in this hard-to-reach, disconnected population.

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KEYWORDS

youth experiencing homelessness; ecological momentary assessment; mobile apps; behavior change

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Introduction

Every year, an estimated 4.2 million youths and young adults in the United States experience some form of homelessness [1]. Black youth, unmarried parenting youth, and gay, lesbian, bisexual, transgender, and queer (LGBTQ) youth are at a higher risk for experiencing homelessness compared with other groups [1-3]. Youth experiencing homelessness (YEH) have disproportionately higher rates of negative health outcomes, including disease, injury, substance use, and trauma [4-6]. They are also at increased risk for victimization and incarceration [7,8]. Consequently, mortality rates among YEH are 10 times higher than those of housed youth in the general youth population, with suicide and drug overdose being the leading causes of death [9,10].

The transient and hidden nature of youth homelessness make it challenging to conduct research with this marginalized population [11]. Unlike stably housed youth, YEH experience barriers to accessing health and social services [12,13]. Even when available, YEH are reluctant to engage with helpful services over concerns for loss of confidentiality and perceived provider stigma, prejudice, and discrimination [14,15]. In-depth interviews from the Voices of Youth Count initiative revealed that the need for YEH to protect their identity and their history of stressed, often toxic relationships with parents and other adults make them less inclined to interact with unfamiliar resources and institutions [16]. For many YEH, weighing out the risks and benefits of engaging with others is paramount because, from their perspective "nothing is for free" [16].

In recent years, the widespread availability of smartphones and advances in mobile technology have made it feasible to conduct ecological momentary assessment (EMA) studies among hard-to-reach populations including YEH [17-19]. EMA collects real-time data as individuals go about their daily lives. As a result, some of the benefits of EMA include a reduction in recall and memory biases, an increase in ecological validity, and the ability to capture intrasubject variability among factors that contribute to behaviors [20-22]. EMA has been extensively used in adult addiction research [23-25], pediatric and adult mental health disorders [26,27], and nutrition and physical activity studies [28,29].

Research shows that EMA is acceptable among stably housed youth, yet the receptiveness of YEH to EMA is not well understood. Although there are similarities in the experience of EMA between the two groups, YEH face different challenges that require unique approaches [30]. To start, recommendations for recruitment of stably housed youth emphasize using schools as a starting point, a source that is not available for many YEH studies [31]. Clinical studies in stably housed youth also rely heavily on clinical institutions, such as primary care clinics, as touchpoints throughout the study, but YEH often face barriers to accessing these institutions [32,33]. Although stably housed youth have reported technology-related issues and recommendations similar to YEH, the lack of availability of outlets to charge a phone and disruptions in connectivity are significant barriers not commonly reported in stably housed youth studies [31,34]. Considering the higher incidence of victimization, trauma, and mental health issues among YEH, they may perceive EMA questions differently; thus, strategies that balance a thorough assessment within the context of potentially traumatic experiences need to be explored. The risks associated with mobile health technology in this vulnerable group is also not well understood.

The few EMA studies conducted with YEH demonstrated high response rates and acceptability [6,18,35]. Compared to previous cross-sectional methods used to understand the daily experiences of this highly mobile group, EMA allows for a more naturalistic approach to studying YEH behavior and their environmental circumstances [36]. Using longitudinal EMA data, Suchting et al [37] expanded on our understanding of shelter use among YEH by predicting patterns of sheltering behaviors. They revealed that stress related to not having a place to stay and experiencing discrimination to be among some of the strongest predictors for YEH not staying in shelters. Santa Maria et al [6] used EMA to capture patterns of YEH rates of drug use and to identify modifiable risk factors for future interventions. In another EMA study, sexual urge and drug use predicted day-level sexual activity, and YEH primarily engaged in condomless sex, increasing their risk for HIV and other sexually transmitted infections [38].

Few studies have explored the usability and acceptability of mobile phone assessments among YEH. Using focus group interviews, Jennings et al [34] found that YEH perceived mobile phone health interventions as beneficial if they addressed their health concerns, maintained their confidentiality, and allowed them access to calling and texting features. YEH were also receptive to EMA using SMS text messaging and had several suggestions for the question format, including the ability to explain answers instead of being limited to preset responses [35]. These findings provide valuable recommendations for YEH EMA studies but more studies are needed to further explore EMA use in YEH and no studies have investigated the perceived impact of EMA on YEH behavior [17,34,39]. We conducted this study to address these gaps and to describe the perceived benefits, usability, acceptability, and barriers to the use of EMA from the YEH perspective.

Methods

Parent Study

Participants in this study were recruited from a parent EMA study examining real-time factors, such as urge, stress, sexual behaviors, and substance use. Youths (N=71) from the parent study were between 18 and 24 years of age, English speaking, experiencing homelessness or unstable housing, and recruited from shelters and drop-in centers serving YEH in 1 city in the southern United States [6]. Youths participated in up to 21 days of EMA that prompted them to complete a brief assessment that asked about stress, affect, sexual activity, substance use, and sheltering arrangements 5 times a day. More information on the parent study can be found in the original publications [6,40].

EMA Survey and Technology

Participants received prompts to complete EMA surveys through a Samsung Galaxy Light smartphone with an Android 4.2

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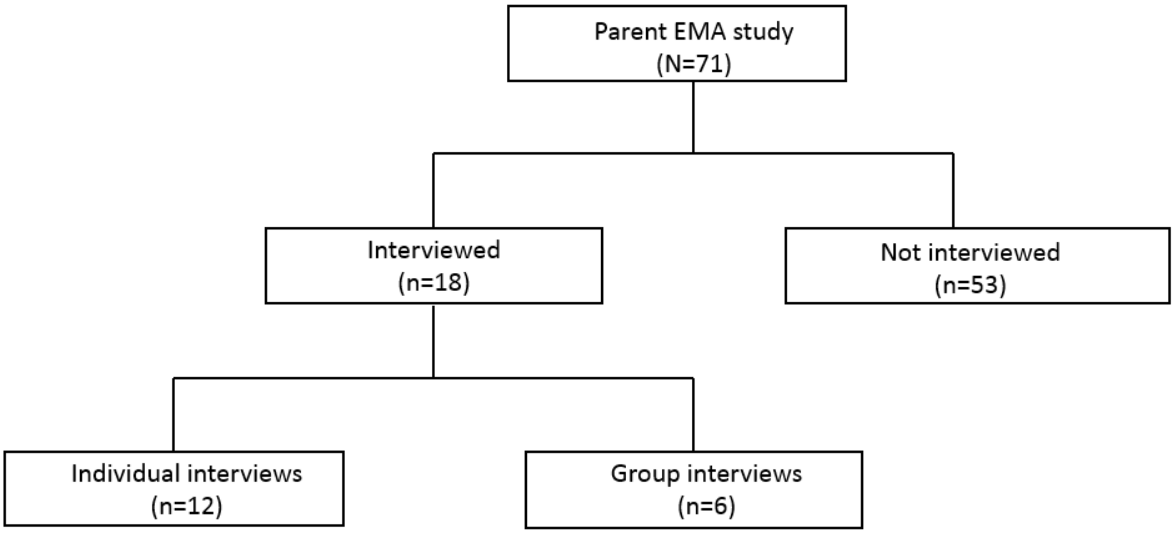
operating system (Google). The surveys took fewer than 5 minutes to complete, and youths were cued visually and audibly for 30 seconds for each assessment. Daily assessments required participants to recall the past 24 hours, and random assessments occurred 4 times a day and focused on assessing real-time affect including feelings of anger, guilt, irritability, shame, and sadness [6]. Urge to use drugs or engage in sex or high risk behaviors including stealing were also assessed. Aside from the assessments, the phones could be used to send and receive phone calls and text messages and provided access to the internet and social media. At the end of the 21-day study period, participants met with the study team to return the study mobile phones and receive grocery store gift cards valued up to US $95 depending on the percentage of random and daily EMAs completed.

Recruitment

After completion of the EMA study, youths were asked if they would like to participate in an exit interview individually or in a small group of peers. Interviews were conducted using a semistructured, conversational guide that inquired about their experience with the EMA app, what they liked and did not like about the app, and how they thought it impacted them. The interview guide was designed to address predetermined themes related to app acceptability and usability with open-ended questions to allow for emerging concepts. Finally, youths were asked if they would use the app again or recommend it to a friend and what they would change about the app or the study to make it better for others. Sessions were audio-recorded and transcribed verbatim. Ultimately, 14 interviews were conducted in total, including 2 group interviews (total of 6 participants) and 12 individual interviews (Figure 1). On average, both individual and group interviews lasted approximately 20 minutes.

Figure 1. Recruitment. EMA: ecological momentary assessment.



Analysis

An inductive approach guided the data analysis for this study. A team of 2 doctoral-trained investigators performed the analyses. First cycle coding included descriptive, attributive, in vivo, process and values coding [41]. Codes were then clustered into categories and patterns to generate an initial codebook. Second cycle coding focused on thematic analysis to identify themes and subthemes. The final codebook was refined and included definitions, exemplars, contrast quotes, and number of discussions identified for each theme. ATLAS.ti (version 7) was used to organize and code the data. Credibility and confirmability of the analysis was established through peer debriefing for each coding cycle, use of thick descriptions from the interview transcripts, and analytic memos during the analysis phase.

Results

Participant Characteristics

A total of 18 youths participated in this study (Table 1). Ages ranged from 19-24 years with a mean age of 21 years. For race/ethnicity, 11 out of 18 (66%) participants identified as male, 10 out of 18 (56%) identified as non-Hispanic Black or African American, 5 out of 18 identified as multiracial (28%), 1 identified as American Indian or Native Alaskan, and 1 participant reported “something else”. Most of the youths identified as heterosexual (14/18, 78%).

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Table 1. Characteristics of youth experiencing homelessness (YEH) participants.

Youth	Age (years)	Gender	Sexual Orientation	Race
1	24	Male	Gay	Non-Hispanic Black or African American
2	21	Female	Heterosexual	Non-Hispanic Black or African American
3	19	Male	Heterosexual	Non-Hispanic White
4	22	Female	Heterosexual	Non-Hispanic Black or African American
5	20	Male	Heterosexual	Multiracial
6	20	Male	Heterosexual	Non-Hispanic Black or African American
7	24	Male	Gay	Non-Hispanic Black or African American
8	21	Male	Heterosexual	Multiracial
9	20	Female	Bisexual	Non-Hispanic Black or African American
10	21	Female	Heterosexual	Multiracial
11	20	Male	Heterosexual	Non-Hispanic Black or African American
12	24	Female	Heterosexual	Something else
13	19	Female	Lesbian	Multiracial
14	24	Male	Heterosexual	Multiracial
15	21	Male	Heterosexual	Non-Hispanic Black or African American
16	19	Male	Heterosexual	American Indian or Alaska Native
17	19	Female	Heterosexual	Non-Hispanic Black or African American
18	22	Male	Heterosexual	Non-Hispanic Black or African American

Perceived Impacts of EMA

Increased Awareness of High Risk Behaviors

The majority of youths reported that the EMA increased their awareness of their high risk behaviors. The daily questions asking about their smoking habits, drug use, and sexual activity served as reminders of the frequency of their behaviors: “It kept me informed of how many drugs I use” (Y14). Another youth reported, “I would notice how many cigarettes I would smoke when I first started this survey, so that really made me like, okay, I really need to stop smoking those” (Y10). This youth further described how the repetition of questions led to increased behavioral and emotional awareness:

> *Yeah, it made me step back and look at everything because like I said, since it’s so redundant, it makes you notice your habits as well because you sit there, and you answer, and you start noticing I’m answering this question so many times this answer or this answer, and you start noticing. Then that makes you think to yourself, maybe I need to try and fix this because that’ll help me change my mood or whatever.* [Y10]

Four youths reported changing their behavior as a result of the EMA surveys. They described decreasing their substance use and taking precautions prior to engaging in any sexual activity: “It just make you think about certain things like you about to get ready to do something or it just makes you think or take precautions about what you’re doing” (Y7). One youth described decreasing his use of marijuana as a result of the survey:

> *I noticed that, you know, the marijuana really wasn’t helping. I still didn’t stop completely at that moment, but you know, down the line, I wean myself off of it. I’m still weaning myself off of it. I haven’t really smoked in like 2 weeks. So that’s good.* [Y17]

Youths reported making changes in their sexual behaviors with some ensuring they had a condom available at all times:

> *With the sex, it kind of helped me slow down a little. We were having sex—me and my girlfriend—and it did kind of slow us down a little bit because I noticed we were just having sex recklessly.* [Y10]

Increased Awareness of Emotional State

Six youths conveyed that the EMA surveys helped them be aware of their emotional state. Youths reported that the words in the questions allowed them to recognize and name their emotions:

> *It was like the way that they ask the questions, it helped me kind of put it in words because I would sometimes feel like fidgety or irritated. I’m like, I’m not really sure why. But then the way they would ask I was like “Ok, that’s probably why.” Maybe that’s the word I’m supposed to use.* [Y3]

Another youth described the survey as a way of coping with their emotions:

> *It help me be more aware of how I was feeling, because it was like you asked the right questions at the right time. So, it’s more like self-coping. Therapy in a way. Like, basically you’re being able to*

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> *acknowledge how you are feeling, like what is causing that emotion that's holding you down.* [Y8]

Youths described the benefits of acknowledging their stress and identifying emotional triggers: "It brings to your own attention that okay, well, a lot of the stress that I'm having is sometimes due to me or it's sometimes due to things around me" (Y15). Another youth reported, "Most of my stress came from not just everyday life but mostly from how I put myself through life" (Y10). One youth described the impact of the survey on her stress and coping skills:

> *I mean, when it's brought to your attention every day or when you basically put it in your own face every day because that's what the survey's doing. It's basically letting you note to yourself. It brings it to your own attention that a lot of the stress I'm having is sometimes due to me or sometimes the things around me, so it helps you take a step back and see how you can attack each situation instead of just running into it blind.* [Y10]

Provided Social Support and Connection

For many youths, participating in the survey made them feel heard and supported:

> *Emotionally, I felt like there was actually somebody who cared or wanted to know how I felt. I like that.* [Y18]

They reported that the ability to not only express themselves but also the knowledge that someone was reading their responses was comforting. One youth described how the survey helped her cope with loneliness:

> *…it was kind of helpful to me because sometimes I had no one to talk to and then I be feeling like I can't express, but when I take the survey and it ask like how you feeling or are you depressed. It make it seem like someone actually going to look at this and say, well, she's feeling this type of way. Somebody actually sit down and cares about your feelings. That's what I liked about the survey.* [Y17]

Seven youths explained that the ability to connect with friends and family through phone calls, text, and social media was most beneficial. One youth used the phone to reconnect with her family whom she had not spoken to for some time: "…haven't talked to my mom in a long time. I finally gave her a call" (Y1).

Acceptability of EMA

Provided a Distraction From Homelessness

In general, YEH were receptive to the EMA surveys. Some reported that the surveys distracted them from homelessness:

> *I be like trying to get my mind off things, like focus on something else. I'll be like "Okay, well I'll take my mind off this and focus on the surveys."* [Y18]

Several reported it helped them avoid risky behaviors:

> *If I'm bored, I get adventurous. If I'm on the phone, I just be still stuck on the phone just watching movies or videos, anything, for hours.* [Y12]

YEH also expressed appreciation for being able to use the phones for other purposes including phone calls and social media:

> *You didn't just give them a phone and oh, here are those surveys. Even though we are young kids, we have access to Facebook, we have access to things we actually do. They can entertain themselves, and they're on the streets, so they can charge the phone and be on the phone all night, something for them to do. It's not just doing surveys on this phone and still sitting outside bored.* [Y15]

Perception of Being Watched

Youths described instances in which they felt that the prompts came as a response to their real-time behavior. They mentioned feeling "watched over" or being monitored especially when the survey questions applied to their real-life situation: "Sometimes I felt like it was the signs; it was kind of weird because it would pop up only when I'm about to do something" (Y17). One youth described his experience after a police encounter:

> *One time I actually thought the phone knew what I was doing because 2 minutes later, I had got into it with the lawman and right after I finished talking to the lawman, the survey came up and its first question was "Did you encounter a lawman or a police officer?" I was like, "really, bro?"* [Y12]

Barriers to Acceptability and Engagement

Redundancy of questions was a frequently mentioned issue. As a result, youths described being able to predict the questions and answering without much thought to their responses: "Because I would get bored because it's just like now, I know exactly what it's going to say, and it's like click, click, click" (Y13). One pregnant youth described that the lack of customized questions was a problem: "Only one time did I get something that asked if I was pregnant, and I was like yeah, and then it asked me the same exact questions it would ask me even if I wasn't pregnant" (Y15). Some youths reported that the lack of response to their answers was dissatisfying. One youth described the following:

> *Let's say, by the third time, I say I'm extremely stressed, maybe that could send y'all a red alert like, "Hey this person's stressed. They might need someone to talk to." Then you could send them a message like, "Are you okay? Want someone to talk to? Need anything?" I feel that would make certain individuals feel a little bit more looked after, a little more cared for. And it's not just like, oh, it's a survey…if you really need somebody, this is for us to find out.* [Y13]

Usability of EMA

Easy to Use but With Glitches

Youths reported that the surveys were easy to navigate but that the questions were often predictable: "…it got to the point where my boyfriend, he knew every question, so he could just type" (Y15). Most youths found the redundancy of questions to be boring and not applicable to their specific situations. Although

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they did not mind the number of surveys administered daily, some of the youths found the timing of the surveys to be challenging: "If you're not on it [phone] or not around it, it'll go off and you hear it…and then you missed it" (Y2). A few of the youths reported "glitches" occurring while taking the surveys describing that the surveys would turn off midway leaving some questions unanswered: "…like it would pop up—sometimes a survey wouldn't pop up; it would just go off, so that's why some of them weren't answered" (Y15).

Connection and Other Technology-Related Issues

Technology-related issues were common. Some described not being able to make phone calls: "…when I try to call out, it'll say only numbers that can be dialed or numbers that are programmed" (Y12). Others reported issues with internet access: "When I first got the phone, it was going really fast; and then like two days after that, everything started slowing down…it got really, really slow" (Y11). Some stated that the slow internet access also slowed down their ability to send the completed surveys. Battery issues were commonly reported by youths who often struggle to find a place to charge their phones: "The app was good, just the phone was bull crap because it only worked for like 2 days, and then after that it just went down" (Y12).

YEH Recommendations for Future EMA Studies

The majority of youths recommended that the survey questions should be customized to each participant to avoid redundancy: "I don't think each survey should say the same thing; I think you should switch it up" (Y15). YEH also expressed that although the questions about mental states and substance use were important, they would also like to be asked everyday life questions such as "How are you feeling today?" or "Are you hungry?" or "Did you work out today?" They also reported that there needed to be more questions and that questions should "go more deep into it [topics]" (Y9). Two youths expressed that they would have liked questions about their plans for the future and where they saw themselves in 5 years. Some of the youths recommended that the ability to type in their responses instead of choosing from preset answers would be preferable:

> *Yeah, type in your answer. "I feel upset because,"… I just feel like they shouldn't be "sometimes," "often," "agree," "disagree". Have distinct answer.* [Y15]

Youths expressed that additional supports should be provided through the EMA surveys. However, they recommended that support should be personalized so that the participants feel "more cared for". Describing this type of support, one youth stated the following:

> *Don't read them a script. Literally sit there and ask them, why do you feel like this? Don't suggest that they go to a mental hospital. Give them encouraging words, and talk to them for a minute, ask them do they feel safe at this moment, and if they don't feel safe, then "Can you call the police for me?" "Can you call the ambulance?" And then take that step.* [Y15]

Three youths recommended that allowing customization of the phone ring tones may help with survey compliance. Others stated that allowing participants to go back and change their answers and to retroactively complete missed surveys would be helpful since surveys may come when they are too busy to respond, or they respond incorrectly:

> *I also think you should make it to where you can be able to go back and redo your answer. I think that is a big part of it because I just—I really like it. I really liked this. It's a good thing to me.* [Y15]

To prevent phones from being stolen, several youths recommended that participants should be screened carefully prior to receiving their phones: "You just have to be pretty strict on who gets them…because people see that it's just a regular phone and not something you have to do a duty on" (Y10). Many of the youths expressed that allowing the youth to keep the phone after the study would help with keeping them connected to social media and provide them access to resources.

Some youths found the timing of the surveys challenging and suggested set times for the survey to increase compliance. One youth indicated the following:

> *…what would be a little bit better is if the times were consistent because the one that I missed, I was on the internet looking up the bus route for something, and it came up, and I'm like in the middle of trying to find the bus route, and then my dad started calling, and then my phone just froze. I was like, if I knew it come at 10:30 and 12:15, I would know, okay, have my phone charged. And I think—and that's why my boyfriend missed so many because he never knew when they were coming, but he never brought his charger. He was like, "Man, if I knew what time it was coming, I'd at least make sure my phone was charged for that time…"* [Y13]

Discussion

Principal Findings

The findings in this study suggest that EMA is acceptable to YEH and may have perceived behavioral benefits. Increased self-awareness as a result of receiving daily questions about their behaviors and emotions led some youths to decrease their substance use and increase condom use before sexual intercourse. Others expressed that the questions helped them recognize stressors that led to negative emotions, and as a result, youths intentionally avoided these emotional triggers in the future. Researchers have previously noted the impacts of frequent assessments on behavior and emotional awareness irrespective of interventions [42,43]. This effect, known as assessment reactivity, results from participants' constant reflection during repetitive behavior evaluations, leading to change [44]. EMA questions may serve as cues to action by providing information and reminders that trigger health-promoting behaviors [42]. However, previous EMA reactivity studies in alcohol abuse, smoking cessation, and medication adherence have found mixed results [44-47]. A randomized control trial evaluating EMA reactivity in smoking cessation discovered that although increased assessments did not promote abstinence, researchers observed small reactivity effects on anxiety, hunger, positive affect, and post-quit

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confidence [47]. To date, no studies have explored this concept in YEH, and it is unclear whether youths sustained their behavior change postintervention. Researchers should consider the effects of assessment reactivity in the design of future EMA studies to anticipate potential confounders in youths' subjective experiences and to assess for weaning effects over time.

Youths felt high levels of perceived support through their interactions with the EMA surveys. Although the surveys were pregenerated, administered at set times during the day, and unidirectional in nature, being asked about their day made youths feel heard and looked after. Tyler and Schmitz [48] observed similar findings in their SMS study with YEH, reporting “perceptions of care and concern” as one of the perceived benefits of participation. These discoveries highlight the degree of loneliness many YEH experience; interactions, even in survey form, appear to alleviate feelings of isolation and depression common in YEH [49]. In this regard, EMA may have unintended therapeutic effects on YEH’s mental well-being, particularly those with low social supports.

Youths unanimously reported that the most beneficial aspect of the EMA study was the ability to connect with friends, family, and other social support through the mobile phone. Access to the internet allowed youths to communicate with their peers through social media and to access multimedia platforms that helped alleviate boredom. Some of the youths used the phones for directions to clinics and grocery stores; one youth reported a friend getting a job interview through the phone. Many of the youths recommended that participants be allowed to keep the phones after the study. This is not surprising, as previous studies observed that mobile phones serve as lifelines for youth [11,39]. Aside from communicating with peers, they used phones to access resources and other forms of support [34]. However, mobile access can have adverse effects with youths expressing concerns for loss of anonymity and misuse of their personal information [34,39]. In this study, YEH did not report these concerns; however, several described feeling watched over and believed that the surveys occurred as a response to their real-time behavior and situation. Future EMA studies should consider the potential for harmful effects of mobile connectivity on YEH privacy; clearly outlining the plans for data management and measures to ensure confidentiality may help to alleviate these fears.

EMA was highly acceptable to YEH. Youths reported that the questions were easy to understand and that the frequency and length of the surveys were manageable. Some of the youths recommended that questions should “go deeper” and that participants should be allowed to provide contextual answers instead of preset responses. Youths also recommended that surveys should be customized to each individual and that redundancy of questions should be avoided. Several youths reported that redundancy led them to answer mindlessly after taking the same survey multiple times. These findings are similar to recommendations from other studies with YEH reporting that the authenticity of questions and the ability to explain their answers were most important [17,34]. YEH emphasized that authenticity may only be realized when they are directly involved in content development [34]. A collaborative approach to EMA study designs may improve participation and provide valuable insights into the YEH experience.

Although YEH reported that the surveys were easy to navigate, they encountered issues with connectivity, phone battery life, and timing. The stalling of the EMA app resulted in incomplete or missed surveys. Youths reported issues with the phone battery life despite frequent charging and experienced slower connectivity as the study progressed. Youths also described instances when they did not receive notification or were unable to complete the surveys on time. Other EMA studies have reported similar issues. Mackesy-Amiti and Booram [50] observed that notification issues (25%), stalling of the EMA app (17%), and battery issues (5%) accounted for most of the problems encountered in their study. A systematic review of the use of EMA methods with youth found that software and hardware malfunctions and connectivity issues were common across many EMA studies [51]. As technical issues can significantly impact data collection and ongoing participation, efforts should be made to provide ongoing technical support to help troubleshoot software and hardware problems. Piloting the phone and app prior to the start of the study may help mitigate potential issues; however, lost phones were a significant problem in this study, and piloting may not always be feasible in this population.

YEH had several recommendations for future EMA research. They emphasized the importance of providing real-time support for themselves and their peers during hard times. For example, youths identified during the EMA as having suicidal thoughts or who are feeling severe depressive symptoms could be connected to crisis personnel for help. Aside from additional support, youths also wished for “normal” interactions and more goal-related questions. For instance, they wanted to be asked how they were doing and about their plans for the future. These findings reflect the perceived stigma YEH experience; being seen as difficult or different from other "normal" youth are negative stereotypes [52]. Including questions unrelated to mental health or high risk behaviors may help to minimize this stigma and signal to YEH that they are valued as a whole individual. Youths also expressed the desire to receive motivational messages to help them through difficult times. Previous studies observed that youths were particularly interested in receiving motivational messages, tips on staying calm, and advice on how to navigate relationships [17,39]. Integrating these preferences into the EMA may improve acceptability and survey compliance.

This study aligns with current literature that EMA has high acceptability and utility with YEH. Several of the findings are similar to those found in stably housed youth; however, the unique challenges faced by YEH and the potential of EMA to impact high risk behaviors are highlighted in this study. Although findings suggest a positive perceived behavior impact, more studies are needed to examine the direct relationship between EMA and behavior change, the impact of assessment reactivity on EMA data, and the sustainability of change postintervention. This study adds to the literature by providing recommendations for EMA research from the perspectives of YEH. Future research is needed to identify strategies for involving YEH in EMA development and understanding barriers

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to participation and compliance. Future EMA studies would benefit from incorporating just-in-time adaptive messages that respond in real-time to EMA data and generate youth-developed motivational, health-promoting messages. Additional trials should be conducted to assess the behavioral impacts of EMA.

Limitations

This study has several limitations. As this is a single-site study with a relatively small sample size, the generalizability of findings to other populations of YEH is limited. The experiences reported here may be unique to those who chose to participate in exit interviews; these youths may have had more positive or negative experiences, which may not be reflective of the experience of all the youths who participated in the original EMA study. There is also an underrepresentation of LGBTQ youth in the sample; estimates suggest that up to half of the general YEH population identify as LGBTQ [53]. As data were collected from both individual and group interviews, more vocal participants might have disproportionately impacted specific themes; however, all efforts to obtain exemplars from a diverse group of youth experiences were made by the researchers during the analysis and the reporting phases of the study.

Conclusions

Findings from this study describe a positive perceived behavior impact on youth high risk behaviors; however, more studies are needed to fully understand the direct effect of EMA on behavior change among a larger and more diverse YEH population. EMA methods are highly acceptable to YEH, but technology and connectivity issues serve as significant barriers to participation and survey compliance. The development of future EMA studies should involve YEH to ensure the authenticity of surveys and address their specific needs.

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Conflicts of Interest

MB is the primary inventor of the Insight mHealth Platform, which was used to develop the smartphone application for this study. MB receives royalties when researchers outside of OUHSC use this platform. Other authors declare no conflicts of interest.

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Abbreviations

EMA: ecological momentary assessment
LGBTQ: gay, lesbian, bisexual, transgender, and queer
YEH: youth experiencing homelessness

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Original Paper

Facebook Ads Manager as a Recruitment Tool for a Health and Safety Survey of Farm Mothers: Pilot Study

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Abstract

Background: Social media platforms have experienced unprecedented levels of growth and usage over the past decade, with Facebook hosting 2.7 billion active users worldwide, including over 200 million users in the United States. Facebook users have been underutilized and understudied by the academic community as a resource for participant recruitment.

Objective: We performed a pilot study to explore the efficacy and cost-effectiveness of Facebook advertisements for the recruitment of an online agricultural health and safety survey.

Methods: We undertook a 1-week advertising campaign utilizing the integrated, targeted advertising platform of Facebook Ads Manager with a target-spending limit of US $294. We created and posted three advertisements depicting varying levels of agricultural safety adoption leading to a brief survey on farm demographics and safety attitudes. We targeted our advertisements toward farm mothers aged 21-50 years in the United States and determined cost-effectiveness and potential biases. No participant incentive was offered.

Results: We reached 40,024 users and gathered 318 advertisement clicks. Twenty-nine participants consented to the survey with 24 completions. Including personnel costs, the cost per completed survey was US $17.42. Compared to the distribution of female producers in the United States, our advertisements were unexpectedly overrepresented in the eastern United States and were underrepresented in the western United States.

Conclusions: Facebook Ads Manager represents a potentially cost-effective and timely method to recruit participants for online health and safety research when targeting a specific population. However, social media recruitment mirrors traditional recruitment methods in its limitations, exhibiting geographic, response, and self-selection biases that need to be addressed.

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KEYWORDS

Facebook; recruitment; advertisement; agriculture; health; safety; survey; online

Introduction

Researchers are facing a range of issues in recruiting participants, including decreasing response rates and increased difficulties in reaching participants through traditional modes such as phone and paper [1-3]. In turn, these challenges are associated with increased recruitment costs. As the presence of social media has increased and as our communication strategies have shifted, researchers are increasingly looking to these systems for potential recruitment to address current challenges.

Facebook is the largest social media platform with over 1.8 billion daily active users and 2.7 billion monthly active users [4]. Of these, over 200 million users are within the United States. This high proportion of users allows Facebook advertising to reach potential research participants in a short period of time. As of 2019, up to 90% of US adults use the internet, a number

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that has been steadily growing [5]. Additionally, although 24% of Americans do not have an internet connection at home, 17% of total US adults use a smartphone without home internet access, thereby increasing the feasibility of internet-based research [6].

One of the largest barriers in recruitment is cost. Mailed survey costs are relatively evenly distributed, ranging from US $6.51 to $30.24; however, this includes high personnel costs [7-9]. Telephone surveys have been observed to range from US $29 to $99 per participant, also requiring high personnel costs [10,11]. Some online health and behavioral studies reported costs as low as US $0.64 per participant, whereas others reported costs up to US $33 per participant; however, the median cost tends to be skewed toward the lower end of the scale [12-15].

Both telephone and mailed surveys require preexisting information to reach a targeted population, whereas Facebook's integrated Ads Manager utilizes its internal user data to determine such demographics. However, this broad targeting introduces further concerns over multiple biases [13,16]. Although more traditional recruitment methods have been used and evaluated for agricultural populations, often with mixed results, our review of the literature indicates that there has been little data reported on the use of Facebook or other social media platforms for recruitment [17-21]. Therefore, we undertook this pilot study to investigate the effectiveness of targeted advertisements on Facebook as a tool to recruit participants in the agricultural sector, and to assess possible self-selection and geographic biases in this sampling method.

Methods

To determine the feasibility and cost-effectiveness of Facebook advertisements for an agricultural health and safety survey, we ran an advertising campaign consisting of three separate advertisements, each with a different agricultural image. The campaign was performed on Facebook from March 9, 2020 to March 16, 2020 at a total cost of US $294, distributed evenly among the three advertisements. Images were selected based on the apparent safety adoption displayed to determine if advertisement imagery affected performance. This included low (overturned tractor), neutral (child feeding a calf), and high (woman sweeping a barn in full personal protective equipment) safety adoption (see Multimedia Appendicies 1-3 for examples of advertising images). These advertisements were run concurrently through the National Children's Center for Rural and Agricultural Health and Safety (NCCRAHS) Facebook page. We investigated the cost per click, cost per participant, and potential geographical biases that arose during this campaign.

We chose the following inclusion criteria to target our advertisements: individuals currently living in the United States, identified as female, within the ages of 21-50 years, and had a "role," as defined by Facebook, in Farming, Fishing, or Forestry (FFF; delineated by Facebook as Demographics > Work > Industries > FFF). Facebook reported 170,000 eligible users according to these criteria. This campaign directed users who clicked on the advertisement to an online, REDCap-hosted consent document outlining a novel open 10-item survey assessing farm family demographics, views on child agricultural safety, and open-ended feedback on the Facebook advertisement they were shown [22,23]. This survey was devised in anticipation of a research project assessing the impacts of relevant news media on farm mothers' knowledge, attitudes, and behavioral intentions toward childhood agricultural safety. No financial incentive was provided for participation. The survey instrument, consent form, and protocol for this study were deemed exempt from review by the Marshfield Clinic Research Institute Institutional Review Board.

We investigated the geographic distribution of advertisements by comparing Facebook's advertisement targeting system performance to an expected distribution based on the number of female producers at the state level [24]. We then mapped the ratio of expected to observed reach of the advertisements.

Results

Over this 1-week period, the total reach of the advertising campaign (measured by number of views) was 40,024 and 318 users clicked on one of the advertisements, representing a click rate of 0.79% (Table 1). Of these 318 visitors, 29 consented to the survey, representing a participation rate of 9.1%, with 24 fully completing the survey for a completion rate of 83%. This yields a completed response rate of 0.06% out of the total reach and 7.5% out of the total clicks. The total cost per click for this study was US $0.92, whereas the cost per participant was US $10.14. With the 17% dropout rate (completed surveys vs consenting participants) and a total personnel cost of US $31 per hour at 4 hours, the total cost per completed survey was US $17.42.

The neutral advertisement depicting a child feeding a calf generated the most clicks with 122 out of 318 total clicks (38.4%). However, the image of a young woman sweeping the barn had the highest click rate at 0.84% (Table 1).

Advertisements were posted more often than expected in eastern states, whereas western states (excluding California, Nevada, and Utah) tended to be overrepresented compared to the distribution of female producers (Figure 1). There was no observed difference in geographical distribution among the three advertising images.

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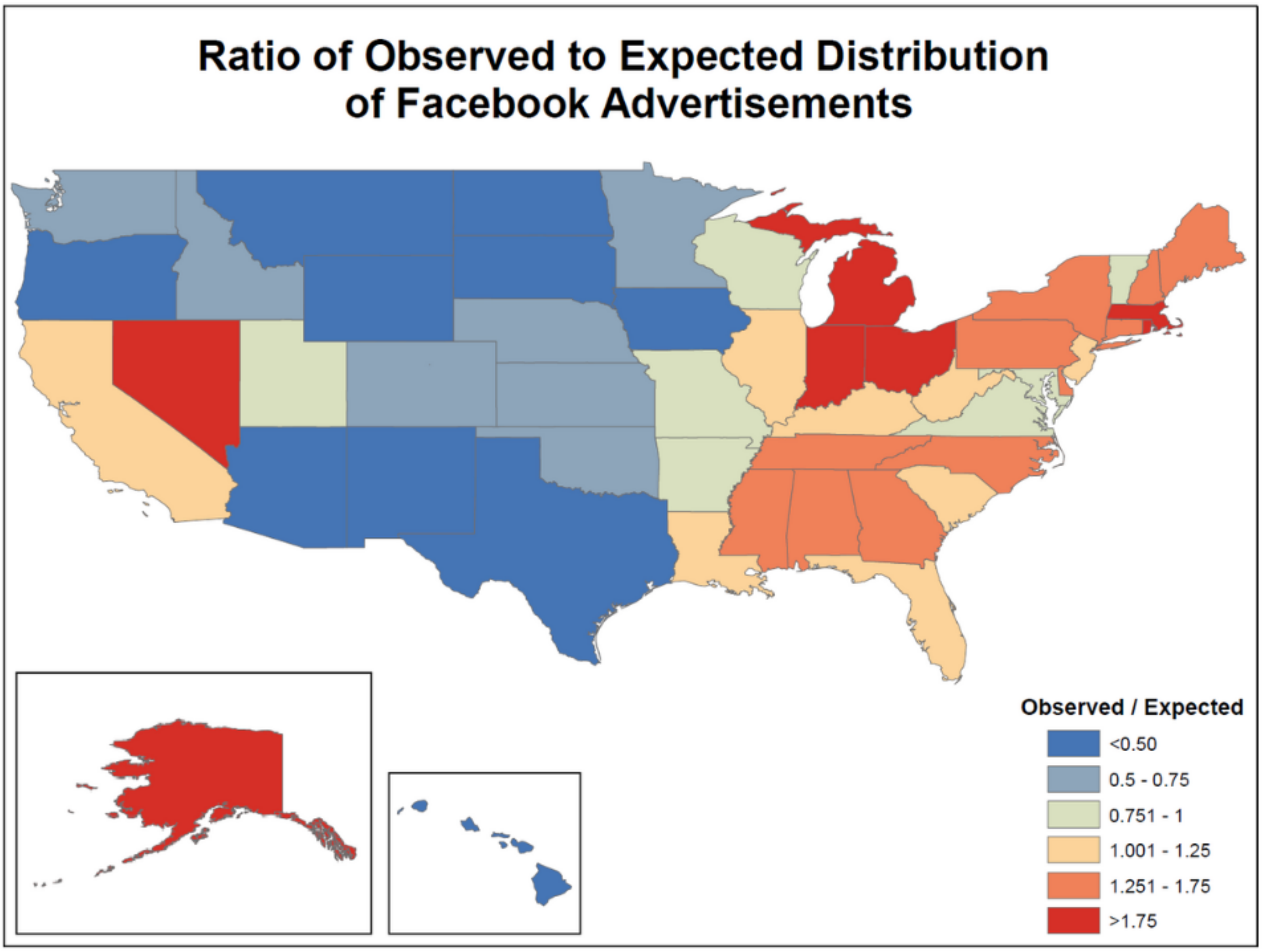
Table 1. Reach and click rate of advertisement images.

Advertisement image	Reach (N)	Click rate, n (%)
Overturned tractor	14,240	102 (0.72)
Child feeding calf	14,652	122 (0.83)
Woman sweeping	11,132	94 (0.84)
Total	40,024	318 (0.79)

Figure 1. Ratio of observed to expected geographical distribution of Facebook ads. Data obtained from the United States National Agricultural Statistics Service 2017 Census of Agriculture.



Discussion

Principal Findings

This pilot project aimed to determine if Facebook Ads Manager could be a useful tool for recruiting samples of the agricultural population for online health and safety surveys. The current adoption of Facebook and other social media in the United States, as well as increasing rates of internet access, show promise for future research to be performed in part or entirely online.

We reached over 40,000 Facebook users at a cost of US $294 and generated a total cost per completed survey of US $17.42. This is comparable to other observed costs ranging between US $0.64 and $33 for online health and behavioral studies; however, we were unable to identify any published studies that utilized Facebook Ads Manager for recruiting an agricultural population such as farmers, ranchers, farm or ranch parents, or farmworkers specifically [12-15]. It should be noted that as advertisements approach the total sampling frame for a study, there is the risk of reaching saturation among the target population, meaning that individuals will be shown the same advertisement multiple times. Further research is needed to determine what diminishing returns, if any, exist when recruiting larger sample sizes and showing a single advertisement multiple times to the same people.

Limitations

This pilot study had several limitations. First, our study had a remarkably small final response rate of 0.06% based on total reached (N= 40,024) and of 7.5% based on total clicks (N=318). Facebook and other online methods of recruitment allow for high scalability with relatively low cost. However, with this low response rate, it is possible for other, larger samples to reach

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a level of saturation among the target population, resulting in advertisements being shown multiple times to potential participants.

Additionally, this study exhibited a level of geographic bias that was algorithmically determined by the Facebook Ads Manager platform. Facebook users across multiple states were shown the advertisement a disproportionately high or low amount when compared to the expected target population residing in those states. Although online studies allow for ease in reaching national and international samples, the risk of bias remains prominent, and appropriate measures should be taken to adjust or account for these discrepancies (eg, data weighting, stratification, quota sampling).

We did not offer or disburse any financial incentive for participation. Although we had 318 visits to the survey, only 29 visitors consented to participate and 24 fully completed the survey. We were also unable to accurately measure response rates and completion rates for each advertisement image. Future studies should ensure that the survey infrastructure is set up to measure and assess these potential differences. This campaign was administered via the NCCRAHS Facebook Page, which then appeared as the host organization ads, and may have influenced which respondents engaged with the advertisements, in turn affecting click rates and completion rates. The provision of compensation could help increase the participation and completion rates; however, measures should be taken to control for the additional self-selection bias such measures could introduce.

It should be noted that we do not have full control over, or knowledge of, Facebook’s mechanisms for targeted advertising. The woman sweeping advertisement had lower reach than the other images, as determined by Facebook, but had the highest click rate. Additionally, Facebook reported 170,000 women, aged 21-50 years, who have a role in FFF. The National Agricultural Statistics Service 2017 Census estimated over 500,000 female agricultural producers between the ages of 21 and 50 years in the United States; this does not include farm hands or women whose spouse works in agriculture [24].

Future Work

We argue for additional research to make use of these relatively underutilized resources alongside sufficient measures to control for geographic and response biases, as well as misrepresentation and data validity. Future research should include data weighting, verifying consistent responses across similar questions, and “insider knowledge” questions [25,26]. More in-depth studies and analyses could offer insight into additional methods for applying these methods to online survey studies and how these methods may differ for agricultural populations.

Conclusion

We were successful in using Facebook Ads Manager to recruit a sample of an agricultural population for an online health and safety survey in a short time frame. We observed low response rates, which were counteracted by a large advertisement reach. This method shares many limitations with traditional survey recruitment methods and requires appropriate measures to limit potential biases. Future research is needed to determine the effectiveness of Facebook Ads Manager on recruiting a large agricultural population and if this method is sustainable.

Acknowledgments

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Authors' Contributions

All authors participated in the conception or design of the work; the acquisition, analysis, or interpretation of data for the work; drafting the work and revising it critically for important intellectual content; final approval of the version to be submitted/published; and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Preview of low safety adoption advertisement.
[PNG File , 709 KB - formative_v5i4e19022_app1.png]

Multimedia Appendix 2
Preview of neutral safety adoption advertisement.
[PNG File , 813 KB - formative_v5i4e19022_app2.png]

Multimedia Appendix 3

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Preview of high safety adoption advertisement.
[PNG File , 914 KB - formative_v5i4e19022_app3.png]

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Abbreviations

FFF: Farming, Fishing, and Forestry
NCCRAHS: National Children’s Center for Rural and Agricultural Health and Safety

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Original Paper

A Heart Rate Monitoring App (FibriCheck) for Atrial Fibrillation in General Practice: Pilot Usability Study

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Abstract

Background: Atrial fibrillation (AF) is a major risk factor for stroke. The current opportunistic screening procedure consists of pulse palpation and an electrocardiogram when an irregular rhythm is found. Smartphone apps that measure heart rhythm could be useful in increasing the detection of AF in a primary care setting.

Objective: We conducted a pilot study with the smartphone app FibriCheck to assess whether the introduction of such an app is feasible.

Methods: Four general practices across Flanders provided patient data for the study. Inclusion criteria for participants were aged 65 or older and a CHARGE-AF score of at least 10%. We excluded patients with known AF or a pacemaker. Participants were asked to measure at least twice a day with FibriCheck (for at least 14 days). They were provided the 36-Item Short Form Survey (SF-36) questionnaire both before and after the study, as well as different surveys concerning their user experience and general perception of technology.

Results: There were 92 participants (36 women and 56 men). The study population was relatively homogenous concerning risk factors and medication use at baseline. During the study period, 5/86 (6%) participants were found to have AF (6 dropouts). The average study period was 23 days and the average number of measurements per day was 2.1. Patient compliance was variable, but high. On the whole, there were no appreciable changes in quality of life. The overall user experience and satisfaction were very high.

Conclusions: FibriCheck is a relatively easy-to-use smartphone app to complement AF screening in primary care. Its implementation in this setting is certainly achievable, and one can expect high rates of patient compliance. Based on these results, a planned cluster randomized trial will be going ahead.

Trial Registration: ClinicalTrials.gov NCT03509493; https://clinicaltrials.gov/ct2/show/NCT03509493

(JMIR Form Res 2021;5(4):e24461) doi:10.2196/24461

KEYWORDS

atrial fibrillation; smartphone app; FibriCheck; primary care

Introduction

Atrial fibrillation (AF) has long been known as an independent risk factor for stroke [1]. It is highly prevalent among older patients in primary care, and the incidence is seemingly on the rise [2,3]. Hospitalizations for stroke are an important financial burden to the society, so a strategy for early and cost-effective screening interventions seems useful [4]. Current best clinical practice points to an opportunistic screening approach to detect AF, in which at-risk patients undergo routine pulse palpations and electrocardiograms (ECGs) when an irregular rhythm has been found [5,6]. Screening appears to be most cost-effective when done from age 65 [7]. Taking an ECG in routine general practice, however, is quite time-consuming. Furthermore, given

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the sometimes paroxysmal nature of AF, it could be missed by an opportunistic screening method during a routine consultation [8]. A significant proportion of these patients remain undiagnosed [9]. Holter measurements and event recorders could partially remedy this issue, but interpretation is again very time-consuming and unlikely to be very cost-effective [10].

Portable heart rate monitoring devices have recently been introduced to provide an on-the-go way to check for arrhythmias in general practice [11]. They could provide a convenient add-on to current opportunistic screening. Since the advent of smartphones, efforts have been made to use the phone's built-in camera to register heart rhythm via photoplethysmography [11,12]. Today, various smartphone apps are available [11,13,14], and they all perform well in terms of diagnostic accuracy and yield [15] and appear to be cost-effective [7].

In Belgium, the Hasselt-based firm Qompium has developed one such smartphone app named FibriCheck. The diagnostic accuracy of this app has already been studied previously [16]. An upcoming cluster randomized controlled trial will study its efficacy as a diagnostic tool to facilitate screening. This pilot study aimed to assess the ease of use and implementation of the FibriCheck app in a primary care setting.

Methods

Recruitment

Practices

This feasibility study ran from June to December 2017. Four general practices across Flanders were recruited in this study (Table 1). Every practice used different medical software to code diagnoses and parameters: a deliberate choice to test the ease with which data could be derived from each software package. Each practice was asked to include around 20 patients.

Table 1. Overview of recruiting practices.

Name of the practice	Place	Team	Medical software
Huisartsencentrum Millegem	Mol, Antwerp	4 GPs[a]	MediDoc
Groepspraktijk Hoeilaart	Hoeilaart, Flemish Brabant	6 GPs, 2 GP trainees	CareConnect
Huisartsenpraktijk Keerbergen	Keerbergen, Flemish Brabant	2 GPs, 1 GP trainees	Windoc
Praktijk Gilissen	Riemst, Limburg	2 GPs, 1 GP trainees	Prodoc

[a] GP: general practitioner.

Participants

We opted to only include patients at high risk for AF to test the suitability of the FibriCheck app. We only included the older population, as AF is more prevalent in this group and they would therefore benefit the most from this intervention. There was no control group. The 5-year risk of AF is commonly indicated using the CHARGE-AF score [17]. This score was calculated manually for each potential participant, by extracting the necessary data from the patient file. Frailty score was calculated according to Tocchi et al [18]. A score of 0 means no frailty, a score of 1-3 means increased risk of frailty, and a score of 4 or more indicates definite frailty.

We opted to exclude patients already on anticoagulants (the mainstay of treatment for AF with higher cardiovascular risk), as this screening intervention would probably not lead to any relevant change in treatment for that population.

The inclusion criteria were (1) a CHARGE-AF score of 10% or more and (2) aged 65 or older. Exclusion criteria were (1) known or already diagnosed AF (including known paroxysmal AF), (2) patient has a pacemaker, (3) patient takes oral anticoagulants, and (4) patient is unable to use a smartphone app due to physical, visual, or cognitive impairment.

Upon selection, participants were asked to sign a consent form to be included in the study.

Participants were given a unique coded account number, which is linked to the specific FibriCheck app on their smartphone. Smartphones were provided in case participants did not own one themselves; others just had to install the app.

At recruitment and at the end of the study, an ECG and a FibriCheck measurement were taken.

The time the physician spent to explain the study to the participants and on educating them how to use the FibriCheck app was registered.

In addition, physicians were asked to indicate what they would have done if the FibriCheck app was not available (ie, if they were not included in the study). There were 2 options: no action (and wait for the patients to consult on their own) or advise a follow-up consultation. Physicians could also indicate what exactly they would have done without the availability of the app, and how many consultations they normally anticipated during a 1-year period.

Measurements

The FibriCheck app uses the smartphone's built-in camera to measure the heart rate. The users are instructed to place their finger on the camera and wait for 60 seconds as a measurement is taken, preferably in the seated position with the arm resting.

At the start of the study, participants were asked to measure at least twice a day with the FibriCheck app and to indicate if they experienced any symptoms preceding the measurement. The minimum required measuring period was 2 weeks; the individual participant's study period ended after a maximum of 4 weeks. Patients were considered incompliant and excluded when there

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were no measurements for 2 weeks or more during the study period, or if they were lost to follow-up.

After measuring, the FibriCheck app reviewed every measurement immediately afterward, with 4 possible outcomes: normal measurement (no tachycardia, no extrasystole, no irregular rhythm; indicated in green), inadequate signal (indicated in blue), measurement requiring urgent attention (possible AF; not signaled to participants in the context of this pilot study), and warning (usually more than 4 extrasystoles, or bradycardia or tachycardia: indicated in orange). Participants were also able to indicate their stress levels with each measurement. The score ranged from 0 (low stress) to 10 (highest stress) with step intervals of 2.5.

Quality of Life

Patients were asked to fill in the 36-Item Short Form Survey (SF-36) questionnaire, to get an impression of their quality of life at baseline. This survey contains 36 questions from various health domains, such as physical functioning or emotional health [19]. It uses graded responses: answers corresponding to more favorable health states receive higher scores (the minimum and maximum being 0 and 100, respectively). The scores for the questions on a specific health domain are then averaged to compile a subtotal score. Each participant was asked to complete the questionnaire again at the end of the study period. The SF-36 questionnaire has been validated for use in general practice [20]. We used the Dutch translation in this study [21].

Technology Perception—App Usability

Participants were provided questionnaires at the beginning of the study, concerning their perception and familiarity of current technology. At the end of the study, a general questionnaire about their use of the FibriCheck app was provided. Answers were graded on a 5-step scale, ranging from “completely disagree” to “fully agree.” These questionnaires were created by the authors and were not validated previously.

Statistical Analysis

A 2-proportion, 2-tailed *Z* test was used to analyze the difference in risk factors and medication between male and female participants in the study. To compare the scores on the various domains of the SF-36 questionnaire, we used a 2-tailed Wilcoxon signed-rank test, as we did not assume normality. The value for any missing item was imputed as the mean value for nonmissing items.

We refrained from calculating the total average score of the SF-36 questionnaire. This is often done to form an idea about the general health of study participants. However, this supposes a 50/50 equilibrium between the mental and physical aspects of health, and this practice is generally discouraged [22].

The minimal clinically important difference for the health-related SF-36 questionnaire was calculated according to earlier studies for similar populations [23,24]. We used a distribution-based method, as an anchor-based method was not feasible for this pilot study. A cut-off value of 1 standard error of measurement (SEM) was used to define a meaningful improvement or deterioration, in line with previous studies [24].

The following formula was used to calculate the SEM, with σ being the SD of a particular test and *r* the reliability coefficient or Cronbach alpha of the same test [23]:

$$\sigma\sqrt{(1-r)}$$

Data for this formula, as applicable to the SF-36 questionnaire, were gathered from the Medical Outcomes Study [25].

The answers to the questionnaires concerning technology perception and usability of the FibriCheck app were weighted according to importance: for instance, “completely agree” (or a similar answer) was assigned a value of 2, “agree” a value of 1, “completely disagree” a value of –2, and so on.

For other data, we used descriptive statistics throughout.

Ethics Approval

This pilot study was approved by the Ethical Committee of Hospital Zuid-Oost Limburg (Genk, Belgium) on June 6, 2017 (registration number B371201731704).

Results

Participants

A total of 92 participants were recruited from the 4 practices listed in Table 1: (1) Huisartsencentrum Millegem (17 patients), (2) Groepspraktijk Hoeilaart (35 patients), (3) Huisartsenpraktijk Keerbergen (20 patients), and (4) Praktijk Gilissen (20 patients).

There were 36 female and 56 male participants in the study population. The mean age was 78 (SD 8.1; range 45-94 years). Ultimately, we did include 4 patients under 65 who met the other inclusion criteria. The rest of the population was 65 or older. The mean BMI was 28.1 kg/m^2 (SD 4.6; range 17.3-42.7 kg/m^2). In our study population, the mean frailty score was 2.6 with 21/92 participants (23%) having a score of 4 or more.

Before the study commenced, participants were asked whether they had used a smartphone before or had the ability to use a smartphone correctly. There was a response rate of 96% (88/92 participants). In total, 16% (14/88 participants) had a smartphone and knew how it worked, 32% (28/88 participants) did not have an idea of what to do with a smartphone, 13% (11/88 participants) had used a smartphone before and could manage, while 40% (35/88 participants) had used a smartphone but found they needed help.

At recruitment and at the end of the study, an ECG and a FibriCheck measurement were taken. Before commencement, 93% of participants (86/92) were in sinus rhythm, 6% (5/92) had ectopic beats, and 1% (1/92) had atrial flutter.

On average, physicians spent around 15 minutes to get participants started with the smartphone and the app (range 5-40 minutes), and another 21 minutes to fill in the necessary administrative paperwork (consent forms, patient education leaflets, etc.; range 10-40 minutes).

The risk factors of the participants, as well as the different medications they were taking at baseline, are listed in Multimedia Appendix 1.

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Physicians would have chosen the “wait and see” approach for 67/92 patients (73%), if the FibriCheck app would not have been available. In this scenario, they anticipated on average between 2 and 3 consultations over a 1-year period. The mean CHARGE-AF score for participants in the “follow-up” group was 20.89, whereas that in the “wait and see” group was 18.60.

Measurements

There were 24 consultations with 18/92 patients (20%) purely because of a FibriCheck finding, as well as 3 hospital admissions (3%) indirectly resulting from a finding on the app. All the aberrant rhythms detected during and at the end of the study are summarized in Table 2.

The average participant study period was 23 days. Participants conducted an average of 49.5 measurements during that time, which amounts to 2.1 measurements per day. Figure 1 shows the average number of measurements for each participant as a line. The “2 measurements per day” criterion is highlighted, which gives an idea about participant compliance.

Table 2. Rhythms detected during the study (N=86).[a]

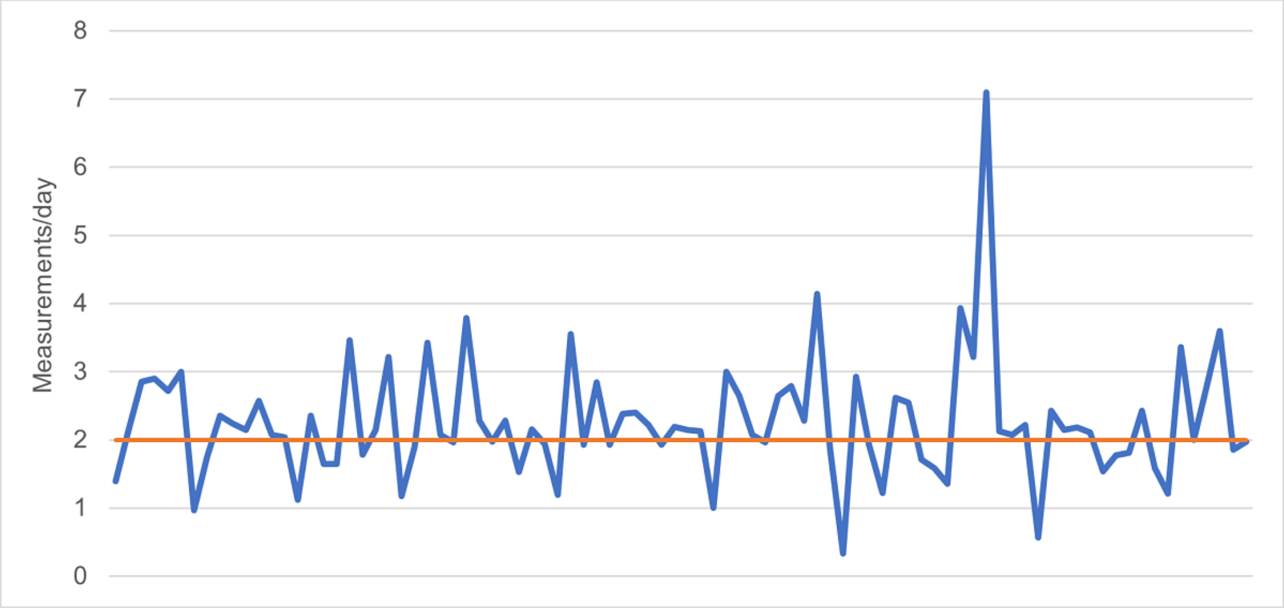
Heart rhythm	Value, n (%)
Ectopic beats (SVES[b]/VES[c])	10 (12)
Tachycardia	2 (2)
Atrial fibrillation	5 (6)

[a] Six dropouts: 4 exclusions by patient request, 2 excluded due to incompliance.

[b] SVES: supraventricular extrasystoles.

[c] VES: ventricular extrasystoles.

Figure 1. Average number of measurements per day, per participant.



A total of 4489 validated measurements were taken for 90 participants in total. Approximately 71% of participants (64/90) had 2 or more measurements per day. A summary of the most common symptoms accompanying the measurements is displayed in Figures 2 and 3. Most measurements did not report a symptom and for each measurement multiple symptoms could be reported. There were a total of 3313 measurements that had a stress level registered. The mean stress level was 2.29.

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Figure 2. Proportion of reported symptoms (N=4449); 40 measurements were not validated by the algorithm due to connection errors.

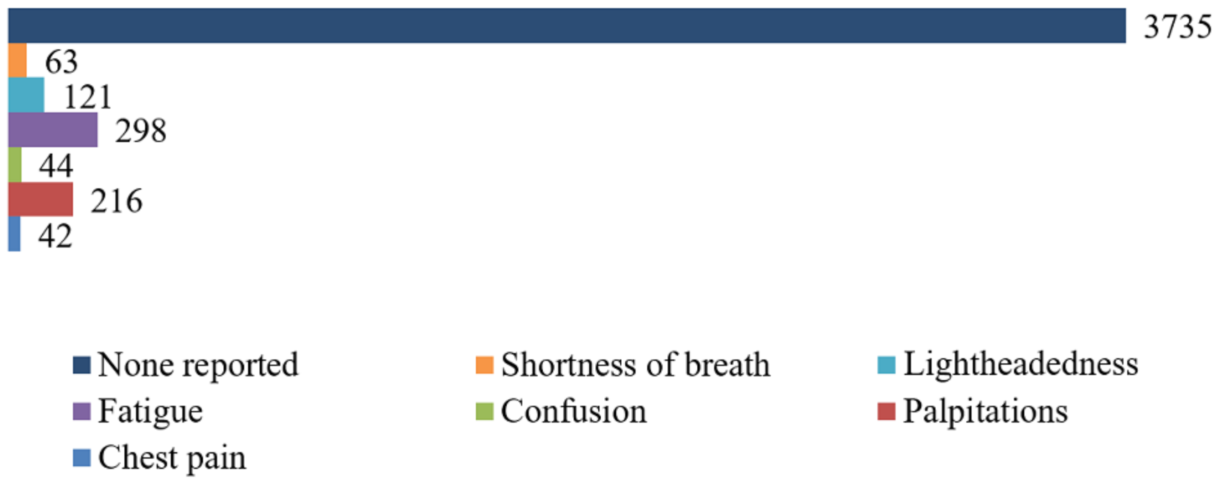
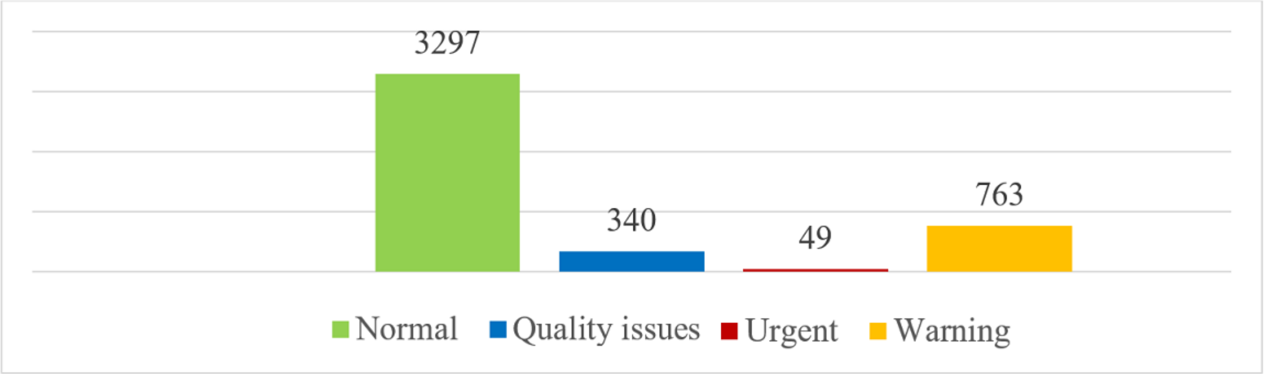


Figure 3. Number of different FibriCheck measurements (N=4449); 40 measurements were not validated by the algorithm due to connection errors.



Quality of Life

In total, 54 participants filled in the SF-36 questionnaire at the start of the study. We excluded 4 patients from the final analysis, because they failed to complete the questionnaire at the end of the study. Multimedia Appendix 2 shows the results for the 50 participants who completed the questionnaire.

Technology Perception and App Usability

The data on the technology perception, gathered at the beginning of the study, and the data on the use of the FibriCheck app, are summarized in Multimedia Appendix 3. The specific questions belonging to each category, together with their weighting, can be found in Multimedia Appendices 4 and 5. Results are weighted according to the different response categories: more positive or more negative responses are thus weighted accordingly. For purposes of readability, we did not plot the neutral answers. The response rates for the technology and FibriCheck surveys were 89% (82/92 participants) and 77% (71/92 participants), respectively.

Participants were most satisfied with the following aspects of the app: simplicity (52/71, 73%), on-the-go heart rhythm analysis (52/71, 73%), and the possibility to be followed remotely (48/71, 68%).

Discussion

Principal Findings

This pilot study concerned the ease of use and implementation of the AF case-finding app FibriCheck in primary care. The study population was rather homogenous, and smartphone familiarity at baseline was relatively poor. We found a high measurement compliance, with most participants finding the app easy to use. AF was detected in 5/86 participants (6%). Overall, the user experience was positive, and most participants agreed the app gave them a feeling of reassurance and could benefit their doctor–patient relationship.

Participants

This pilot study merely focused on the feasibility of the introduction of an AF case-finding app in a primary care setting. As we were testing the app itself rather than its effect on the detection rate of AF, we did not add a control group and focused only on those patients we thought would benefit the most from such an app.

The study population of 92 participants was predominantly male, but there were no differences between men and women regarding risk factors and medication use at baseline. However, the proportion of men with a history of thrombosis or peripheral vascular disease was significantly greater (*P*=.02 for both). In

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addition, our study population was generally overweight, so it might not be representative of the average general practice population.

Smartphone familiarity was rather poor in our study. Use of smartphones does tend to be lower in older populations, for reasons such as a lack of interest in current technologies, visual impairments, or financial problems [26]. However, most participants in our study had no problems using the FibriCheck app. There was some preliminary work involved in acquainting participants with the app, which took around 15 extra minutes in our study. This is not extraordinary, though quite significant in the daily schedule of a general practitioner.

Measurements

An important feature of this pilot study was patient compliance. As this was a preliminary study in anticipation of a larger cluster randomized trial, we set the bar for noncompliance quite low: only participants with no measuring activity for 2 weeks or more were excluded from the study.

The 2-week mark proved easy to reach: the average study period was 23 days. This timeframe was chosen deliberately, as 14 days seem to be a sufficient time to detect most AF cases [27]. The average number of measurements per day was 2.1, with a large spread (Figure 1). Around 71% (64/90) of participants measured twice a day or more. Methodologically similar studies found compliance rates ranging from 75% to 95% [13,27], whereas in another study the measurements were performed in the presence of a trained personnel [14].

The proportion of participants with AF in this study was 6% (5/86), higher than other comparable studies or the general population [13,27,28], most likely because we only included high-risk patients and possibly because of the effect of screening. Another device study [14] differed in the study design, which makes comparison difficult. The most indicated symptoms when conducting a FibriCheck measurement (if there were any) were fatigue and palpitations, in line with findings from a similar study [13].

Quality of Life

We asked participants to complete the SF-36 questionnaire both before and after the study, to see if there were any appreciable changes in quality of life. There were no changes in any of the SF-36 health domains, except for Emotional Well-being, which showed a significant decrease ($P<.001$). This could be due to any number of factors: added stress due to the enrollment in the study in general, or anxiety because of preoccupation with heart disease in particular, possibly amplified by having to test the heart rhythm at least twice a day. Patient anxiety could potentially be diminished when the device does not give direct feedback about the results, as in an ECG app [13].

Technology Perception and App Usability

The participants in our study were very accepting of the current technology and very open to try the FibriCheck app, as most could see its benefit if data protection was properly ensured. Another study found that technology acceptance among the elderly seems to be increasing, provided certain barriers (privacy issues and design) are well taken care of [29]. The FibriCheck app was found to be easy to use, and it gave most participants a feeling of reassurance and safety. They also believed it improved their doctor–patient relationship.

Strengths and Limitations

This was the first study to assess the feasibility of integrating the FibriCheck app in a primary care setting. The study population was sufficiently homogenous to be able to draw some relevant conclusions. There was no control group, as this was merely a feasibility study. A comparison with routine care was thus not possible.

Overall, there were varying amounts of missing data, though generally not very much (up to 4.0% [26/644 data points] for the demographic data) and at acceptable levels for the different surveys. We decided to ignore missing data when reporting descriptive statistics but opted for mean value imputation in the surveys.

Conclusions and Implications for Practice

Integrating a smartphone app such as FibriCheck in primary care seems to be an easy way to complement routine screening. We found high rates of patient satisfaction, reassurance, and compliance. Smartphone familiarity might still be an issue, although most participants of this study had no problem using the app.

The findings in this study pave the way for the routine use of new technology in a general practice setting. Given the widespread use of smartphones, screening apps could be a cost-efficient way of complementing routine care with smart technology. Apps like FibriCheck could potentially increase AF detection in general practice, compared with traditional screening, decreasing the burden of associated morbidity and mortality. As technology acceptance among the elderly will continue to increase, so will the relevance of screening apps. Cost–benefit issues and potential barriers to large-scale implementation have yet to be identified.

A cluster randomized trial, to compare the diagnostic yield of FibriCheck with usual care, is planned (ClinicalTrials.gov NCT04545723). In short, the results of this pilot study indicate that the implementation of a smartphone screening app in general practice is easy and feasible, which could guide future trials by shifting the focus away from practical issues, toward the specifics of screening and diagnosis.

Acknowledgments

This study was funded by Qompium (based in Hasselt, Belgium), the developer of the FibriCheck app. They also provided technical assistance and smartphones for participants who did not have one. Study data are available for extraction from their servers.

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Authors' Contributions

SB wrote the manuscript and performed final statistical analyses. BV conceived the study design and assisted in writing. TP participated in data extraction, collection, and analysis. All authors proofread the final manuscript.

Conflicts of Interest

TP is an employee of Qompium, the study's funder. Other authors declare no conflicts of interest.

Multimedia Appendix 1
Risk factors and medication of participants at baseline, for men and women.
[PDF File (Adobe PDF File), 139 KB - formative_v5i4e24461_app1.pdf]

Multimedia Appendix 2
Comparison of SF36 domain scores, at start and end of study (N=50).
[PDF File (Adobe PDF File), 94 KB - formative_v5i4e24461_app2.pdf]

Multimedia Appendix 3
Questionnaires concerning technology perception and FibriCheck usage.
[PDF File (Adobe PDF File), 94 KB - formative_v5i4e24461_app3.pdf]

Multimedia Appendix 4
Technology perception questionnaire with weighting.
[PDF File (Adobe PDF File), 98 KB - formative_v5i4e24461_app4.pdf]

Multimedia Appendix 5
FibriCheck usage questionnaire with weighting.
[PDF File (Adobe PDF File), 106 KB - formative_v5i4e24461_app5.pdf]

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Abbreviations

AF: atrial fibrillation
ECG: electrocardiogram
SEM: standard error of measurement

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Original Paper

User Perspectives on Barriers and Facilitators to the Implementation of Electronic Health Records in Behavioral Hospitals: Qualitative Study

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Abstract

Background: Despite the rapid adoption of electronic health records (EHRs) resulting from the reimbursement program of the US government, EHR adoption in behavioral hospitals is still slow, and there remains a lack of evidence regarding barriers and facilitators to the implementation of mental health care EHRs.

Objective: The aim of this study is to analyze the experience of mental health professionals to explore the perceived barriers, facilitators, and critical ideas influencing the implementation and usability of a mental health care EHR.

Methods: In this phenomenological qualitative study, we interviewed physicians, nurses, pharmacists, mental health clinicians, and administrative professionals separately at 4 behavioral hospitals in the United States. We conducted semistructured interviews (N=43) from behavioral hospitals involved in the adoption of the mental health care EHR. Purposeful sampling was used to maximize the diversity. Transcripts were coded and analyzed for emergent domains. An exploratory data analysis was conducted.

Results: Content analyses revealed 7 barriers and 4 facilitators. The most important barriers to implementing the mental health care EHR were the low levels of computer proficiency among nurses, complexity of the system, alert fatigue, and resistance because of legacy systems. This led to poor usability, low acceptability, and distrust toward the system. The major facilitators to implementing the mental health care EHR were well-executed training programs, improved productivity, better quality of care, and the good usability of the mental health care EHR.

Conclusions: Health care professionals expected to enhance their work productivity and interprofessional collaboration by introducing the mental health care EHR. Routine education for end users is an essential starting point for the successful implementation of mental health care EHR electronic decision support. When adopting the mental health care EHR, managers need to focus on common practices in behavioral hospitals, such as documenting structured data in their organizations and adopting a seamless workflow of mental health care into the system.

(JMIR Form Res 2021;5(4):e18764) doi:10.2196/18764

KEYWORDS

electronic health records; mental health care; qualitative study; mobile phone

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Introduction

Background

Mental illnesses are common and costly for patients and their families. It is estimated that in 2017, 970 million people worldwide had a psychiatric or substance use disorder. The largest number of people had an anxiety disorder, estimated at approximately 4% of the population [1]. More than half of Americans will have had a clinically significant mental illness, such as a psychotic disorder, a major depressive disorder, an anxiety disorder, or a substance use disorder [2]. People with mental illnesses also have higher rates of coexisting medical diseases, lower life expectancies, and health care costs that are 2-3 times those of people without mental illnesses [3]. If medical information is shared and managed between medical institutions, this problem can be effectively managed by reducing duplicate prescriptions and proactively detecting and intervening in psychiatric problems. Prerequisites for the exchange of medical information are the dissemination of electronic health records (EHRs).

The Health Information Technology for Economic and Clinical Health (HITECH) Act was prompted in 2009 by evidence that the use of EHR can improve the quality of care delivered [4]. HITECH drove annual increases in EHR adoption by 8% points after implementation of the act’s incentive program [5,6]. However, EHR use in mental health settings is still lagging behind. Compared with general medicine and surgical hospitals possessing certified EHRs, only 49% of psychiatric hospitals have certified EHRs as of 2017. The number is lower than rehabilitation (89%), children’s (87%), and acute long-term care (59%) hospitals [6,7].

Previous Studies

Previous studies have suggested that the use of EHRs has greatly impacted the ways in which health care professionals document and manage patient information [8-11]. Functions in mental health care EHRs as well as their provision in hospitals are important. In fact, previous studies revealed that 27.7% of patients with bipolar disorder and 27.3% of patients with depression lacked a diagnosis of their mental illness in their primary care EHRs. Furthermore, data on mental health patient-provider encounters occurring in nonprimary care settings were often completely absent from the primary care record [12]. A previous study suggested that 3 prominent barriers to the adoption of mental health care EHRs should be considered: complex privacy-related laws and regulations, inadequate financial incentives, and assistance for psychiatric providers [2]. Another study suggested that EHRs designed for mental health care must satisfy the needs of clinicians for the successful uptake of necessary information and improvement in patient experience to disseminate them efficiently [13]. Although a number of studies have evaluated the effectiveness of EHRs, there have been few studies on barriers and facilitators to the adoption of mental health care EHRs from the perspective of mental health clinicians, nurses, pharmacists, and administrative professionals in mental hospitals.

Aim

The objective of this study is to analyze barriers and facilitators to the adoption of mental health care EHR. To address them, we thoroughly interviewed end users with a qualitative research method when they make transition from paper medical documents to EHRs.

Methods

Design

In this study, we used phenomenology. It is an approach to qualitative study that focuses on the commonality of an experience within a participating group. Through a phenomenological approach, we aim to construct a universal meaning of experience. By conducting a qualitative analysis based on semistructured interviews with mental health clinicians and administrative professionals, we sought to explore barriers, facilitators, and ideas regarding the implementation and usability of a mental health care EHR. This study followed the Consolidated Criteria for Reporting Qualitative Research Guidelines (Multimedia Appendix 1 [14]).

Setting and Participants

This study was conducted at 4 behavioral hospitals under the same parent corporation. The hospitals provide both inpatient and outpatient services for mental health and substance abuse treatments in 2 states.

In 2017, corporate leaders decided to implement an EHR. Owing to the lack of sophisticated behavior-oriented EHR systems, they launched a project to customize an advanced medical EHR into a behavioral version by tailoring it to the workflow of behavioral hospitals. The long-term goal was to adopt this mental health care EHR, called BESTCare 2.0B, across all the behavioral hospital branches after successfully implementing a standardized mental health care EHR in the first hospital [15-17].

The pilot project was initiated at a behavioral hospital in California. The hospital was selected because it was the most acute hospital with more complicated workflows than its sister hospitals. A group of clinicians and business analysts from the vendor underwent a 2-month on-site gap analysis. They then worked with information technology engineers for 6 months to customize a general hospital’s EHR into a behavior-specific version.

One of our researchers, DL, is a business analyst who participated in developing a standardized version of the mental health care EHR for the Aurora hospitals. In the pilot project, he analyzed the paper-based workflow by determining requirements, helped to design the To-Be process, and suggested alternatives. He also trained physicians, nurses, pharmacists, mental health clinicians, and administrative professionals before the implementation; supported the go-live process; and followed up with modification requests from 2 hospitals located in California. With his extensive experience in the mental health care EHR implementation project and with the help of other trainers, the study participants were selected through purposive sampling. We concluded candidates to be suitable for the

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interview based on the following criteria: (1) must be an active user of the mental health care EHR; (2) is identified as a representative of their job group in having a profound understanding and is responsible for knowledge management inside the department; or (3) must be at a management level and must be well acquainted with the electronic process with the mental health care EHR. Then we contacted the CEO and directors to schedule the interview with the identified candidates. However, as some of the candidates were unavailable during the interview sessions, we asked the directors to recommend a substitute who best matched the aforementioned criteria. Therefore, this study had originally planned purposive sampling but conducted snowball sampling to find the rest of the study participants. As for the quota, we mainly focused on studying users with a clinical background, such as physicians, nurses, pharmacists, and mental health professionals. The study only included a few administrative professionals who best represented their job group, as stated in the criteria. As many physicians from hospital A submitted requirements, suggestions, and feedback while developing the standardized version of the mental health care EHR, the largest number of physicians were interviewed as they best understood the system and its implementation. Hospital B was relatively smaller in size than hospitals A, C, and D and had fewer staff to interview. However, because of fewer human resources, administrative departments such as Health Information Management (HIM) were much more in need of using and maximizing the benefits of the mental health care EHR. They were recommended for the interview by others as acknowledged to be thoroughly aware of how the system works. Only one pharmacy director ran the inpatient pharmacy in all 4 hospitals, and they were all interviewed. The director of clinical services in hospital A had retired and was unavailable.

One of the criteria for purposefully selecting our research participants was that the person had to be identified as a representative of their job group in terms of having a profound understanding and should be responsible for knowledge management inside the department or had to be at a director level and well acquainted with the electronic process. To identify these participants, we collected opinions from mental health care EHR trainers who also supported each department at the time of go-live process. In addition, we had the director from each department confirm that they are suitable for the interview when asking to schedule the time. However, in terms of gender ratio, age distribution, and experience of EHRs, there were apparent limitations because when considering these aspects, not all participants fit into the aforementioned criteria. For example, all physician participants who met the criteria were male. Of the 20 nurses, 15 were female and 5 were male. More than half of them were in the age group between 31 and 40 years. There was only one pharmacy director in each hospital, and all were female. In addition, the 4 hospitals could not fully represent mental health hospitals. They are located in only 2 states—2 in California and 2 in Arizona. At a minimum, state law, clinical practice, and work patterns can be different from one state to another, requiring at least more than one hospital in each state to represent mental health hospitals in the United States.

The interview was conducted at 4 of the 5 behavioral hospitals where the mental health care EHR was implemented. A semistructured interview questionnaire was formed through biweekly meetings until every researcher agreed on the contents of the questionnaire (Textbox 1).

Textbox 1. Semistructured interview questionnaire.

Interview questions

- What was your first impression of the mental health care electronic health record (mental health care EHR) implemented in this hospital?
- Did you have experience with other behavioral or general electronic health records before?
- How long did it take for you to get comfortable with the mental health care EHR?
- Were there any barriers to the implementation of the mental health care EHR?
- What do you think would have helped to better implement the mental health care EHR?
- What screens or functions do you use in the mental health care EHR and how do they impact your daily practice?
- Do you think the communication has gotten better or worse with the mental health care EHR?
- How is the navigation when using the mental health care EHR?
- What do you think of the Clinical Decision Support System in the mental health care EHR?
- What are your thoughts on using tablet PCs in the inpatient unit? How would you like to utilize tablet PCs on the floor?
- Are there any issues with the mental health care EHR that need to be resolved?
- Do you think the mental health care EHR is well customized for the behavioral workflow? Is there anything missing?
- What functions or features do you want to add to the mental health care EHR?
- Do you have any suggestions or recommendations for the mental health care EHR to improve your work experience?
- Is there anything else you want to mention regarding the mental health care EHR?

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After a thorough review of the data by 2 experienced qualitative investigators, we created a preliminary codebook, with separate codes for patient and physician transcripts. Using inductive content analysis, the authors coded all transcripts with additional steps to ensure validity. We addressed discrepancies and reached a consensus in biweekly meetings. Throughout the coding process, the team discussed and revised the codebook and returned to the previously analyzed transcripts to ensure consistency.

As the mental health care EHR was launched at the hospitals in different time periods, the hospital's length of experience in using the mental health care EHR varied at the time of the interview, as presented in Table S1 of Multimedia Appendix 2. Before the adoption of the mental health care EHR, 2 hospitals located in California had been using paper, except for a stand-alone electronic pharmacy management system for the pharmacist to enter paper-signed medication orders. In contrast, physicians, pharmacists, and nurses from 2 hospitals in Arizona had been using a legacy computerized physician order entry (CPOE) system. The characteristics of participating hospitals are presented in Table S1 of Multimedia Appendix 2.

The study participants were selected through purposive sampling [18]. We aim to include participants from various professions who had in-depth knowledge of the work process with the mental health care EHR. Potential quotas for purposive sampling were more than 20 people for doctors and nurses and more than 3 people each for administrative positions and pharmacists to listen to the opinions of direct users of the mental health care EHR and those of support positions.

Several participants were recommended by hospital management. Most of them were generally acknowledged as *Superusers*, whom their colleagues would look for if they initially ran into an issue with the mental health care EHR, implying that they had a good understanding of the operation of the mental health care EHR in day-to-day tasks.

Data Collection

DL and KL conducted face-to-face, semistructured interviews. DL, a male researcher with a BA degree who had been working in the pilot project in developing the mental health care EHR as a business analyst, led the interview. He had also trained physicians, nurses, pharmacists, and mental health clinicians before the implementation of the mental health care EHR in 2 Aurora hospitals located in California. The positive relationship with the study participants in the 2 hospitals helped to create an open atmosphere, thereby encouraging them to speak more at ease about their experience. A female researcher with an MS degree, KL, who had no previous relationship with the study participants, took notes during the interviews. Both interviewers received training for qualitative interviews. Interviews were audio recorded in a closed office or conference room with a recording device and lasted from 20 to 60 minutes. Nobody was present in addition to the participants and researchers. During the sessions, DL followed a semistructured interview questionnaire that covered topics related to their experiences and thoughts regarding the mental health care EHR. Although most of the sessions were conducted one-on-one, 4 sessions were interviewed in a group of 2 and 1 session was interviewed in a group of 3 because of working shifts and time limitations. The questions for the group interviews were identical to those of the one-to-one interviews. The researchers adopted the interview guidelines that were developed based on previous research and approved by members of the eHealth research team at Seoul National University Bundang Hospital (SNUBH).

Data Analysis

We used an explorative content analysis method to capture the perspectives concerning the barriers and facilitators when adopting an mental health care EHR. The recorded interviews were transcribed by an external professional transcription service and were further repeatedly reviewed and corrected by a researcher (DL) to enhance the accuracy of the transcriptions. All anonymized transcriptions were uploaded to Dedoose software and coded for analysis. To ensure reliability, the transcripts were independently read and coded by 2 individual researchers (DL and KL). The initial codes were inductively generated from the data. The codes were grouped into 3 major themes: barriers, facilitators, and suggestions or ideas by each profession. The identified barriers and facilitators relevant to the study were discussed regularly until both researchers agreed that they had reached saturation. All the researchers verified the results until we reached a consensus on the clarified themes.

Ethics

Before the interviews, the researchers explained the research objectives and purpose of the study. Consent forms were signed by all participants voluntarily. None of the participants refused the interviews. This study was approved by the Institutional Review Board of Human Research of SNUBH, Republic of Korea (Protocol No. B-1904-534-301).

Results

Participant Demographics

We conducted interviews between October 31, 2020, and November 19, 2020. A total of 10 physicians, 20 nurses, 4 pharmacists, 5 mental health clinicians, and 4 administrative professionals participated in the interviews. Many management-level personnel such as medical directors, chief nursing officers, directors of each department, and managers or supervisors also participated. From a total of 43 participants, the study included 19 directors, 10 managers or supervisors, and 14 end users, as presented in Table 1.

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Table 1. Demographic characteristics of participants (N=43).

Category and variables	Value, n (%)
User group	
Physicians	10 (23)
Nurses	20 (47)
Pharmacists	4 (9)
Mental health clinicians	5 (12)
Administrative professionals	4 (9)
Gender	
Male	18 (42)
Female	25 (58)
Age (years)	
<30	1 (2)
31-40	18 (42)
41-50	8 (19)
51-60	9 (21)
61-70	6 (14)
≥70	1 (2)
Career (years)	
<9	15 (35)
10-19	12 (28)
20-29	10 (23)
30-39	4 (9)
≥40	2 (5)
Number of EHRs[a] used before	
0	9 (21)
1	7 (16)
2	11 (26)
≥3	16 (37)
Management level	
Director	19 (44)
Manager or supervisor	10 (23)
End user	14 (33)
Facility	
Hospital A	13 (30)
Hospital B	9 (21)
Hospital C	11 (26)
Hospital D	10 (23)

[a] EHR: electronic health record.

A total of 10 physicians included 8 psychiatrists and 2 internists. Nurses were working in various locations and roles, including inpatient ward nurses, medication nurses, assessment and referral nurses, education nurses, and utilization review nurses. In all 4 hospitals, only 1 pharmacy director operated the inpatient pharmacy during the day with one or more pharmacy technicians. Therefore, we interviewed all the 4 pharmacy directors. Mental health clinicians included licensed therapists, counselors, and social workers. Administrative professionals included HIM professionals, compliance officers, and business development officers.

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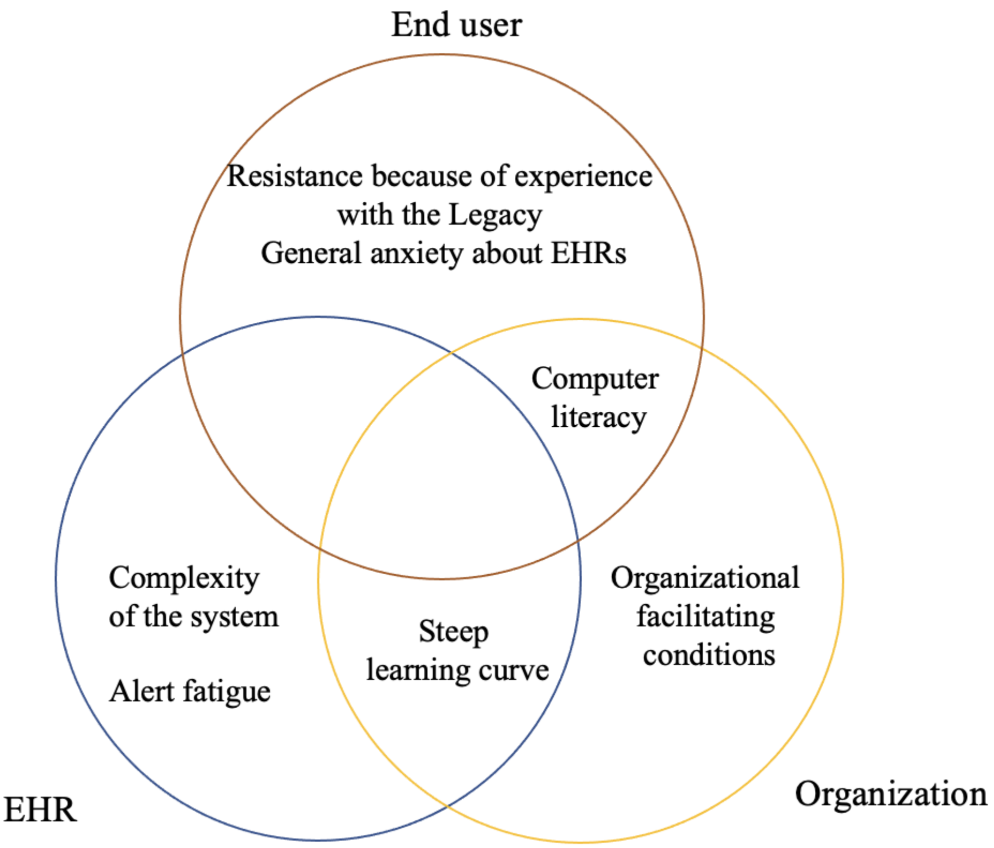
Barriers

We found 7 major barriers to benefitting from the mental health care EHR (Figure 1).

Figure 1. Parties or elements requiring improvement to overcome the 7 barriers. EHR: electronic health record.



Computer Literacy

The skill sets to handle tasks with an EHR varied by profession. Nurses most frequently reported that their colleagues encountered difficulties with computer proficiency. A number of them were simply not exposed to computers in the past. The lowest level of computer literacy was having trouble with double-clicking the mouse. Although the mental health care EHRs required single clicks most of the time, failing to double-click disrupted nurses to proceed to the next step. The next hurdle for nurses familiar with controlling the mouse and keyboard was not being able to manipulate multiple screens and functions according to their needs:

> *We have some nurses that aren't really used to working on computers. They didn't have to before for this job really. That was the biggest challenge.* [B022, Nurse]

Physicians mostly mentioned having trouble with slow typing, because of the relatively lengthy psychiatric assessments and narratives that summarize the patient’s diagnosis and condition. Almost all of these participants self-referred themselves as being old.

General Anxiety Toward EHRs Among Staff

Not only did the staff with inadequate computer skills physically have trouble with the EHR but they also had psychological pressure in the process. The spread of anxiety in using the mental health care EHR had been affecting some of the older staff to consider quitting when perceiving the system as too modern for themselves:

> *The first day I came, I thought maybe I'm going to put out my resignation letter. I didn't know where this was leading me to.* [B031, Nurse]

All physicians who were trying the mental health care EHR for the first time reported that they did not have a good first impression of the system. This became a mental barrier to accepting the new technology:

> *It came across as very detailed, but complicated and overwhelming. Especially for somebody like me who is not EHR experienced. I haven't had an EHR before. No, I have no experience with other EHRs before this one.* [C001, Physician]

Complexity of Mental Health Care EHR

The layout of the user interface (UI), including the alignment of patient information, orders, medical records, assessments, exam results, and a bird’s-eye view of the patient’s treatment history, had often been reported to be complicated at first. The majority of physicians who had not been using an EHR before provided negative comments about the perceived complexity and ease of use:

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> *The first impression, honestly, was that it's going to be too much work and that it's not that easy to use.* [C002, Physician]

Many nurses, if not overwhelmed by their low computer literacy, have reported difficulty with the mental health care EHR in finding specifics on many different screens. The mental health care EHR had set its core features in each specialized screen and allowed multiple ways to access them to accommodate preferences of each user. That, in the beginning, confused the nurses, as they had the broadest range of access to screens from the nursing module, multidisciplinary care plans, and even order-related screens:

> *For the nursing piece, there's quite a bit to navigate through finding the medical care plans, finding the "Order Entry." The navigating for nursing is by far the hardest in the building and the most in-depth.* [B026, Nurse]

Pharmacists generally thought that information displayed to them was too detailed. They reported that it was not a problem for them clinically, but the barrier was more related to the pharmacy system being too big for its size and resources available in a small inpatient pharmacy:

> *If you're in a larger hospital where there's a lot of staff, this is appropriate. But where we don't have as much staff, I think, and we're a smaller hospital, I think all of the different features, it's a little too much and overwhelming for everyone.* [B027, Pharmacist]

Steep Learning Curve

Among the mental health professions, the majority of the inpatient nurses perceived that there was a lot to understand to get used to the routine tasks conducted in their stations through the mental health care EHR:

> *It's just that, to learn so many new things all at once was the hard part, I think.* [B006, Nurse]

On the contrary, mental health clinicians and administrative professionals mentioned far less difficulty in overcoming the learning curve.

Alert Fatigue

Some pharmacists complained of the excessive number of alerts from the Clinical Decision Support System (CDSS) when verifying medication orders. Although these alerts were categorized into multiple levels, which required different actions such as selecting a reason for overriding if it was a high-level alert and having to read and pass the informative message if it was minor, some reported the fatigue to be accumulating regardless:

> *What came up was "high dose over recommended max," but there's so many alerts that I feel as if everyone's going through decision fatigue, because everyone's just like, "bypass, bypass."* [B010, Pharmacist]

Inpatient nurses had a similar issue with *New order alert* notifications. This feature refers to nurses receiving alerts regarding any new or updated orders from physicians issued to patients in their inpatient ward. Although this feature provided options to control the frequency of alert notifications by oneself, some nurses had turned this off because of alert fatigue:

> *They're constantly getting the [New order] alerts and sometimes the nurses will turn that feature off to not have to keep getting those alerts.* [B017, Nurse]

Knowing the circumstances, some nurse managers made requests to modify the system by turning on the nurse's alert notification by default.

Organizational Facilitating Condition

The corporate central medical committee has been managing the medical contents and regulatory compliance of the 4 hospitals. Notably, it played a vital role in the adoption of the mental health care EHR by standardizing the electronic forms and their contents. Although the participants appreciated the overall facilitating condition, physicians mentioned that clinical materials needed correction even after the implementation:

> *I think it definitely is a robust system. The thing is that a lot of it is our own doing. I don't think the [mental health care EHR] had anything to do with it. Forms we asked are added as we told them, but some of them need to change. For example, there is an element called "patient insight." All the choices are related to poor insight, so you have to use "Other" and then write it. "That patient has fairly good insight."* [C009, Physician]

In addition, some participants pointed out that there were technical support and communication channels to the corporate committee. However, organizational decision making should have been more agile after adoption:

> *And so the channel is there, but in the process when we all launched this, the changes were very slow. ...the impression I got is that it was very slowly implemented at the time.* [C002, Physician]

The fact that the corporate committee did not follow up and provide feedback for the modification requests swiftly as expected by end users seemed to negatively impact even those who were satisfied with the successful adoption of the mental health care EHR:

> *I think the initial implementation was very good. Very good. The follow-up, not so much. As I go along and it is very difficult to communicate, to who is the one who is going to address it and what is the priority? ...I think we make a request to the hospital identified person and we don't know then what happens.* [C009, Physician]

Resistance Because of Experience With the Legacy System

As mentioned earlier, unlike the hospitals in California, 2 hospitals in Arizona had been using a legacy CPOE system. Experiences of pharmacists and nurses with the legacy system had affected the perceived usability of the newly adopted mental health care EHR. The resistance from a couple of pharmacists

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was because of the idea that one screen was sufficient for the task, as compared with 3 separate screens full of information:

> *Our old system, everything was on one screen. The doctors were entering orders on one screen. We were verifying on the same screen. It was all done on the same screen. There's three screens now. Whereas before, everything was just done on one screen. It wasn't all of this information.* [B020, Pharmacist]

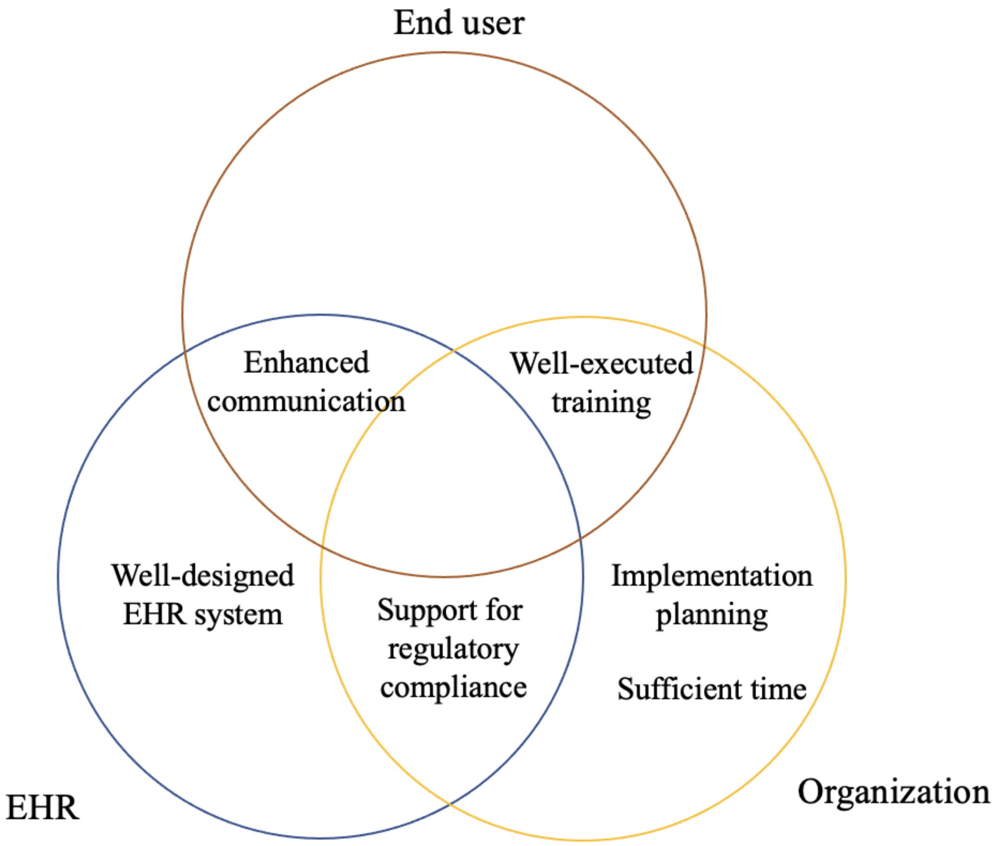
They also previously performed the Closed-Loop Medication Administration (CLMA) with a barcode scanner. CLMA, which greatly reduces medication errors by checking the 5 rights, was no longer available with the mental health care EHR. The absence of a legacy system's drug administration scanning functionality caused medication nurses to feel ill at ease during the administration process. While acknowledging other benefits and strengths of the mental health care EHR, nurses were asked to add back the safety net that was in place:

> *We had the scanning features. We had the [CLMA] alerts. It's really just fine tuning so that they feel comfortable with it.* [B026, Nurse]

Facilitators

We found 4 significant facilitators to benefitting from mental health care EHRs (Figure 2; Textbox 2).

Figure 2. Parties or elements related to facilitators. EHR: electronic health record.



Textbox 2. Facilitators to benefitting from the mental health care electronic health record.

Mental health–centered electronic health record (EHR)

- EHR tailored to behavioral workflow
- Support multidisciplinary documentations
- Support regulatory compliance

Well-designed EHR system

- Easy to use (perceived ease of use)
- Improved productivity
- Good usability
- Flexibility of forms

Advantages of using an EHR

- Easy access to patient information
- Improved patient safety and quality of care
- Enhanced interprofessional communication

Implementation strategy

- Well-executed training
- Sufficient implementation time
- Implementation planning

Mental Health–Centered EHR

In terms of accommodating its unique workflow, physicians who had experience with other EHR systems addressed the fact that the system accomplished that minimum but crucial requirement and showed gratitude for not being a workaround within a general EHR:

> *This mental health care EHR is more comprehensive and more relevant to psychiatry. With other EHRs, relevance to psychiatry is not high. They have a little bit of a section of psychiatry. This is more relevant, and I find it comprehensive, easy to use, and navigate it very well.* [C001, Physician]

Nurses and mental health clinicians echoed the same thoughts. From nurses working in the intake department who first assessed and admitted the patient to the nurses working in the inpatient unit, all had agreed that the work process was well integrated into the mental health care EHR:

> *This mental health care EHR is drastically different. I think it fits well for what we do, workflow wise. I have no issues using it, training on it.* [B001, Nurse]

Another element that differentiates mental health from other specialties is the multidisciplinary treatment team working together to provide patient care. The team discusses the patient's problems and collectively sets up treatment plans and documents parts of the sections defined by the job group. The mental health care EHR supported multidisciplinary documentation, and this was a great relief to mental health professionals:

> *All the clinical forms and everything that we need to do, treatment plans, all that, it flows nicely.* [B012, Mental health clinician]

In addition, administrative professionals and directors felt that the mental health care EHR contributed in ensuring that the regulatory requirements were in place. Regulatory compliance had always been a delicate issue when working on paper. However, it proved to be less of a burden when the mental health care EHR managed to satisfy the surveyors with what was mandated:

> *I'm in charge of all the joint commission and Center for Medicare and Medicaid surveys, and the mental health care EHR has everything in there that a surveyor would want to see. I got to give it to them, they did a good job form-wise, to make sure everything was there.* [B013, Administrative professional]

Well-Designed EHR System

In addition to developing an EHR to run in the behavioral setting, it was equally crucial for the mental health care EHR to deliver the advantages of using a thoroughly designed electronic system. Despite having a high number of negative first impressions from all professions, many felt that the mental health care EHR was easy to learn during the training sessions. Most physicians found that this system was not difficult at all:

> *Ordering is pretty self-explanatory. Overall it's well presented. I think presentation-wise, it is clear. I think initially there were a lot of tabs that made some sort of concern on how many tabs there were, to kind of get adjusted. But after the first training session it*

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> *actually made sense and it felt organized in a categorical way.* [C004, Physician]

Although numerous nurses had to break out of their comfort zone in trying out modern technology, they started to gain confidence in a short time period:

> *And when I first started to see it, it became clear to me that it was going to be pretty easy. So very user friendly and easy to follow. I liked it. I made the correlation between a smartphone with the apps. So, my brain got it.* [B001, Nurse]

Superusers shared their thoughts of the mental health care EHR with their colleagues when training for go-live process. Positive opinions on the perceived ease of use encouraged a vast majority of the nurses to see what they could take advantage of every day:

> *I tell people this when I'm training them, if you can use your smartphone, you can use the mental health care EHR. It's that simple. I tell people it's one of the easiest systems I have used. So that would make it in itself one of the best systems. And I have had a few nurses that have worked at other hospitals and they too have said that this is one of the easiest systems that they have used. Overall it's very easy to follow. It's very easy to figure out and you can solve it on your own. So, yes, it's definitely efficient, effective, and easy.* [B001, Nurse]

To mental health clinicians who facilitated group sessions for patients, using the mental health care EHR meant spending much less mental and physical effort throughout the day:

> *After it launched, I was very excited. It was quick and fast. Going from printing out over 200 documents a day and using over 200 labels a day, running out of pen ink, hand cramps. So I was excited that it was electronic because things were done smoother.* [B021, Mental health clinician]

In addition, mental health clinicians highlighted efficiency, the time-saving merit of the system, in completing electronic attendance and daily documentation tasks within the time frame:

> *What we have now is efficient and it's cut a lot of time out because we used to have to sign all the notes then go and put them all in the charts. That was terrible. It just took forever.* [B033, Mental health clinician]

Participants also emphasized that the multitaskable UI had greatly helped to access additional information without disruption of the main task in hand:

> *Navigation-wise it's good. I like that you can view two screens at the same time, because that really helps. If I'm talking to a patient about meds, I can have my documentation open, but also looking at the meds. We like that and a lot of the nurses like that. Being able to close an item, open another item quickly, rather than some EHRs, where you have to document this and to move on, you have to document here. We're able to jump around and move.* [B005, Nurse]

Another characteristic of the mental health care EHR is the support of personalization options to accommodate end users' preference according to their work patterns. Many nurses and mental health clinicians indicated the customizable *My Favorite menu* to be helpful in setting the tasks and documentation in a certain order they can simply follow in sequence:

> *The favorite menu for me is my favorite. Because I can really just save the documents that I regularly use and search from there. The quick mental health care EHR shortcuts. Those shortcuts make a huge, huge difference.* [B021, Mental health clinician]

This personalization feature was beneficial for nurses who had trouble remembering where to go for their routine work. Having the favorites set up to all end users, especially to nursing staff, before go-live process became a priority that ensured a smoother transition:

> *All the nursing staff, we tried to help them set up their favorites and all that so it would be ready to go.* [B013, Administrative professional]

The flexibility of the mental health care EHR had also been reported as a relief to the administrative professionals. Knowing that the *Form generator* can add or edit documentation templates in an instant made it easy for the staff to accept the new electronic system:

> *Usually when we have a problem and you get it done pretty quick, and no EHR is perfect. I know that. But as long as when we need something changed, it's fairly easy to change it. I know I've asked (Corporate coordinator) a couple times just to switch a couple things around and he can do it himself, which is nice.* [B013, Administrative professional]

Advantages of Using an EHR

Participants were delighted to enjoy the universal benefits of using an EHR. A common theme among participants was improved access to patient information. With the help of the mental health care EHR, the difficulty in finding physical patient charts, which was delayed if occupied by another staff member, and, therefore, not being able to access patient information promptly had been resolved:

> *It actually makes my job so much easier because I can access the information from whatever location I'm at, as opposed to going to the units and pulling out the charts. And it's easier for me to get the information at the same time someone's looking into the chart, because otherwise I have to wait to see when it's available.* [B006, Nurse]

Before, administrative professionals who did not even work in inpatient or outpatient units had greater difficulty in locating patients' charts. Finally, they were able to access patient information in time through the mental health care EHR:

> *This mental health care EHR has really helped me because it used to be I could never get information. I'd have to go pull the patient's chart, I'd have to go to the unit, I'd have to go to Medical Records and try. So it wasn't until we got the mental health care EHR*

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> *that I could even look this up. Before, we weren't capturing that. It was captured on the paper chart, but I couldn't find it easily at all.* [B007, Administrative professional]

Participants believed that the mental health care EHR had improved patient safety and quality of care provided to the patients. Physicians and nurses were pleased that the mental health care EHR's CDSS alerts helped them to be less prone to making medication errors compared with writing orders in paper and sending it to the pharmacy:

> *It [CDSS] gives that extra layer of protection for the patient.'* [C004, Physician]

> *Especially with the alerts just for medication alone. Because before on paper, we'd have to wait anywhere from 20 to maybe two, three hours when pharmacy would get the information, enter it and realize, Oh, that patient has an allergy or these two medications are contraindicated. That system tells you right then and there. So that's helpful.* [B001, Nurse]

They reported that any mistakes made were caught instantly by other clinicians, not to mention that they did not have to decipher handwriting anymore:

> *Medication errors are definitely going down. In this way, everything is in print. Everything is concrete so that if it is a mistake, if the doctor's ordering in different ways, the pharmacist and nurse can visualize and then say, "Hey, this is the wrong way," communicate with the physician because they can see the order very clearly. It definitely improves the patient's safety.* [C005, Physician]

Participants were very satisfied with the enhanced interprofessional communication. As mental health involves collaboration from various clinicians, participants felt that better communication between the members of the treatment team empowered to work together toward the established goals:

> *I think communication is better with the mental health care EHR because there is continuity of care, communication amongst the team, the different disciplines. I think the mental health care EHR has really put us to another level unlike before. I can see if I'm working on that patient and the counselor is working on that patient, I'm able to read the note what the patient did in the group. So I think it's really amazing.* [B019, Nurse]

Mental health clinicians were also impressed that they began to receive feedback from other clinicians when using the mental health care EHR. They were positive toward the mental health care EHR in creating a sense that they are actually working collectively as a team, reflecting the work of their colleagues. This was less likely to be observed with paper charts:

> *As far as communication as a whole, I found that we've had social workers come up to us in our department, "Wow, your notes are so detailed," and "Oh, your notes are really descriptive with your team," and it's great that they're really reviewing the chart and taking time to read other's documentation.* [B021, Mental health clinician]

Implementation Strategy

All participants considered training to be the most influential factor in getting used to the mental health care EHR and ready for transition. A couple of physicians who were aged more than 70 years at the time of implementation stated that good training sessions had changed their attitude positively toward the adoption of mental health care EHR:

> *The first training experience was actually very, very good. I felt very comfortable using the system.* [C004, Physician]

Many nurses and mental health clinicians were also pleased with the thorough training sessions and continuous support from trainers. Training sessions were scheduled by each department for a maximum of 15 users in one session with 2 or 3 trainers. Instructions were provided by their work patterns with real-life scenarios set up in the training environment of the mental health care EHR. All users had to pass the competency test at the end of the training session for what they had learned. By observing the users going through the competency test during the session, trainers were able to easily identify the additional guide they needed:

> *I thought that the rollout was really good. I think it was very thorough in teaching all of us what we needed to know.* [B012, Mental health clinician]

Additional training was provided to staff who needed more help. The training room was open for practice to welcome those who needed extra hours and one-on-one training:

> *I think the people that came out and trained us last time were really helpful. I really liked them. I felt like they were always there when we needed them. So the training was for, in my opinion, really, really good. I don't think that that could have been much better.* [B032, Nurse]

The trainers not only guided them with well-prepared contents and extra training sessions but also put much effort into encouraging and boosting morality. Many end users were known to have gained confidence in overcoming the mental barrier at this time:

> *When I attended the third time, I met one of the senior trainers. So I called him, I said, "You know what? This, your (mental health care EHR) is going to send me out of job." He started laughing. He said, "[Name], I know you can do it." ...And he started showing me. That was the end. The third time, I got it. The first time, I was totally lost.* [B032, Nurse]

Another facilitator that was frequently mentioned by participants was having enough time for accepting the mental health care EHR. The implementation support team meticulously planned the initial transition from paper to the mental health care EHR during the go-live process and the implementation process, keeping up with the project schedule. Users had a minimum of 2 months for preparation, even after the customization of the

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mental health care EHR. Even physicians mentioned that the given time was sufficient:

> *I think they have been very kind and they have been very patient. And that was very helpful. Compared to the other hospitals where I work, we didn't have this much support. And they have taken a good amount of time for the implementation.* [C005, Physician]

When asking the participants what would help the remaining sister hospitals in adopting the mental health care EHR, nurses also stressed that giving time for transition and training is critical:

> *I would have a recommendation, maybe some more time, which they did give us. I think the trainers we had really did a good job. They gave us time, they weren't like hurrying us, no. So I would put emphasis on that.* [B019, Nurse]

According to some participants, one of the most effective implementation plans was to use the forms in the mental health care EHR even before the go-live process. This way, everyone was already well acquainted with the contents of what was to come, and when using the electronic version, at least the forms were the same and much easier. They felt that the benefits of the mental health care EHR were easily recognized in this aspect:

> *So it's almost exactly what we were doing on paper. Just a computer form, quicker, better, nicer.* [B001, Nurse]

Ideas

Alerts to Address the Legal Status

In behavioral hospitals, psychiatric patients are often admitted with an emergency hold in which the law permits the facility to process an involuntary admission in certain circumstances. Although the duration for hold varies by state, all states have emergency hold laws, and mental health professionals need to address the duration before the permitted hold ends. Nurses were very eager to have a stronger level of alert, even hard stops, to notify physicians and nurses for further action. In their opinion, addressing hold was the top priority and simply showing the current status and remaining hours was not enough to draw attention:

> *Maybe by suspending some kind of function to where it's not going to let you move forward until this is addressed. A pop up screen that offers, "not addressed" or "addressed." So, it can change the legal status to show that the user has not taken care of this order yet. If it was not addressed, let's say by either discipline, doctor or nurse, hold ended one minute ago, boom, a pop up should appear. Showing it that the user needs to obtain legal status or order needs to be written. It's day two now and it still says pending, because somebody didn't address it. I think that would be helpful.* [B013, Administrative professional]

Autorecommendation of Laboratory Exams for Antipsychotics

Some pharmacists suggested that the mental health care EHR would be more helpful if the laboratory exams were paired with antipsychotics to be autorecommended when a physician issues orders. As they pointed out, one of the main objectives of an electronic system is to assist clinicians in removing burdens and to reduce human errors. Although the mental health care EHR was reported to be robust in handling complicated orders and protocols, they also wanted additional, automated support and guidance:

> *So when you have certain medications that are ordered, certain antipsychotics, I would think it would be helpful if ones would pop up and then the doctor could select, "Depakote, liver enzyme test" where they don't have to actually remember it and it just pops up, and then they just select which ones.* [B010, Pharmacist]

Use of Tablet PCs

To most of the participants, a well-designed mental health care EHR was satisfying in many ways. However, its limitation was clear. Users cannot carry it around and access it instantly. Although hospitals had laptops throughout the facility in some consultation rooms, medication rooms, and offices, many reported that the use of tablet PCs would be much more beneficial in certain areas. In 2 hospitals, nurses working in the intake department did not use laptops for assessment. They reported that entering results into the mental health care EHR via a computer after the assessment was quicker than the paper process; however, they felt that tablet PCs would make it easier to complete the intake assessment and receive electronic medical consent in the consultation room. They did not mind entering one long narrative later at the end:

> *I think tablets would be good in the Intake rooms when we're doing all the consents for the meds, because we have them just hand signing everything. I think it actually would be great in the Intake. I think that would speed things up and help out. Absolutely, it would. 100%.* [B029, Nurse]

Mental health clinicians shared the same thoughts in using tablet PCs to complete group notes during the group session. As of now, they were jotting down notes on paper to later recall and complete the notes on the computer:

> *If the tablet had (the bEHR) that I could go to them for the assessment part, that would make it easier. Because then I could tell them I'm just going to do an assessment real quick and check the boxes.* [B033, Mental health clinician]

Some nurses thought the round sheet was a perfect example of making use of a tablet PC. They believed forms that consisted of simple markings, the selection of drop-down menus, and only a few notes were good candidates:

> *Because every 15 minutes we have a sheet of paper that has a thousand check boxes and you check where they were, what they were doing. Every 15 minutes.*

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> *Someday if we can come up with a form and have it all on a tablet.* [B013, Administrative professional]

Physicians also mentioned the round sheet, based on the idea that the few forms remaining in paper can switch to electronic forms by using tablet PCs:

> *I think if we had a tablet and the mental health worker doing the rounds does it, it's entered in the system right away versus you're writing it on paper and then having to put it in later. So I think it's much more efficient and less chance for errors to do it with a tablet right there.* [C006, Physician]

Discussion

Principal Findings

In this study, we found 7 major barriers and 4 major facilitators when implementing a mental health care EHR in behavioral hospitals. Of the 7 barriers, 3 are related to ease of use: computer literacy, complexity of the system, and steep learning curve. Other barriers include alert fatigue, poor organizational support, and general anxiety about the new environment. Of the 4 facilitators, 2 are related to the system itself: mental health–centered and well-designed mental health care EHR. One of the main facilitators is related to expectations from system use: improved communication, improved productivity, and better patient care. Organizational support relevant to implementation strategies is also an important facilitator. To the best of our knowledge, this is the first study to analyze the barriers and facilitators that are important for the introduction of mental health and EHR using qualitative methodology.

Overlapping Characteristics of Barriers and Facilitators

An interesting finding is that the barriers and facilitators share overlapping characteristics. For example, some participants were worried about organizational support. However, some of them were satisfied with the support, such as good training and well-executed implementation planning. This means that a well-organized implementation plan and an educational support of an institution is one of the crucial elements for successful adoption of mental health care EHRs. The results also suggest that not only group education but also individual education programs that meet the needs of individual users are important. This finding is consistent with that of previous studies [19,20].

Differences by the Job Group

Opinions were divided by the job group on organizational support for the introduction of the mental health care EHR. Among the study participants, the executive level persons thought that the institution had fully supported the introduction of EHR, but end users did not. This is because the end user needs to frequently use the mental health care EHR directly in the field.

Differences by Age Group

The average age of participants was not high. Of the total participants, 61% (26/43) were aged between 30 and 50 years. Only 16% (7/43) of the participants were aged above 60 years. However, older age can interfere with the adaptation of the new system, combined with vague anxiety about the introduction of the new system and concern about one's own computer comprehension. The older staff had general anxiety because of their physical ability to use computers and psychological pressure. They even showed their thoughts by saying that they "[considered] quitting when they saw the system for the first time," which is similar to a previous study showing that age is associated with satisfaction with EHR use [21,22].

Facilitators and Barriers Relevant to the Unique Workflow of Psychiatric Health Care

One of the essential features of a mental health care EHR is that the system should accommodate its unique workflow. The psychiatry department differs greatly from other departments in terms of work processes. General tests, such as specimens and imaging tests, are performed less frequently, and questionnaires and question-based tests are performed more frequently. There are also more text-based records than other departments. As a result, EHR is more likely to serve as a greater barrier than other departments in retrieving and using psychiatric records for care. In a systematic review of barriers to EHR adoption, the author revealed that work process challenges are one of the most frequently mentioned barriers [22].

Furthermore, psychiatry has more complex privacy-related regulations than most other areas of medicine [2]. Study participants placed great emphasis on the function. Exchange and integration of medical information among psychiatric hospitals is more likely to occur when integrating federal regulations into a workflow through mental health care EHRs [2]. In fact, participants were satisfied that mental health care EHRs supported regulatory compliance. At the same time, when participants were asked to comment on how the system could be improved, they suggested to improve their function.

Facilitators and Barriers Relevant to Training

Many participants stressed the importance of education. They mentioned several times the importance of well-executed training in implementation strategy, one of the facilitators. In the introduction of EHRs, the age of trainees is an uncorrectable factor. However, general anxiety according to age or computer literacy is an area that can be solved by personalized in-depth training. The initial barriers caused by steep learning curves or the complexity of the mental health care EHR can also be addressed with personalized training. Indeed, users were highly satisfied with scenario-based training that could occur in a clinical setting. Therefore, practical, personalized training that fits the needs of mental health care EHR users is important [23,24]. As a matter of fact, one of the participants emphasized the importance of training:

> *Initially I had concern on how many tabs there were to get adjusted, but after the first training session it made sense and it felt organized in a categorical way.*

Barriers That Can Be Solved by the Improvement of Mental Health Care EHR

In terms of the complexity of the system, doctors, nurses, and pharmacists had different levels of desired functions. In the case of pharmacists, for example, small hospitals do not need the

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complex functions used in large hospitals because of the narrow range of drugs they handle. The complex functions of EHRs, developed for tertiary hospitals, can hinder the work of small hospitals. This problem can be solved by using cloud-based EHRs. Developed in a multitenancy structure, cloud-based EHRs can provide customized services to select and use the functions required by each medical institution. Alert fatigue is one of the issues that is always mentioned when implementing the CDSS [25,26]. The problem is that first-time EHR users can have a negative perception of the system and it can interrupt the workflow, requiring continuous improvement of the CDSS for psychiatric practice [27].

Ideas

Some pharmacists suggested a more advanced CDSS function that pairs antipsychotics with recent laboratory values and recommends appropriate medications when they issue orders. The nurses were very eager to have a stronger level of alert about legal status because it is more strict and mandatory for psychiatric hospitals to follow governmental regulations than other general hospitals. The CDSS for the mental health care EHR can be different from the CDSS for other medical departments because psychiatric patients normally have multiple medications that should be modified based on laboratory values and heterogeneous text-based medical records that should be managed in every psychiatric hospital they visit. Therefore, the CDSS for the mental health care EHR is important and difficult to develop and implement at the same time [28,29]; however, the reason the psychiatric CDSS is crucial to improving mental health and the eagerness of users for an advanced CDSS can be promoters to disseminate mental health care EHR quickly and effectively.

To use the findings of this study to effectively introduce mental health care EHRs, it is necessary to recognize that there are general difficulties in introducing EHRs, as in other medical departments. Computer literacy, alert fatigue, and steep learning curves are barriers to the introduction of any type of EHR and can be overcome by user-centered repetitive training. It is important to fully inform users about the purpose and effectiveness of EHR adoption before the introduction of EHRs and ensure that all users are well trained and use the system in advance. In addition, a function or workflow specific to psychiatry should be fully implemented in EHR.

Limitations and Future Research

Strengths of this study include the breadth of clinical disciplines and experience possessed by the end users of the mental health care EHR whom we interviewed; users of 4 hospitals who actually introduced mental health care EHRs were interviewed to investigate in detail the barriers and facilitators in introducing EHRs. The interview methodology for the qualitative analyses also provided a greater depth of understanding about the factors that are important to end users of the mental health care EHR.

A limitation of this study is that participants were recruited from behavioral hospitals that use the same mental health care EHR system. Therefore, what the interviewees mentioned in this study may be applied only to the system. However, in this study, we tried to obtain insights that can be generalized as much as possible without being dependent on a specific system so that we could draw lessons that can be applied to psychology and EHR in general, regardless of the characteristics used by users.

Future research could collect various opinions from hospitals using different mental health care EHRs and examine whether the barriers and facilitators proposed in this study apply equally to other hospitals using different EHRs.

Conclusions

EHRs represent a key element of health care redesign. The introduction of EHRs is also important in psychiatric hospitals because it reduces drug-related errors and medical errors by sharing medical information among medical staff and makes it easier to apply regulatory rules to the workflow. Psychiatric EHR developers and hospitals should strive to effectively disseminate EHRs by accurately recognizing end users' perspectives on barriers and facilitators identified in this study.

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Authors' Contributions

SJ and HH drafted the entire manuscript and are the first authors. DL and KL conducted the interviews. DL analyzed the data and drafted the *Methods* and *Results* sections. SY and HL contributed to the discussion of the data. KL supervised the entire process and is a corresponding author

Conflicts of Interest

None declared.

Multimedia Appendix 1
Consolidated Criteria for Reporting Qualitative Research report.
[DOCX File , 16 KB - formative_v5i4e18764_app1.docx]

Multimedia Appendix 2

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Additional information on study hospitals and participants.
[DOCX File , 44 KB - formative_v5i4e18764_app2.docx]

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Abbreviations

CDSS: Clinical Decision Support System
CLMA: Closed-Loop Medication Administration
CPOE: computerized physician order entry
EHR: electronic health record
HIM: Health Information Management
HITECH: Health Information Technology for Economic and Clinical Health
SNUBH: Seoul National University Bundang Hospital
UI: user interface

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Original Paper

Reasons for Discontinuing Active Participation on the Internet Forum Tinnitus Talk: Mixed Methods Citizen Science Study

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Abstract

Background: Tinnitus Talk is a nonprofit online self-help forum. Asking inactive users about their reasons for discontinued usage of health-related online platforms such as Tinnitus Talk is important for quality assurance.

Objective: The aim of this study was to explore reasons for discontinued use of Tinnitus Talk, and their associations to the perceptions of Tinnitus Talk and the age of users who ceased logging on to the platform.

Methods: Initially, 13,745 users that did not use Tinnitus Talk within the previous 2 months were contacted and the response rate was 20.47% (n=2814). After dataset filtering, a total of 2172 past members of Tinnitus Talk were included in the analyses. Nine predefined reasons for discontinued usage of Tinnitus Talk were included in the survey as well as one open question. Moreover, there were 14 predefined questions focusing on perception of Tinnitus Talk (usefulness, content, community, and quality of members' posts). Mixed methods analyses were performed. Frequencies and correlation coefficients were calculated for quantitative data, and grounded theory methodology was utilized for exploration of the qualitative data.

Results: Quantitative analysis revealed reasons for discontinued use of Tinnitus Talk as well as associations of these reasons with perceptions of Tinnitus Talk and age. Among the eight predefined reasons for discontinued use of Tinnitus Talk, the most frequently reported was not finding the information they were looking for (451/2695, 16.7%). Overall, the highest rated perception of Tinnitus Talk was content-related ease of understanding (mean 3.9, SD 0.64). A high number (nearly 40%) of participants provided additional free text explaining why they discontinued use. Qualitative analyses identified a total of 1654 specific reasons, more than 93% of which (n=1544) could be inductively coded. The coding system consisted of 33 thematically labeled codes clustered into 10 categories. The most frequent additional reason for discontinuing use was thinking that there is no cure or help for tinnitus symptoms (375/1544, 24.3%). Significant correlations ($P<.001$) were observed between reasons for discontinued usage and perception of Tinnitus Talk. Several reasons for discontinued usage were associated with the examined dimensions of perception of Tinnitus Talk (usefulness, content, community, as well as quality of members' posts). Moreover, significant correlations ($P<.001$) between age and reasons for discontinued use were found. Older age was associated with no longer using

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Tinnitus Talk because of not finding what they were looking for. In addition, older participants had a generally less positive perception of Tinnitus Talk than younger participants (*P*<.001).

Conclusions: This study contributes to understanding the reasons for discontinued usage of online self-help platforms, which are typically only reported according to the dropout rates. Furthermore, specific groups of users who did not benefit from Tinnitus Talk were identified, and several practical implications for improvement of the structure, content, and goals of Tinnitus Talk were suggested.

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KEYWORDS

tinnitus; Tinnitus Talk; Internet forum; dropout; reasons for discontinuation

Introduction

Tinnitus is defined as the perception of sound without an external source and shows considerable heterogeneity [1]. A promising opportunity for the investigation of this heterogeneity lies in using the internet to gather big data through the support forum Tinnitus Talk, which has been continuously running since March 2011; based on Google Analytics statistics, there were about 2 million unique visitors to Tinnitus Talk from March 2019 to February 2020. The Tinnitus Talk support forum also serves as a hub or signpost for patients with other hearing diseases such as Ménière disease, hyperacusis, or hearing loss, as Tinnitus Talk is encountered when searching the internet for initial information relating to already diagnosed problems or new symptoms.

Tinnitus Talk is an internet platform for accessing, sharing, and discussing information related to tinnitus and other hearing diseases (see also Dandage et al [2]). Tinnitus Talk is free of charge and the full content is available without any restrictions for all internet users. However, registration is required for active participation such as for adding comments and discussion posts, as well as for receiving the Tinnitus Talk newsletter and forum notifications. User posts are supervised by Tinnitus Talk administrators on an ad hoc basis and upon users' requests in terms of good manners, to prohibit commercial activities, avoid aggressive or abusive posting, and to maintain the logical thematic structure of threads (ie, to supervise the correct localization of discussion posts in appropriate threads).

In May 2018 (the time period of this study), the content of Tinnitus Talk included information sorted into six main sections providing visitors and users with general information about tinnitus and similar hearing issues: Tinnitus (including Research News, Support and Treatments), Pulsatile Tinnitus, Hyperacusis & Ear Pain, Off-Topic, Knowledge Base (including Success Stories and Awareness & Fundraising), and Tinnitus Talk (for general announcements). An additional section, Doctor's Corner, provides users with access to professional support.

Thus, Tinnitus Talk can best be described as a patient online space enabling computer-mediated communication. Tanis [3] identified two groups of users of health-related online fora. First, there are those who benefit from using the forum. These are frequently users who can cope with their problematic situation and encourage other patients via their use of the forum. The second group includes those whose health situation does not get better by using the forum. These users typically use the fora primarily for discussion. As online resources take on a more and more important role in health care, there is an urgent need to investigate their impact scientifically. As emphasized by De Martino et al [4], the overall quality of online health-related information is poor, and the control and regulation of this information are very difficult. However, unverified and misleading information can influence patients' opinion, confidence of physicians, as well as their perceived quality of care.

There is an enormous wealth of information from health-related fora that can be scientifically investigated [5-7]; however, this type of research is still at a very early stage. One important approach is investigation of the dynamics of users' presence and active participation in health-related fora. In this context, it is of crucial importance to understand when and why a member of a patient forum discontinues active participation. Users who discontinue using Tinnitus Talk can be classified as inactive users if they return to the forum after a certain period of absence, or as dropouts if they never return to the platform. Previous research on tinnitus self-help interventions showed that the rate of dropout ranged from 0 to 66% [7]. Some very recent studies explored the use of eHealth tools among tinnitus patients (eg, [8-10]). A first attempt toward understanding the characteristics of users who discontinued using Tinnitus Talk was recently made in a master's thesis published by Hegde [11]. Outside the context of tinnitus, a qualitative study explored the reasons for dropping out of psychotherapy, and found that dissatisfaction with the quality of psychotherapy was the most important factor for patients [12].

The aim of this study was to focus on the lapsed members of Tinnitus Talk in more detail, and to analyze the reasons for discontinued use. Discovering these reasons is necessary for several purposes. First, this feedback could provide an important source for development of the content and structure of health-related fora. Second, identifying patients' reasons for discontinuing use of Tinnitus Talk enables recognizing particular groups of users for which further membership in the forum is no longer beneficial, becomes counterproductive, or even harmful. By analyzing users' views on reasons for discontinuing activity in the forum in this citizen science project, original insight into the world of tinnitus sufferers could be obtained. Furthermore, we were interested in determining the association between reasons for discontinuing the use of Tinnitus Talk and perception of the Tinnitus Talk forum. Intuitively, more negative perceptions of Tinnitus Talk could be associated with a higher probability of discontinuing use of the forum. Moreover, we

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were interested in potential associations between age and perceptions of Tinnitus Talk and reasons for discontinuing use, since older participants might have more problems with using the internet than younger participants [8,9]. Accordingly, our research questions were as follows: (1) What are the reasons for discontinuing the use of Tinnitus Talk? (2) Are users' perceptions of the Tinnitus Talk forum related to discontinuing the use of Tinnitus Talk? (3) Is age related to users' perceptions of Tinnitus Talk or reasons for discontinuing the use of Tinnitus Talk?

Methods

Study Design

Tinnitus Hub, a UK-based nonprofit organization that operates Tinnitus Talk, contacted 13,745 users that had not used Tinnitus Talk within the previous 2 months. They were contacted via email, and the study was also announced in newsletters and via forum notifications. The response rate was 20.47% (n=2814). Participants had to complete an English online survey (SurveyMonkey) including questions about perceptions of Tinnitus Talk and reasons for discontinuing use of Tinnitus Talk.

Participants

Participants of the survey included 2814 individuals who had discontinued use of Tinnitus Talk for at least 2 months. As the answers on the survey questions were not mandatory, the number of answers for each question differed. Participants who did not answer the question "Why did you stop using Tinnitus Talk" were excluded from the analyzed dataset, resulting in a final sample of 2172 participants. There were no significant differences between excluded and included participants in terms of age, gender, status of tinnitus and hyperacusis, and onset of tinnitus or hyperacusis (Table 1).

The sample included mostly male participants with a mean age of 55.70 years. Over 80% of the participants were from English-speaking countries: United States, United Kingdom, Canada, Australia, New Zealand, and Ireland. In general, over 60% of users reported using Tinnitus Talk monthly or even less frequently prior to discontinuing use. Most participants had chronic tinnitus, and the onset of tinnitus symptoms was at least 1-2 years prior for over 91% of the respondents.

Table 1. Comparison of characteristics of included and excluded participants.

Characteristic	Included (n=2172)	Excluded (n=642)	Statistic for comparison	*P* value
Age, mean (SD), n	55.70 (14.36), 2157	55.55 (14.89), 497	$t_{2,652}=0.213$, $d=0.01$	.83
Gender, n (%)			$\chi^2_3=2.073$, critical $\chi^2=7.815$, β err prob=0.802, power (1–β err prob)=0.198	.56
Male	1332 (61.33)	309 (48.13)		
Female	794 (36.56)	190 (29.60)		
Other	6 (0.28)	0 (0)		
Prefer not to say	15 (0.69)	2 (0.31)		
Diagnosis of tinnitus and/or hyperacusis, n			$\chi^2_1=0.844$, critical $\chi^2=3.841$, β err prob=0.849, power (1–β err prob)=0.151	.36
Yes	2116	491		
No	49	8		
Time since onset of tinnitus (n=2659), n			$\chi^2_9=14.076$, critical $\chi^2=16.919$, β err prob=0.253, power (1–β err prob)=0.747	.12
Not applicable	15	4		
Up to 3 months	21	4		
4-6 months	47	5		
6-12 months	110	21		
1-2 years	275	50		
2-3 years	320	67		
3-5 years	400	77		
5-10 years	338	99		
10-20 years	307	78		
More than 20 years	337	84		
Time since onset of hyperacusis (n=2220), n			$\chi^2_9=6.624$, critical $\chi^2=16.919$, β err prob=0.625, power (1–β err prob)=0.375	.68
Not applicable	1,301	285		
≤3 months	17	3		
4-6 months	17	3		
6-12 months	46	13		
1-2 years	88	16		
2-3 years	95	15		
3-5 years	107	16		
5-10 years	77	18		
10-20 years	46	10		

Instrument

The instrument was a cross-sectional online survey in the English language. The final survey questions resulted from a discussion among members of the research team and with the Tinnitus Talk managers. The research team created questions based on the information provided in a qualitative study on experiences of nonadherence to internet-delivered cognitive behavior therapy [13]. Specifically, one author (TP) developed items based on the results reported by Johansson et al [13] to investigate reasons for discontinued usage of self-help platforms. TP then discussed these items with the coauthors, adjusted them as needed, and sent the final items as suggestions to the Tinnitus Talk manager team. The Tinnitus Talk team then decided which

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of these items/suggestions they wanted to add to the survey items that they had developed on their own (eg, users' perception of the Tinnitus Talk forum). The Tinnitus Talk team then asked previous Tinnitus Talk users (no use of the forum for at least 2 months) to complete the final survey instrument. The question of the survey that served as the focus of this study refers to the reasons for discontinued usage. Participants provided reasons for the discontinued usage of Tinnitus Talk by choosing one or more than one answer of a multiple-choice question with eight suggested reasons and an additional open-ended option where participants could list other reasons.

Moreover, we were interested in the relation between discontinued usage and the user's perception of the Tinnitus Talk forum. Users' perception of Tinnitus Talk was estimated on a 5-point Likert scale (1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree, and 5=strongly agree), and included items that measured usefulness, content, community, and quality of forum members' posts. Three items measured the usefulness (U1, U2, U3), three items measured the content (CN1, CN2, CN3), four items measured the community (CM1, CM2, CM3, CM4), and four items measured the quality of forum members' posts (Q1, Q2, Q3, Q4).

Analyses

Overview of Mixed Methods Approach

A mixed methods approach was employed. Quantitative analyses were used to examine the reasons for discontinued usage; users' perception of Tinnitus Talk; and correlations between reasons and perception, reasons and age, and perception and age. The qualitative analysis was employed to explore users' free-text answers given to the open-ended option on other reasons for discontinued usage of Tinnitus Talk. This type of design prioritizes quantitative analysis followed by a qualitative sequence, providing a complete answer to a research question by including both quantitative and qualitative methods [14].

Quantitative Data Analysis

Quantitative data were analyzed in IBM SPSS Statistics for Windows, Version 25.0. Statistical tests (*t* test and χ^2 test) were performed to evaluate differences between included and excluded participants in terms of age, gender, tinnitus/hyperacusis status, and time since symptom onset. Mean (SD) values were calculated for responses to questions that addressed users' perception of Tinnitus Talk, and data are presented as frequencies (n, %) for responses to the questions that described reasons for discontinued usage. Multiple-choice answers were dummy-coded for the analyses, with 1 indicating presence and 0 indicating absence of the specific reason. Additionally, the Pearson correlation coefficients (*r*) between age, reasons for discontinued usage, and users' perception of Tinnitus Talk were calculated with the Bonferroni-corrected adjusted *P* value. All statistical tests were performed two-tailed and significance was judged at $P<.05$.

Qualitative Data Analysis

Qualitative data analysis focused on the users' free-text answers given to the open question on other reasons for discontinuing the use of Tinnitus Talk. This open question generated textual data. The number of characters was not limited. Among the total number of participants (N=2172), almost half (n=1075) utilized this option and provided free-text data for subsequent analysis. The average length of answers was 22 words.

Grounded theory methodology (GTM) [15] was utilized for exploration of the qualitative dataset. GTM allows for generating a theory through the informed and open-minded examination of data. Furthermore, GTM provides a set of systematic coding approaches that supports the formation of a tailor-made category system, with the use of open coding and constant comparison of developed codes [16,17]. GTM is based on the inductive conceptualization of qualitative data. In this study, all of the testimonies (N=1075) written in English and gathered via the SurveyMonkey internet platform were manually coded in a line-by-line manner in the Open Coding and List Coding modes of ATLAS.ti 8.4.4.

The goal of the coding process was to understand and classify the "other reasons" for discontinuing active participation on Tinnitus Talk, which were formulated by the participants as free-text answers. Inductively developed codes were assigned to words, phrases, or entire testimonies to identify the relevant text parts and to label them as the particular answers to the research question (ie, the conceptual framework for the coding procedure was delimited by the research question). The codes were generated to represent the meaning of each answer. The meaning similarity, which was determined by the authors' subjective judgment, was the key to developing the coding system. The process of establishing codes was gradual in terms of GTM. In some cases, code labels were borrowed from the participants' own formulations. The partial overlap of free-text answers with predefined reasons was not an issue, because this question allowed for multiple-choice answers. After initial coding of the first 200 testimonies, the coding system was adjusted by two authors (MK and SB) to improve accuracy of the codes and to eliminate subjective evaluation. After this step, previously coded testimonies were revised. Subsequently, the codes were clustered into categories to identify the structure of the dataset.

Results

Reasons for Discontinued Usage of Tinnitus Talk

Overview of Reasons

Table 2 shows the overall frequencies of reasons selected for discontinued usage, which refer to the percentage of the given answers, as each participant could provide multiple reasons. The most frequently selected predefined reasons for discontinued usage of Tinnitus Talk included not finding what users were looking for (R1), not needing Tinnitus Talk after they found what they were looking for (R2), or no longer needing Tinnitus Talk because their condition improved (R4). A surprisingly high number of discontinued users added free text for other reasons (R9). In total, 1654 particular reasons were identified in their answers, more than 93% of which (n=1544) were inductively coded to investigate the research questions. The remaining (6.65%, n=110) text included other reasons that could not be meaningfully coded and were therefore excluded as

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miscellaneous. As shown in Table 2, the most frequent other reason was thinking that there is no cure or help for tinnitus symptoms (O6), followed by being busy (O3), avoidance (O2), having positive hope (O4), still using Tinnitus Talk (O8), acceptance/habituation (O1), content issues (O10), improvement (O5), technical issues (O9), and other health issues (O7).

The coding system consisted of 33 thematically labeled codes clustered into 10 categories (Table 3). The description of each category follows, along with some illustrative quotes for each category.

Table 2. Users' reasons for discontinuing the use of Tinnitus Talk.

Question	Participants, n (%)
Multiple choice question: Why did you stop using Tinnitus Talk? (select all that apply) (N=2695)	
R1: I could not find what I was looking for on Tinnitus Talk	451 (16.7)
R2: I found what I was looking for on Tinnitus Talk and did not need it any more	340 (12.6)
R3: I perceived negative effects from using Tinnitus Talk	190 (7.1)
R4: I did not need Tinnitus Talk anymore because I improved	297 (11.0)
R5: I prefer to share in a face-to-face manner	135 (5.0)
R6: Tinnitus Talk was too complicated	93 (3.5)
R7: I preferred to use a different forum	45 (1.7)
R8: I preferred to use Facebook groups	69 (2.6)
R9: Other (please specify)	1075 (39.9)
Other (categories based on analyses of free-text answers) (N=1544)	
O1: Acceptance/Habituation	140 (9.1)
O2: Avoidance	178 (11.5)
O3: Busy	212 (13.7)
O4: Hope/Positive	160 (10.4)
O5: Improvement	92 (6.0)
O6: No cure/help	375 (24.3)
O7: Other health issues	49 (3.2)
O8: Still using Tinnitus Talk	154 (10.0)
O9: Technical issues	88 (5.7)
O10: Content issues	96 (6.2)

Table 3. Categories and codes for other reasons (R9 in Table 2).

Category	Codes
Acceptance/habituation	Acceptance of tinnitus; Habituation with tinnitus
Avoidance	Avoidance strategy; Reading about tinnitus makes it worse
Busy	Busy, but like to be more active; I'm busy; Lack of time; Some other issues
Hope/positive	Compliments to Tinnitus Talk; Hope expression; New information about tinnitus awaited
Improvement	Improved via something else; Mild tinnitus only
No cure/help	Depression expression; Long time with tinnitus; Negativism of users; No cure, so what; No solution found here; Nothing usable on Tinnitus Talk; Resignation; Tinnitus is back; Tinnitus is too individualized; Tinnitus Talk is not helping
Other health issues	Health issues other than tinnitus
Still using Tinnitus Talk	Did not stop!; I access it occasionally; I'm fine with emails; Not stopped, just paused; Visiting, not logging in
Technical issues	I forgot; Technical issues
Content issues	Vague/outdated info; What to do (advice)

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No Cure/Help

The most common other reason (375 of 1544 quotes, 24.3%) for why participants discontinued the use of Tinnitus Talk was related to the fact that they considered tinnitus to be an incurable disease, and participants shared a conviction that no help is available for their suffering. The most frequently occurring code in this category was therefore labeled as “Resignation” (72 quotes).

> *Also the negative attitude of the majority of the community is not helping either, I don’t blame anyone, tinnitus, and other diseases are sad, and it’s completely fine to be sad about it. I am sad about it, everyone’s sad about it, but promoting this sadness won’t help anyone, or at least it won’t help me.*

Busy

The second highest number of testimonies (212 of 1544 quotes, 13.7%) reflected a personal situation in that participants were fully occupied with other activities such as work duties, important life situations, or some other activities/issues. Under these conditions, spending time on Tinnitus Talk—and sometimes on the tinnitus itself—no longer was a priority, at least for a while.

Testimonies clustered in this category were either very short (eg, “too busy” or “no time”) or provided detailed information about particular activities that led the participants to refocus their attention from suffering from tinnitus to other issues, with the exception of serious health issues, which were sorted in a separate category.

Avoidance

The third most common category (178 of 1544 quotes, 11.5%) reflected that a strategy, sometimes reported as based on own experiences of simply not dealing with tinnitus (including avoiding the use of Tinnitus Talk), was the only way to achieve partial relief from tinnitus symptoms. In other words, discontinuing use of Tinnitus Talk was part of an overall avoidance coping strategy:

> *I miss some of the people from Tinnitus Talk but I decided it was best to avoid it for a while.*

Hope/Positive

The fourth most common category (160 of 1544 quotes, 10.4%) clustered positive testimonies addressed to Tinnitus Talk (coded as “Compliments to Tinnitus Talk,” 97 quotes), expressions of hope, and expectations of new positive information from the field of research and possible treatment of tinnitus in the future (63 quotes).

> *I’m now waiting on a scientific breakthrough, when this happens, and a proper treatment is available I will once again share my experiences and learnings. What I have shared certainly has helped others and given them a little hope.*

Still Using Tinnitus Talk

Importantly, the fifth most frequent category (154 of 1544 quotes, 10.0%) showed that despite the fact that only users who were recognized to have stopped their active participation on Tinnitus Talk were invited to the study, they had actually continued visiting the forum, typically as not logged-in visitors of the website. Codes clustered in this category pointed to the following participants: (i) those who were not aware as to why they were recognized as discontinued users of Tinnitus Talk, (ii) those who reported that they had paused in using Tinnitus Talk but are planning to come back, (iii) those who accessed Tinnitus Talk only occasionally, (iv) those who explicitly reported that they visit Tinnitus Talk but without being logged in, and (v) those who limited their participation to reading emails from Tinnitus Talk.

Acceptance/Habituation

This sixth most frequent category (140 of 1544 quotes, 9.1%) represented examples of participants who achieved a state of habituation with tinnitus. In some cases, this achieved habituation was associated with a long duration of tinnitus. The following quote indicated a typical reasoning for deciding to discontinue the use of Tinnitus Talk in this group:

> *I’ve become habituated to the noise and it no longer bothers me to any extent and staying in a forum just reinforces it as a problem which I’ve now accepted.*

Furthermore, in some cases, habituation was characterized by its temporality and fragility, and some participants reported the fluctuation of tinnitus symptoms.

Content Issues

The seventh category (96 of 1544 quotes, 6.2%) mirrored the weak points of Tinnitus Talk’s content and operation but also provided a wide scale of valuable recommendations for particular improvements. Approximately half of the testimonies from this category commented on the poor quality of the content of Tinnitus Talk. Information on Tinnitus Talk was considered to be vague or too general, outdated, overwhelming, regurgitated/repetitive, conflicting, untrustworthy, not authoritative, or anecdotal:

> *One of many shotgun approaches to fixing something on a “maybe this’ll work” basis. I’m not willing to do experiments. It’s depressing enough having the disease.*

Improvement

Surprisingly, the participants offered many potential improvements of Tinnitus Talk, including a system of evaluation of posts in terms of their helpfulness. The eighth most frequent category (92 of 1544 quotes, 6.0%) comprised mainly individual examples of improvements for tinnitus, and cases of present mild states of tinnitus. A relatively wide scale of solutions for reducing tinnitus symptoms were offered, including the use of hearing aids, attending special tinnitus courses, biofeedback, biomagnetic therapy, neurotin or neuromonics medication, ketogenic diet, and special relaxation sounds on YouTube (eg, rain on a tent, waterfall). It should be kept in mind that these are users’ opinions and are not evidence-based recommendations.

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Technical Issues

The ninth category (88 of 1544 quotes, 5.7%) consisted of two almost equal parts. First, discontinued use based on technical or formal issues (eg, limited internet access, forgotten password, Tinnitus Talk emails in spam folder, or not being aware they were previous users of Tinnitus Talk). Second, other participants in this group simply articulated the reason of discontinued use as "I forgot."

Other Health Issues

The last category (49 of 1544 quotes, 3.2%) explained that their discontinued use of Tinnitus Talk is based on preoccupation with other health disorders (eg, Ménière disease, cancer) either for themselves or people close to them.

Users' Perception of Tinnitus Talk

We analyzed the users' perceptions of Tinnitus Talk based on items that refer to usefulness (U), content (CN), communication (CM), and quality of the member posts (Q), which were rated on a 5-point Likert scale with 1 representing "strongly disagree" and 5 representing "strongly agree" (Table 4). Overall, *usefulness* was estimated as slightly above average, with participants finding what they needed on Tinnitus Talk (U1). However, they did not find *better quality of information* as compared to other sources (U2), and the fact that Tinnitus Talk provided *information in English* was not considered to be a problem (U3). The highest-rated aspect of the users' perception of Tinnitus Talk referred to the content, which was rated as *organized, clearly structured* (CN1) and *easy to understand* (CN2). Users also reported not being generally negatively *overwhelmed with the amount of content* (CN3). The users' perception of the Tinnitus Talk community was estimated on the higher end of average for a *connection to other members* (CM1), *the attitude of most of the members* (CM2), and *feeling welcomed* (CM4). However, *forming connections with positive impact* was not rated very highly (CM3). Estimation of the quality of Tinnitus Talk members' posts from the perspective of discontinued users included *perception of the helpfulness of the information* provided by forum members (Q1). The *content* was not estimated as negative (Q4). Although there was some *conflicting information* (Q2), the participants also considered that the *provided information is factually correct* (Q3).

Table 4. Users' perceptions of Tinnitus Talk scored on a 5-point Likert scale (1=strongly disagree and 5=strongly agree).

Question	Mean (SD)
Usefulness (U): How useful was Tinnitus Talk to you as a source of help or information?	
U1: I found what I needed on Tinnitus Talk	3.48 (0.86)
U2: I found better quality information from other sources	2.74 (0.90)
U3: I would have preferred help/information in a language other than English	1.87 (0.95)
Content (CN): What did you think of the content of Tinnitus Talk?	
CN1: The content was well organized and clearly structured	3.76 (0.69)
CN2: The content was easy to understand	3.90 (0.64)
CN3: The forum has too much content for me	2.59 (0.88)
Community (CM): What did you think of the Tinnitus Talk community?	
CM1: I found enough members to relate to or connect with	3.46 (0.82)
CM2: I appreciated the attitude of most members	3.72 (0.75)
CM3: I made connections that positively impacted me	2.90 (0.89)
CM4: I felt welcome	3.65 (0.79)
Posts (Q): How did you find the quality of forum members' posts?	
Q1: The advice/information provided by forum members was helpful	3.60 (0.76)
Q2: There was conflicting advice/information	3.08 (0.82)
Q3: The advice/information provided was factually correct	3.35 (0.66)
Q4: I felt the content was negative	2.43 (0.84)

Correlations Between Predefined Reasons for Discontinued Usage and Perception of Tinnitus Talk

As participants could choose multiple reasons for discontinuation, we applied dummy coding for this variable; if a reason was selected, it was coded as 1 and otherwise was coded as 0. Significant correlations (Bonferroni-corrected $P<.001$) were found between several predefined reasons (R1-R8 in Table 2) for discontinued usage of Tinnitus Talk and users' perception of Tinnitus Talk among 135 correlations assessed for the eight predefined reasons (Table 5).

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Table 5. Correlation between users' perception of Tinnitus Talk and predefined reasons (N=2124-2157).

Variable	R1[a]	R2[b]	R3[c]	R4[d]	R5[e]	R6[f]	R7[g]	R8[h]	Age
U1: I found what I needed on Tinnitus Talk									
r	–0.39	0.23	–0.06	0.22	–0.01	–0.11	–0.02	0.00	–0.18
P value	<.001[i]	<.001	.006	<.001	.71	<.001	.25	.94	<.001
U2: I found better quality information from other sources									
r	0.04	–0.05	0.10	–0.01	0.00	0.02	0.09	0.06	–0.07
P value	.07	.04	<.001	.81	.96	.37	<.001	.009	.002
U3: I would have preferred help/information in a language other than English									
r	–0.04	0.05	0.06	.04	0.03	–0.01	–0.01	–0.02	–0.17
P value	.06	.02	.009	.06	.19	.69	.74	.43	<.001
CN1: The content was well organized and clearly structured									
r	–0.26	0.14	–0.08	0.14	–0.03	–0.20	–0.06	–0.01	–0.11
P value	<.001	<.001	<.001	<.001	.11	<.001	.003	.51	<.011
CN2: The content was easy to understand									
r	–0.20	0.12	–0.07	0.12	–0.04	–0.22	–0.05	0.00	–0.11
P value	<.001	<.001	.003	<.001	.09	<.001	.03	.97	<.001
CN3: The forum has too much content for me									
r	0.12	–0.05	0.09	–0.07	0.03	0.15	0.05	0.03	0.01
P value	<.001	.02	<.001	.001	.17	<.001	.04	.21	.73
CM1: I found enough members to relate to or connect with									
r	–0.30	0.15	–0.05	0.21	–0.05	–0.15	–0.03	0.01	–0.19
P value	<.001	<.001	.03	<.001	.02	<.001	.16	.74	<.001[i]
CM2: I appreciated the attitude of most members									
r	–0.17	0.13	–0.19	0.13	–0.03	–0.10	–0.06	-0.01	–0.08
P value	<.001	<.001	<.001	<.001	.17	<.001	.007	.78	<.001
CM3: I made connections that positively impacted me									
r	–0.26	0.12	–0.02	0.25	0.01	–0.11	–0.03	0.00	–0.20
P value	<.001	<.001	.31	<.001	.77	<.001	.21	.91	<.001
CM4: I felt welcome									
r	–0.25	0.13	–0.03	0.18	–0.03	–0.14	–0.03	0.01	–0.21
P value	<.001	<.001	.25	<.001	.23	<.001	.15	.61	<.001
Q1: The advice/information provided by forum members was helpful									
r	–0.30	0.18	–0.11	0.19	–0.03	–0.14	–0.05	–0.01	–0.16
P value	<.001	<.001	<.001	<.011	.23	<.001	.02	.72	<.001
Q2: There was conflicting advice/information									
r	0.07	–0.01	0.19	0.01	0.00	0.08	0.00	–0.04	–0.10
P value	.001	.66	<.001	.66	.94	<.001	.95	.08	<.001
Q3: The advice/information provided was factually correct									
r	–0.18	0.14	–0.14	0.08	0.00	–0.10	–0.05	0.03	–0.07
P value	<.001	<.001	<.001	<.001	>.99	<.001	.03	.15	.001
Q4: I felt the content was negative									
r	0.10	–0.09	0.32	–0.04	–0.03	0.09	0.03	0.00	–0.02

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Variable	R1[a]	R2[b]	R3[c]	R4[d]	R5[e]	R6[f]	R7[g]	R8[h]	Age
P value	<.001	<.001	<.001	.05	.15	<.001	.13	.87	.42
Age									
r	0.15	–0.14	–0.14	–0.28	0.00	0.04	0.05	0.02	—[j]
P value	<.001	<.001	<.001	<.001	.91	.10	.02	.26	—

[a] R1: I could not find what I was looking for on Tinnitus Talk.

[b] R2: I found what I was looking for on Tinnitus Talk and did not need it anymore.

[c] R3: I perceived negative effects from using Tinnitus Talk.

[d] R4: I did not need Tinnitus Talk anymore because I improved.

[e] R5: I prefer to share in a face-to-face manner.

[f] R6: Tinnitus Talk was too complicated.

[g] R7: I preferred to use a different forum.

[h] R8: I preferred to use Facebook groups.

[i] $P<.001$ refers to an adjusted $P<.000370=.05/135$ (15×9).

[j] Not applicable.

The reason for discontinued usage of *not finding what they were looking for on Tinnitus Talk* (R1) was negatively correlated with *usefulness* (U1). This indicated that the users' reason for discontinued usage was associated with the perception of the usefulness of Tinnitus Talk, which included not being able to find what they needed. The same reason was negatively correlated with perception of Tinnitus Talk's *content,* which was not seen as *well organized and clearly structured* (CN1) or *easy to understand* (CN2), and was positively correlated with the aspect of the content that described the forum *as having too much content* (CN3). One of the explanations of what the users were looking for and could not find on Tinnitus Talk (R1) was revealed by analyzing their perception of communication on the forum (CM). They did not find *enough members to relate or to connect with* (CM1), did not appreciate *the attitude of most members* (CM2), did not make *connections that made a positive impact on them* (CM3), and did not *feel welcome* (CM4). The users also did not find the *quality of the information* they were looking for. This included perception of the advice/information provided by forum members as *not helpful* (Q1), *factually not correct information* (Q3), and *perception of the content as negative* (Q4).

On the other side, there was a group of discontinued users who did find what they were looking for on Tinnitus Talk but subsequently discontinued using the forum (R2). Their reason for discontinued usage was positively correlated with *usefulness* (U1), meaning that they did find what they needed on the forum. They also found the content to be *well organized and clearly structured* (CN1), and *easy to understand* (CN2). The perception of the communication on Tinnitus Talk was generally positive, including *finding enough members to connect with* (CM1), appreciating *the attitude of most members* (CM2), *making connections with a positive impact* (CM3), and *feeling welcome* (CM4). They perceived the quality of the information provided by other members to be *helpful* (Q1), *factually correct* (Q3), and they did not perceive the *content as negative* (Q4).

The correlations between the reason of perceiving negative effects from using Tinnitus Talk (R3) and the perception of the forum clarified their discontinuation of usage. They found *better quality of information from other sources* (U2), did not perceive the forum's *content as well organized and clearly structured* (CN1), they perceived that it had *too much content for them* (CN3), and they did not appreciate *the attitude of most members* (CM2). Additionally, they did not find advice/information provided by forum members to be helpful (Q1), perceived information as conflicting (Q2) and not factually correct (Q3), and felt that the content was negative (Q4).

Users who discontinued using the Tinnitus Talk forum because their condition had improved (R4) also *found what they needed* (U1). Their perception of the content was positive. They perceived the forum content as *well organized and clearly structured* (CN1), and *easy to understand* (CN2). Their perception of the communication between members was also positive; namely, they found *enough members to connect with* (CM1), appreciated *the attitude of most members* (CM2), made *connections with positive impact* (CM3), and *felt welcome* (CM4). The perceived quality also reflected the satisfaction of these members, as they found the *advice and information provided by other members to be helpful* (Q1) and *factually correct* (Q3).

The reason for discontinued usage of the forum because the users *prefer to share in a face-to-face manner* (R5) or they *prefer to use a Facebook group* (R8) was not significantly correlated with any of the 14 items related to perception of the forum.

The correlation between perceptions of the Tinnitus Talk forum by the users who discontinued because they found it to be *too complicated* (R6) revealed more specific aspects they found to be problematic. First, they could *not find what they needed* (U1). Their perception of the forum's content was negative because of *not being organized and clearly structured* (CN1), *not easy to understand* (CN2), and *having too much content* (CN3). They did not find *enough members to connect with* (CM1), they did not appreciate *the attitude of most members* (CM2), did not make *connections with a positive impact* (CM3), and they did not *feel welcome* (CM4). They also did not find the *information*

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provided by the forum's members to be helpful (Q1), *advice and information were perceived as conflicting* (Q2) and *not factually correct* (Q3), and they felt that *the content was negative* (Q4).

The reason for discontinued usage of the Tinnitus Talk forum because of a *preference to use a different forum* (R7) was positively correlated with finding *better quality of information from other sources* (U2).

Correlations Between Other Reasons for Discontinued Usage and Perception of Tinnitus Talk

Correlations were also calculated between the 10 qualitatively coded "other" reasons (R9 in Table 2) for discontinued usage and the users' perception of Tinnitus Talk with a total of 150 correlations assessed (Table 6).

Significant correlations were only found between reasons labeled as "Busy" (O3), "Hope/Positive" (O4), "No cure/help" (O6), "Still using Tinnitus Talk" (O8), and "Content issues" (O10) and users' perception of Tinnitus Talk. There were no significant correlations between the reasons labeled as "Acceptance/Habituation" (O1), "Avoidance" (O2), "Improvement" (O5), "Other health issues" (O7), and "Technical issues" (O9) with users' perspective of the Tinnitus Talk forum.

A negative correlation was found between the reason labeled as "Busy" (O3) and the perception of the *content was negative* (Q4), meaning that those who discontinued usage due to being busy did not find the content to be negative. Users who had positive hope (O4) thought that *the content was well organized and clearly structured* (CN1) and that *the advice/information provided by forum members was helpful* (Q1).

The discontinued users who thought that there is no cure or help (O6) could *not find what they were looking for on Tinnitus Talk* (U1). They also did not find the *content to be well organized and clearly structured* (CN1) or *easy to understand* (CN2). Regarding their perception of the other members, they did not find enough *members to relate to or connect with* (CM1), did not appreciate *the attitude of other members* (CM2), did not make *connections that positively impacted them* (CM3), and did not *feel welcome* (CM4). Additionally, the perception of the *quality of the forum* was rated as lower in this group, with not perceiving the advice provided by other members as *helpful* (Q1) or *factually correct* (Q3). In fact, they felt that the content was *negative* (Q4).

The users that stated that they are in fact still using Tinnitus Talk (O8) could *find what they were looking for* (U1). They perceived the content as *well-organized and with a clear structure* (CN1) and there was *nottoo much content* for them (CN3). They found *enough members to relate to* (CM1), appreciated the *attitude of most members* (CM2), made *connections that positively affected them* (CM3), and *felt welcomed* (CM4). This reason was also positively correlated with perceiving the *advice of forum members as helpful* (Q1) and the content was not considered to be *negative* (Q4).

The users who discontinued using Tinnitus Talk because of content issues (O10) could *not find what they were looking for* (U1), and did not find that *the content was well organized and clearly structured* (CN1) or *easy to understand* (CN2). They also did not find *enough members to relate to or connect with* (CM1), did not make *connections that positively impacted them* (CM3), and did not *feel welcome* (CM4). The advice/information provided by forum members was *not helpful* (Q1), there was *conflicting advice/information* (Q2), and *factually not correct information* (Q3).

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Table 6. Correlations between users' perception of Tinnitus Talk and other reasons (N=1436-1527).

Variable	O1[a]	O2[b]	O3[c]	O4[d]	O5[e]	O6[f]	O7[g]	O8[h]	O9[i]	O10[j]
U1: I found what I needed on Tinnitus Talk										
r	0.07	0.05	0.05	0.08	–0.01	–0.17	0.01	0.16	–0.01	–0.14
P value	.005	.04	.06	.003	.73	<.001[k]	.60	<.001	.79	<.001
U2: I found better quality information from other sources										
r	–0.05	–0.02	0.02	–0.04	0.08	–0.01	–0.05	–0.03	0.04	0.04
P value	.06	.46	.53	.10	.002	.72	.08	.25	.10	.08
U3: I would have preferred help/information in a language other than English										
r	0.00	0.06	–0.01	–0.03	0.03	0.00	–0.03	–0.03	0.00	–0.02
P value	.88	.02	.58	.30	.22	.87	.19	.29	.99	.35
CN1: The content was well organized and clearly structured										
r	0.03	0.03	0.05	0.10	–0.03	–0.11	0.03	0.11	–0.05	–0.15
P value	.26	.20	.05	<.001	.24	<.001	.24	<.001	.07	<.001
CN2: The content was easy to understand										
r	0.06	0.04	0.07	0.06	–0.05	–0.10	0.06	0.08	–0.06	–0.13
P value	.03	.09	.01	.01	.05	<.001	.03	.004	.02	<.001
CN3: The forum has too much content for me										
r	–0.02	0.03	–0.03	–0.04	–0.01	0.09	–0.05	–0.11	0.00	0.07
P value	.38	.20	.21	.12	.71	<.001	.07	<.001	.86	.01
CM1: I found enough members to relate to or connect with										
r	0.05	0.04	0.03	0.07	0.00	–0.12	0.00	0.11	–0.01	_0.13
P value	.08	.15	.32	.006	.93	<.001	.91	<.001	.65	<.001
CM2: I appreciated the attitude of most members										
r	–0.01	0.04	0.04	0.07	–0.01	–0.11	0.04	0.11	–0.04	–0.07
P value	.74	.16	.12	.005	.80	<.001	.17	<.001	.18	.006
CM3: I made connections that positively impacted me										
r	0.05	0.02	0.01	0.03	0.04	–0.14	0.00	0.10	0.04	–0.13
P value	.08	.54	.65	.19	.09	<.001	.86	<.001	.13	<.001
CM4: I felt welcome										
r	0.04	0.03	0.01	0.06	0.03	–0.11	0.02	0.14	–0.05	–0.12
P value	.11	.20	.58	.02	.23	<.001	.47	<.001	.04	<.001
Q1: The advice/information provided by forum members was helpful										
r	0.09	0.06	0.08	0.10	–0.01	–0.20	0.02	0.11	–0.02	–0.19
P value	.001	.02	.003	<.001	.68	<.001	.38	<.001	.51	<.001
Q2: There was conflicting advice/information										
r	–0.06	0.04	–0.08	–0.02	0.04	0.07	–0.03	–0.05	–0.03	0.13
P value	.03	.13	.002	.56	.16	.007	.26	.06	.21	<.001
Q3: The advice/information provided was factually correct										
r	0.03	–0.01	0.05	0.05	–0.02	–0.11	0.02	0.05	0.02	–0.10
P value	.29	.72	.05	.06	.40	<.001	.45	.05	.40	<.001
Q4: I felt the content was negative										
r	0.00	0.08	–0.10	–0.01	0.00	0.13	–0.03	–0.11	–0.01	0.05

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Variable	O1[a]	O2[b]	O3[c]	O4[d]	O5[e]	O6[f]	O7[g]	O8[h]	O9[i]	O10[j]
P value	.97	.001	<.001	.64	.98	<.001	.22	<.001	.83	.06
Age										
r	–0.06	–0.15	0.08	–0.06	0.01	0.04	0.06	–0.01	0.05	0.03
P value	.02	<.001	.001	.01	.68	.09	.03	.68	.05	.33

[a] O1: acceptance/habituation.

[b] O2: avoidance.

[c] O3: busy.

[d] O4: hope/positive.

[e] O5: improvement.

[f] O6: no cure/help.

[g] O7: other health issues.

[h] O8: still using Tinnitus Talk.

[i] O9: technical issues.

[j] O10: content issues.

[k] *P*<.001 refers to an adjusted *P*<.000333=.05/150 (15×10).

Correlations between Reasons for Discontinued Usage of Tinnitus Talk and Age

Correlations Between Predefined Reasons for Discontinued Usage of Tinnitus Talk and Age

As summarized in Tables 5 and 6, older users discontinued usage of Tinnitus Talk because they *could not find what they were looking for* (R1, R2), whereas younger users were more likely to discontinue usage of Tinnitus Talk because they *perceived negative effects* (R3) or because *they improved and no longer needed Tinnitus Talk* (R4).

Correlations Between Other Reasons for Discontinued Usage of Tinnitus Talk and Age

The only significant correlation between age and other reasons (R9 in Table 2; 10 qualitatively coded categories in Table 3) was found between age and *avoidance*, with avoidance being more prevalent among younger users (O2).

Correlations Between Users' Perception of Tinnitus Talk and Age

As shown in Table 5, older users *did not find what they needed on Tinnitus Talk* (U1) and would *not prefer information in other languages* (U3). Older users also did not *perceive the content as well organized and clearly structured* (CN1) or *easy to understand* (CN2). They also did not find *enough members to communicate with* (CM1), did not *appreciate the attitude of most members* (CM2), did not make *connections with positive impact* (CM3), and did not *feel welcomed* (CM4). They did not find *information provided by forum members to be helpful* (Q1) but also did not *perceive information as conflicting* (Q2).

Discussion

Reasons for Discontinued Usage of Tinnitus Talk

This study assessed a wide range of reasons for why users discontinued use of the health-related internet forum Tinnitus Talk. Moreover, one of the aims of this study was to provide explanation and understanding of these reasons. Previous similarly oriented studies were mainly focused on the measurement of dropout rates from various health-related web-based platforms with very inconsistent findings [7].

We quantitatively analyzed eight predefined reasons for discontinued usage and qualitatively coded the open option for other reasons. The eight predefined reasons can be categorized into three subgroups. The first subgroup included characteristics of the forum as a reason for discontinued usage, such not finding what one was looking for on Tinnitus Talk (R1), perceiving negative effects from using Tinnitus Talk (R3), and perceiving Tinnitus Talk as too complicated (R6), accounting for 27.2% (listed as a reason 734 times among the total of 2695 reasons listed) of the reasons for discontinued usage. The second subgroup included reasons related to no longer needing the forum, either because they already found what they were looking for on Tinnitus Talk (R2) or because their condition improved (R4), accounting for 23.6% (637/2695) of the reasons listed. The third group of reasons referred to the preference of other sources of information, including sharing in a face-to-face manner (R5), preference of a different forum (R7), or preference of using Facebook groups (R8), accounting for only 9.2% (249/2695) of the total reasons. The remaining reasons fall into the group "other" reasons (39.9%, 1075/2695), which were additionally qualitatively analyzed. Based on these results, the Tinnitus Talk forum could improve with respect to these specific aspects that led to discontinuation.

Users' Perception of Tinnitus Talk

Additionally, the users' perception of the Tinnitus Talk forum revealed that the aspects with the lowest scores were a preference for help/information in a language other than English and that the content was negative. The aspects with the highest scores referred to perceiving the content as easy to understand as well as organized and clearly structured, and appreciation of the attitude of most members. The calculated correlations between the reasons for discontinued usage and the users' perception of Tinnitus Talk revealed associations that provide

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clearer insight into the relevant characteristic of the forum and its discontinued usage.

Correlations Among Reasons, Perception of Tinnitus Talk, and Age

The reasons from the first subgroup, that refer to aspects of Tinnitus Talk such as not finding what they were looking for, perceiving negative effects, and perceiving the forum as too complicated, were significantly correlated with aspects of usefulness such as not finding what they want, content aspects, communication aspects, and some of the aspects of the quality of members' posts. The perception of negative effects from using Tinnitus Talk was significantly correlated with some aspects of usefulness, content, communication, and quality.

The reasons from the second subgroup, those that refer to no longer needing Tinnitus Talk either because of finding what they needed or because their condition improved, perceived positive aspects of usefulness, content, communication, and quality.

The reasons from the third subgroup, referring to a preference of other sources such as face-to-face sharing or Facebook groups, did not have a significant correlation with almost any aspect of users' perception of Tinnitus Talk, with the exception of a positive correlation between preferring another forum and finding better-quality information from other sources.

Additionally, older users did not perceive Tinnitus Talk as useful and well organized or easy to understand, and did not find there to be good communication or good quality of other members' posts. Older users were also more likely to stop using Tinnitus Talk because they could not find what they were looking for, whereas younger users discontinued because of perceiving more negative effects from using Tinnitus Talk or because their condition improved. These results imply that Tinnitus Talk might not be the best suited platform for older users, possibly due to a larger amount of online information as they might not be used to that type of information processing.

Analyses of "other" additional reasons revealed that users who discontinued using Tinnitus Talk because they were too busy did not perceive the content as negative. In addition, users who had positive hope perceived the content to be well organized and clearly structured, and that the advice/information provided by forum members was helpful.

The users who discontinued to use Tinnitus Talk because they think that there is no cure or help did not find what they needed on the forum, and did not find that the content was organized well and clearly structured or easy to understand. They also did not find enough members with whom they could relate, did not appreciate the attitude of most members, did not make connections that positively impacted them, and did not feel welcomed. Moreover, they did not find the advice from other forum members to be helpful or factually correct, and they felt that the content was overall negative.

The users who reported that they were still using the forum found what they needed on Tinnitus Talk, thought that the content is well organized and clearly structured, and that there was not too much content. In general, they found the communication with forum members to be positive through connection with other members, appreciated the attitude of most members, made connections with positive impact, and felt welcomed. They also found that the information provided by forum members was helpful and that the content was not negative.

The users who discontinued using the forum because of content issues did not find what they needed, and did not find that the content was well organized and clearly structured or easy to understand. These members showed dissatisfaction in terms of communication with forum members, as they not find enough members to relate to, did not make connections that positively impacted them, and did not feel welcomed. They also did not find the information provided by forum members to be helpful, and they perceived conflicting and factually incorrect information.

The acceptance of a disease seems to be of crucial importance in the treatment of tinnitus and other chronic diseases [18]. The ability to accept having tinnitus was also understood by some participants as a condition in achieving a state of habituation. To be able to accept tinnitus could be achieved in different ways. Another strategy of how to cope with tinnitus is the avoidance of tinnitus-related themes and thoughts, as reported by participants in this study. This strategy may be helpful in the short-term, but can create problems in the long-term. The avoidance strategy only temporarily helped many of the participants to relieve their symptoms. Although some of them achieved a state of habituation, they reported that this was only for a limited time period (also see Figure 1).

Surprisingly, several valuable recommendations for improvement of the Tinnitus Talk platform were found in testimonies, including ideas to assist users in finding, evaluating, and summarizing the information on Tinnitus Talk, which was recently elaborated by Dandage et al [2]. Some participants of our study reported helplessness related to the strong negativism of several Tinnitus Talk users and their radical posts, which attracted high attention of other users and frightened mainly new users. To maintain and moderate the content is very difficult, especially when the forum is operated on a nonprofit basis.

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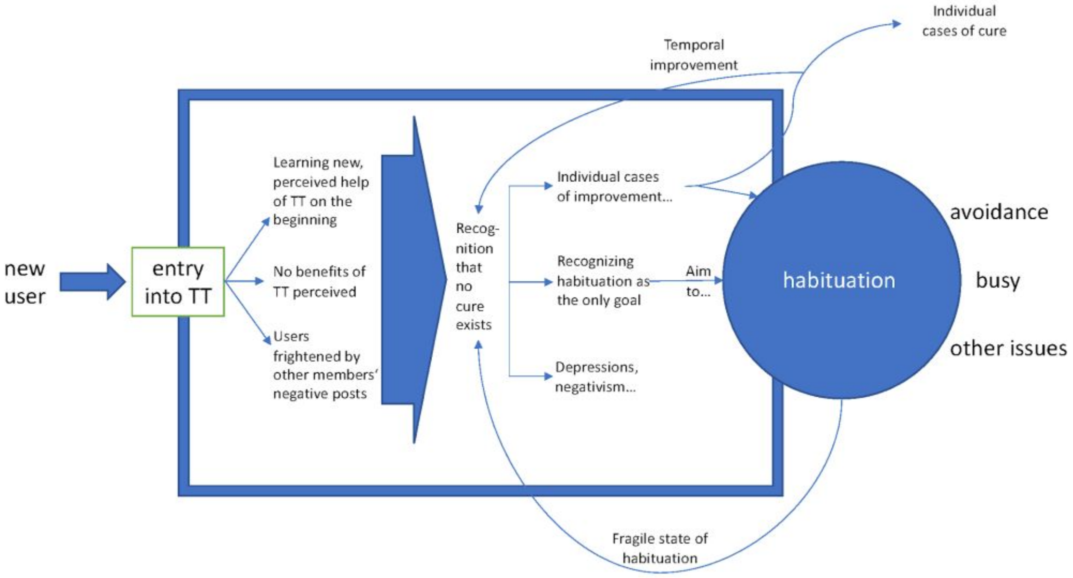
Figure 1. Process model of participation on Tinnitus Talk (TT).



Process Model of the Use of Tinnitus Talk

Based on the qualitative analysis, a process model of the use of Tinnitus Talk may be suggested (Figure 1). In testimonies, some participants explained their journey retrospectively from starting as newcomers to Tinnitus Talk with recent onset of tinnitus until becoming a well-informed user who gradually managed to habituate.

The proposed process model tries to reconstruct the experience of Tinnitus Talk users over time. At the beginning, Tinnitus Talk is typically the first or one of the very first resources for tinnitus-related information the user encounters. Gradually, the user's own tinnitus experience is complemented by accumulated knowledge from Tinnitus Talk. In the quantitative analysis, we found that information saturation (ie, they found what they were looking for but they did not need it anymore) was the second most frequently reported reason for discontinuing the use of Tinnitus Talk. Thus, this process model depicts how Tinnitus Talk works in terms of information saturation among users. Furthermore, it illustrates different pathways of using Tinnitus Talk according to various situations of users. As this study was cross-sectional and we did not assess the time at which a user started using Tinnitus Talk, this model is rather vague. Thus, future longitudinal research is necessary to evaluate this model, which was constructed based on the free-text answers given by only some Tinnitus Talk users.

As we specifically assessed perceptions from a group of lapsed Tinnitus Talk users, there may be many other reasons and motivations to participate in Tinnitus Talk. Health-related fora help a patient cope with their disease, find an important source of social support, feel understood, and allow them to also offer help to other sufferers. The fact that the participants were recruited based on their 2-month absence from the Tinnitus Talk forum is an important limitation of this study. Although this allowed us to more precisely target the group of discontinued users, the perceptions on Tinnitus Talk presented in this study can at best only reflect this group, but cannot be considered as representative for all users of the forum, which comprises approximately 2000 active members. On the other side, complete sampling of lapsed members of Tinnitus Talk was performed and the feedback rate was considerable for an analysis of a group that quit a forum. When interpreting the results, it should also be kept in mind that users of Tinnitus Talk are not representative of other individuals with tinnitus. Previous research has shown differences between Tinnitus Talk users, users of the Track Your Tinnitus smartphone app [19], and patients at an outpatient tinnitus center [20]. According to the criteria applied for the selection of participants, we still detected some users who in fact did not discontinue the use of Tinnitus Talk but are rather taking a break; in other words, they are lurking in more or less a passive way for new information such as a breakthrough in new possibilities of tinnitus treatment.

Another limitation of this study relates to the results of the qualitative analysis, which cannot be generalized, but provide us with a variety of examples that are valuable for understanding individual cases. Moreover, the insight based on participants' testimonies enables developing new hypotheses for future research. In addition to contributing to understanding users' reasons for discontinuing the use of a health-related internet forum, several interesting questions for future research have emerged, including (1) How strong is the contagion effect of negativism on various health-related discussion fora in various groups of users? (2) Is there any effect of using Tinnitus Talk on the severity of tinnitus, which can be accessed with the Tinnitus Handicap Inventory [21] (3) What is the accuracy of the health-related advice and recommendations posted by users of Tinnitus Talk when evaluated by medical experts? (4) Does the use of Tinnitus Talk induce some transformation of emotions in various groups of users?

There are also many challenges and calls for qualitative studies in the field, including (1) determining the extent to which users of Tinnitus Talk understand their disease, (2) how they experience their active participation on Tinnitus Talk, or (3) how they perceive the forum to induce or moderate their health-related anxieties or hopes. For future research, it would also be stimulating to link the survey answers of this study to the users' activities in the forum (ie, behavior, posts, and overall performance on Tinnitus Talk). Unfortunately, this was not possible in this study, which directly targeted only the (presumed) lapsed members. However, we investigated a group of users that are usually out of research scope in the health field. This study revealed this particular group of lapsed users as a very important resource of feedback for preventing dropouts, for improvement of health-related internet fora, and for identification of some weak points and potential risks of health-related fora. The identification of these weaknesses and risks could be utilized as a source of opportunities for improvement.

This study brings forth a variety of practical implications. Reasons that led users to discontinue their active participation on Tinnitus Talk offers valuable feedback for providers of the forum as well as for providers of other health-related fora in the following areas: (1) targeting of communication (eg, newsletters, emails) to specific groups of users, with regard to whether they are newcomers or long-time users; (2) optimization of the structure according to various groups of users (eg, content navigation for newcomers, sections structured for people with different degrees of severity and subtypes of diseases); and (3) evaluation of users' posts by other forum members as well as by doctors/physicians (eg, in terms of relevance, helpfulness, or potential harm; see also Dandage et al [2]). Some proposals for improvement would require a substantial amount of work and sufficient financial resources on the side of Tinnitus Talk nonprofit providers, namely with respect to continuous content edits, preparing thematic summarizations, quick answering of users' questions, and in "putting the records straight." However, this last suggestion seems to be particularly relevant for health-related fora in general, because the quality of discussion posts dramatically fluctuates [22-24]. In addition to the potential dissemination of misleading health-related information, the high occurrence of negativism in users' posts was considered by some users as a call for a reaction or intervention from the side of Tinnitus Talk providers.

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Authors' Contributions

SB, MK, MS, and TP substantially contributed to analyses and interpretation of data, drafting the article, and final approval of the version to be published. TP, MS, WS, RP, GA, HG, SH, MV, GH, BL, and CP substantially contributed to conception and design, acquisition of data, revising the manuscript critically for important intellectual content, and final approval of the version to be published. SH, MV, and GH also contributed to the Tinnitus Talk platform.

Conflicts of Interest

HG, MV, and SH work for Tinnitus Hub, a nonprofit provider of Tinnitus Talk. They participated in the preparation and distribution of the data mining instrument, and coauthored information about background, history, and functionalities of Tinnitus Talk. The other authors declare no conflicts of interest.

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Abbreviations

CM: communication
CN: content
GTM: grounded theory methodology
Q: quality of member posts
U: usefulness

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Original Paper

Brief Interventions via Electronic Health Record Messaging for Population-Based Suicide Prevention: Mixed Methods Pilot Study

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Abstract

Background: New opportunities to create and evaluate population-based selective prevention programs for suicidal behavior are emerging in health care settings. Standard depression severity measures recorded in electronic medical records (EMRs) can be used to identify patients at risk for suicide and suicide attempt, and promising interventions for reducing the risk of suicide attempt in at-risk populations can be adapted for web-based delivery in health care.

Objective: This study aims to evaluate a pilot of a psychoeducational program, focused on developing emotion regulation techniques via a web-based dialectical behavior therapy (DBT) skills site, including four DBT skills, and supported by secure message coaching, including elements of caring messages.

Methods: Patients were eligible based on the EMR-documented responses to the Patient Health Questionnaire indicating suicidal thoughts. We measured feasibility via the proportion of invitees who opened program invitations, visited the web-based consent form page, and consented; acceptability via qualitative feedback from participants about the DBT program; and engagement via the proportion of invitees who began DBT skills as well as the number of website visits for DBT skills and the degree of site engagement.

Results: A total of 60 patients were invited to participate. Overall, 93% (56/60) of the patients opened the invitation and 43% (26/60) consented to participate. DBT skills website users visited the home page on an average of 5.3 times (SD 6.0). Procedures resulted in no complaints and some participant feedback emphasizing the usefulness of DBT skills.

Conclusions: This study supports the potential of using responses to patient health questionnaires in EMRs to identify a high-risk population and offer key elements of caring messages and DBT adapted for a low-intensity intervention. A randomized trial evaluating the effectiveness of this program is now underway (ClinicalTrials.gov: NCT02326883).

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KEYWORDS

suicide; suicide prevention; dialectical behavior therapy; caring message; web-based; NowMattersNow.org; prevention

Introduction

Background

Significant momentum supports the work of suicide prevention in health care settings as well as the inclusion of people who have personal experience with suicidal thoughts and behaviors, including systems changes initiatives such as Zero Suicide and new national patient care guidelines such as Recommended Standard Care for People With Suicide Risk: Making Health Care Suicide Safe [1-3]. However, there are significant challenges that hamper major advancements in the field. Although research support for clinical and tertiary treatments

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exists, these treatments are often intended for those who have already made suicide attempts or have been hospitalized for suicide-related reasons and they likely only have a minimal effect on suicide rates of the overall population [4,5]. This may be because of limited availability and postvention focus. Intensive tertiary interventions for suicidal patients, such as dialectical behavior therapy (DBT) and cognitive behavioral therapy (CBT) for suicide prevention, require significant clinical training for clinicians[6,7]. For patients, they are often costly, time intensive, and inaccessible. Empirically supported interventions target individuals who have already engaged in a suicide attempt [8]. Meanwhile, clinical responses to patients who report suicidal ideation generally focus on acute crises and risk management, such as safety planning, emergency room care, and inpatient psychiatric care. Unfortunately, this sometimes leads to coercive interactions because the onus is on the patient to prove that they are no longer suicidal or *at risk* to leave the health care setting [9].

Selective prevention—otherwise known as secondary or indicated prevention—focused on outreach, support, and skills development would allow for a more collaborative approach. Owing to several conceptual, methodological, logistical, and ethical challenges, selective prevention for suicide remains to be relatively unexplored. Effective selective prevention for suicide requires three things: (1) accurate methods for identifying those at risk before a suicide attempt, (2) effective interventions suitable for large-scale delivery, and (3) acceptable and efficient models for population-based delivery.

The Patient Health Questionnaire (PHQ) [10], a depression questionnaire commonly documented in electronic medical records (EMRs), can be used to identify those greater short-term (3% risk of suicide attempt in the following month) and long-term (5-10 times greater risk for suicide and suicide attempt over the following 2 years) risks [11,12]. These risk levels are specific to PHQ item 9, which asks whether the patient, over the past 2 weeks, has been bothered by “thoughts that you would be better off dead or of hurting yourself in some way.” Responses of “more than half the days” or “nearly every day” are linked to the elevated risk described, and the risk remains to be significant when controlling for the total score of the remaining PHQ items and demographic variables. More recently, PHQ scores in combination with other EMR data have been used to predict suicide attempts and suicide using empirically derived risk scores [13].

A promising low-intensity intervention is caring messages, comprising brief, nondemanding, unsolicited caring messages sent by a health care provider over time. Although caring messages studies are not without limitations, data suggest that they may reduce the incidence of suicide in psychiatric patients [14,15]. It has also been shown to reduce additional suicide attempts [8,16-18]. Caring messages is among the few interventions that have replicated such findings [2,14,19-21]. The Institute of Medicine and the National Action Alliance for Suicide Prevention identify caring messages as a promising and recommended intervention [2,22], and it has been adapted for email [23]. A possible mechanism of action for caring messages is that it may address a lack of social connections [24].

DBT, another intervention, is a high-intensity treatment demonstrated to reduce suicidal behaviors by teaching individuals how to effectively manage intense emotions and tolerate distress [6]. Reductions in suicidal behaviors have been replicated across at least four DBT randomized controlled trials targeting suicidal individuals [19,25-28]. The key elements of DBT can be adapted for brief interventions. In a component analysis of DBT and a subsequent literature review, preliminary analyses suggest that one element—skills training—is effective in reducing suicidal behaviors [29,30]. Skills training has subsequently been adapted for brief, population-based interventions [31-34].

For the delivery of such interventions, the population-level impact requires a model that is affordable and scalable. Web-based interventions have the potential to reach large numbers of high-risk individuals and have been shown to be effective for support inside and outside medical settings [35-38]. Such interventions have demonstrated effects over usual care, in some cases comparable with in-person treatment [39-43]. Intervention websites, both with and without human support, are scalable for population-based uses in ways that in-person interventions are not [44]. Evidence supporting web-based adaptations of high-intensity treatments such as CBT warrants the development and testing of a web-based DBT skills intervention. The advantages of intervention websites include 24-hour accessibility, greater perceived privacy, and flexibility of location.

Meanwhile, EMR systems can be used not only to support the delivery of web-based interventions but also to identify those at risk and to support patient-provider secure messaging used for intervention. EMRs with secure messaging have the potential to significantly increase the efficiency and dissemination of suicide prevention and suicide attempts. Secure messaging has been successfully used to deliver low-intensity interventions [45-47]. Secure messaging can be used to support the delivery of web-based interventions traditionally delivered in person, such as CBT and motivational interviewing.

Objectives

This pilot study aims to assess the feasibility, acceptability, and engagement of a brief suicide prevention intervention in preparation for a full-scale randomized trial. We evaluated this by measuring patient response to an invitation to a web-based, population-based suicide attempt and suicide prevention intervention, intended to be easily adapted into large health care systems, which included elements of DBT and caring messages.

Methods

Overview

We evaluated the feasibility, acceptability, and engagement of a brief web-based suicide prevention intervention using qualitative and quantitative methods. The intervention included EMR-mediated secure messaging linked to a web-based DBT skills platform. Participants included outpatients who were receiving care within Kaiser Permanente Washington, a health system serving approximately 700,000 people in Washington State, which routinely administers the PHQ to all patients

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receiving care for mental health conditions [10,48]. Patients were eligible if they were aged 18 years or older, had ID verification for secure email messaging through the EMR, had sent or read a secure message in the past year, and had completed a PHQ depression severity questionnaire in the previous week and responded “more than half the days” or “nearly every day” to item 9 (“Thoughts that you would be better off dead or of hurting yourself in some way”). Previous research in this setting indicates that this group would have an expected risk of suicide attempt of approximately 4% over the following year [11,12].

Over the course of 3.5 months, we used an automated EMR data query program to pull 6 samples, identify 60 individuals, and conduct outreach via secure messaging accessible on a mobile app or website. We used this sample size, which could be considered large for a pilot, to gain confidence in our estimates for the feasibility of a large clinical trial. We sent secure message invitations to the DBT skills program approximately every other week to between 5 and 20 eligible participants for each sample (starting at the top of the list) to evaluate ideal caseload management. Invitations were sent 1 to 2 weeks after the visit, if an elevated PHQ item 9 was involved. Patient care continued to be the responsibility of the behavioral health and primary care providers in the Kaiser Permanente Washington system who had administered the PHQ at the recent visit. In addition, a suicide risk protocol involving follow-up by study clinicians (author 1 or 3) for those who indicated imminent risk over secure message was in place, although the protocol was not triggered during the study. The study procedures were approved by the organization’s institutional review board, which included a waiver of research consent for patient identification and intervention invitation; however, this restricted the analysis of additional data (eg, descriptive data of eligible participants). The waiver of consent for patient identification and intervention invitation was granted because this pilot and subsequent trial involved no more than minimal risk and because the purpose of the pilot was to evaluate the feasibility and acceptability of procedures planned for the randomized trial of outreach. Evaluating only patients who actively consented to receive intervention would have yielded a result of questionable validity and generalizability.

The invitation messages, and the messages that followed, can be conceptualized as having two elements: a caring message (a brief and unsolicited expression of care) and support for a web-based DBT skills intervention (Textbox 1). We do not know whether the combination of these elements will be effective, which is not measured in this pilot. The footer of each message included the coach name and title and also included the option to opt out of additional messages, noting that messages were part of a research project and would be part of the EMR, and included numbers to call in case of immediate crisis. The secure message invitation included a link to a web-based video consent form (Multimedia Appendix 1). Patients who did not open the invitation received a telephone call. Those who opened it but did not visit the consent received a secure message reminder. Invitation messages were designed based on patient feedback that they would be most drawn to an intervention that made them feel cared for (eg, subject lines expressing concern), that was personalized, that others like them had found helpful, and that included examples with real people [49,50]. Once consent was confirmed, participants arrived at the landing page of the DBT skills site.

The web-based DBT skills site included four DBT skills (mindfulness, opposite action, mindfulness of current emotion, and paced breathing). This content focused on training in specific skills to manage upsetting or painful emotions that can precipitate suicidal thoughts and behavior. Content was based on a brief DBT skills face-to-face intervention developed and pilot-tested by the first author [33] and included a video-based series of didactic and personal story demonstrations of DBT skill use with a team of collaborators with lived experience of suicidal thoughts and behavior (Team Now Matters Now). DBT experts, including the DBT developer Marsha Linehan, also consulted on intervention development. The website landing page included a brief orientation video describing the intervention content and what to expect (Multimedia Appendix 2). Below the video on the landing page was a list of the four DBT skills, with a brief description (eg, “Mindfulness - A way to be present for what is most important in your life”; Textbox 2). Participants could also choose to learn more about Team Now Matters Now or provide feedback about the program. The DBT skills content was housed on a Health Insurance Portability and Accountability Act–compliant modular software platform (DatStat). Each of the four DBT skills followed the same path that included a 30-second overview or *teaser*, a 5- to 8-minute didactic video describing the skill as it might in a traditional DBT skills group, several 1- to 5-minute demonstration videos with real people talking about how they used the DBT skill in their own life, and a 1-page practice assignment similar to what one might find in a DBT skills group. One could return to the landing page to select another skill at any point in the pathway of a particular skill. In addition to the other benefits of web-based interventions outlined in the introduction, they also provide a consistent patient experience and are baked in fidelity [51].

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Textbox 1. Secure message invitation.

Dear [First Name]

Sometimes a little extra help can be just what someone needs to get through tough times.

A new web-based program called Now Matters Now was designed to give you that help when you need it. The program uses real people to teach specific coping skills, like mindfulness and paced breathing.

We invite you to try Now Matters Now today. Learn more at <Link to Intervention Website>

We care about you.

My job is to encourage you to use the program over the next three months and to practice the skills you are learning. If you haven't visited the program in a while, I'll send you a message to remind you. If you have visited, I'll check with you about what you find helpful.

I'll communicate with you through messages, and in order to message you, I will access your medical record.

Sending care,

Textbox 2. Dialectical behavior therapy skills site landing page text.

- TEAM NOW MATTERS NOW—Introducing the real people who use these skills and helped develop this program
- MINDFULNESS—A way to be present for what is most important in your life
- OPPOSITE ACTION—Living a full and healthy life, despite what negative or unhelpful emotions and thoughts are telling you to do
- MINDFULNESS OF CURRENT EMOTION—Observing, honoring, and moving through strong emotions without being controlled by them
- PACED BREATHING—A different and scientific approach to the old saying "Just Breathe"
- GIVE US FEEDBACK—Did you have technical problems with this program? Do you want to give us feedback about the program, good or bad?

The DBT skills intervention was supported by an interventionist or program *coach* for 3 months. In line with the stage model of behavior therapies, the interventionist for this study was the lead intervention developer (UW) [51-53]. This included caring messages outreach and support for the use of the DBT skills site. For 2 months, the coach delivered this support exclusively via secure messaging, reaching out approximately once per week for participants' engagement and less frequently for those who had not responded to the most recent secure message. For the third month, the patient could continue to engage in the intervention or send the coach messages and the coach would reply, but the coach would not actively outreach or prompt the patient. The intervention coach did not provide psychotherapy but instead provided caring messages as well as outreach in the form of reinforcement and contingency management surrounding the use of the DBT skills site. This would include following up with patients who had not visited the site in several weeks, suggesting specific skills they might find useful or thanking the patient for visiting the site and include a tip or point relevant to the DBT skill they viewed (Textbox 3 provides an example of this type of message). The research team met weekly with the senior investigator (author GES) to ensure safety monitoring and coach fidelity. The senior investigator also had access to review the secure messages of the coach to monitor secure message fidelity to the described approach.

Textbox 3. Coach outreach/and support message example.

Hi [First Name],

I'm writing to check-in from the Now Matters Now program. Do any of the skills look interesting to you to try?

Paced Breathing is a breathing technique that can calm the mind and body naturally. Some people like to use Paced Breathing when they're feeling nervous or anxious. It can also be a helpful way to clear the mind if you're having a difficult time falling asleep.

The key to Paced Breathing is to have your exhale be longer than your inhale. It can be a good way to center yourself and makes it easier to then practice other skills.

If you try it, let me know how it goes.

To learn more, please click the link below:

[link to Consent "form" video]

Take care,

Feasibility, Acceptability, and Engagement

We evaluated feasibility by measuring the proportion of invited patients who opened the program invitation, the proportion of patients who visited the consent page, and the proportion of patients who consented. We qualitatively evaluated acceptability by using secure message feedback that the coach received from patients invited to participate and summarized relevant themes [54]. We evaluated engagement by measuring the proportion of participants who began using the DBT skills site and the

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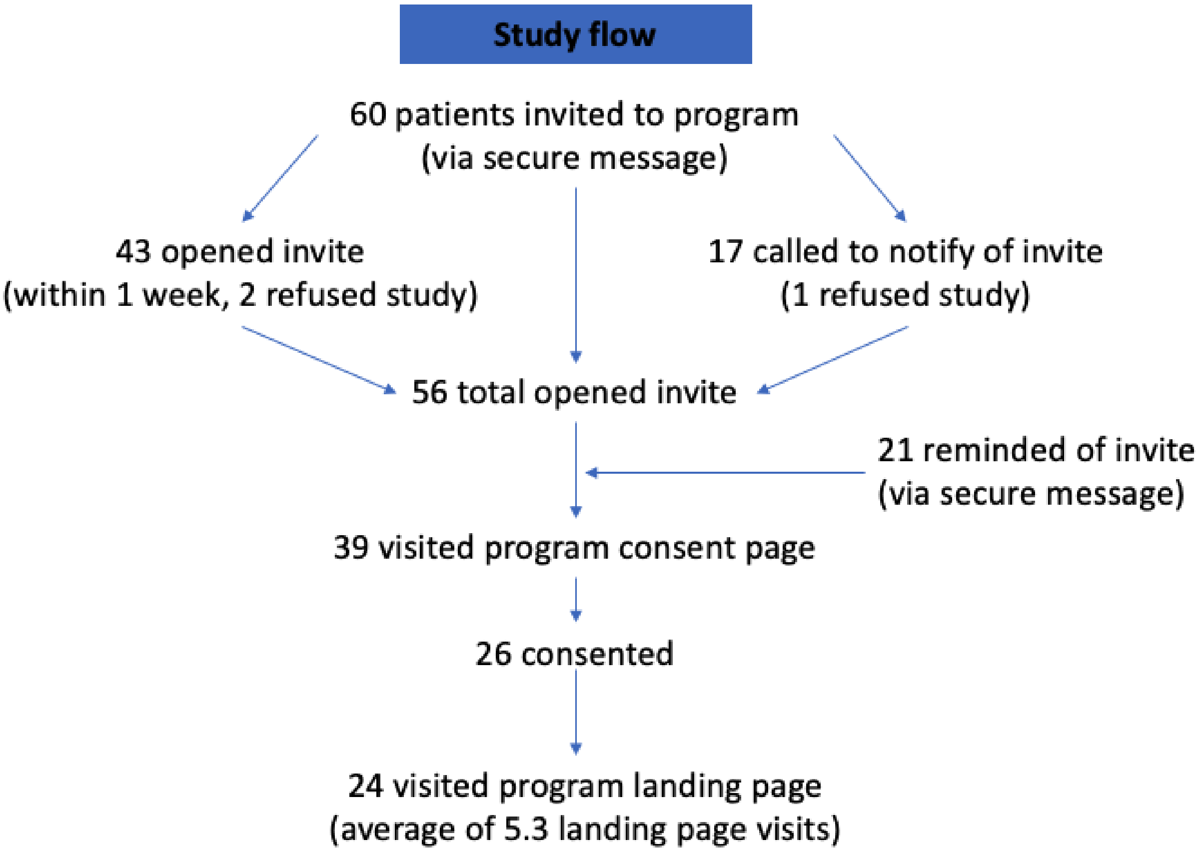
number of site visits. We also measured visits to each of the featured DBT skills in the program among a subset of the sample, and the first 20 participants were invited. We did not collect engagement data beyond the first 20 patients eligible for this pilot study because the original purpose of these analyses was to help confirm that the training website was working as planned (to help evaluate the feasibility of a large randomized trial).

Results

Feasibility

In total, 60 patients were invited to participate (Figure 1). Of these 60 patients, 17 (28%) patients did not open the invitation within 1 week of delivery and received a telephone call (10 were left a voicemail and 7 were spoken to). Up to 2 secure message reminders were sent to 35% (21/60) of patients. Overall, 3% (2/60) of patients refused to participate. Furthermore, 93% (56/60) opened the invitation (indicating that these people did, as far as we know, read and *receive* the caring message aspect of this contact), 65% (39/60) clicked the link to the consent form, and 43% (26/60) consented to participate.

Figure 1. Study flow.



Acceptability

The coach received no complaints from those invited to participate in the program. The feedback the coach received via secure messaging mainly included descriptions of how participants had used the program, specifically their helpful experiences practicing each of the four program skills and the challenges they experienced. One participant described a helpful experience in trying mindfulness skills, which involved bringing attention and awareness to their thoughts:

> *I did the first lesson last night—I was able to use it today when I started having negative thoughts that wouldn't stop. I cleared my mind and started looking at the trees, buildings and other things around me and noticing the little details of things. It actually calmed me down and gave me a sense of control.*

Another participant described the experience of practicing paced breathing:

> *I am doing my best to make the Paced Breathing a daily practice. I forget sometimes until I am "over the edge" and am in deep panic/terror, but I can still even then use the breathing to help get me feeling more calm.*

Another participant described a powerful experience using an opposite action, which involved choosing to do the opposite of ineffective emotional urges:

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> *Yesterday I began the module called "Opposite Action" and printed it out after I completed it. Doing it was empowering but also very emotional for me.*

Finally, a participant described a plan to use mindfulness of current emotion, which involved learning how to bring attention and awareness to the bodily sensations of emotions:

> *I used [a DBT skill] about 5 times today when I was out walking—it keeps my emotions under control, so I don't start crying. I'm going to try [the]"mindful emotion" thing tomorrow. I appreciate [my health care organization] offering something like this—I like having concrete tools I can use.*

In terms of challenges, participants described difficulties in using their skills effectively while experiencing intense emotions. For example, one participant described:

> *One inescapable problem I have found is that once the line that gets crossed where "there is no hope" of being able to turn around the anxiety, I have little ability to do anything constructive to stop the terror from escalating ... if I am not too "far gone" the skills do help to lower the physical and mental/emotional distress.*

Engagement

In total, 92% (24/26) of the participants that consented had visited the landing page of DBT skills. These DBT skills site users logged in on an average of 5.3 times to the home page (SD 6.0, range 1-26). We examined a subsample of those consenters to look at engagement in the specific DBT modules (eg, opposite action). Among the first 20 participants enrolled, 19 (95%) read the invite. Of these 19 participants, 12 (63%) visited the website and 8 (42%) agreed to participate. Of those who consented, participant engagement in the different skills ranged from 38% (3/8) for paced breathing to 88% (7/8) for opposite action (Table 1).

Table 1. Dialectical behavior therapy skill engagement for subsample (N=8).

Program visits	Opposite action	Mindfulness	Mindfulness of current emotion	Paced breathing
Visited at least once, n (%)	7 (88)	4 (50)	6 (75)	3 (38)
Average visit, range (min)	23 (1-54)	34 (2-65)	13 (1-57)	18 (3-30)
Visited at least twice, n (%)	4 (50)	3 (38)	1 (13)	3 (38)
Visited 3 times or more, n (%)	2 (25)	3 (38)	1 (13)	1 (13)

Discussion

Principal Findings

This pilot study demonstrated the feasibility, acceptability, and engagement of a population-based intervention involving active elements of caring messages and DBT. Specifically, we demonstrated that by using an accurate method for identifying those at risk for suicide and suicide attempt—in this case, PHQ item 9—we can adapt existing interventions to be suitable for delivery on a large scale and that these models are promising for intervention delivery.

The number of patients who received the initial message that involved elements of caring messages was high (56/60, 93%). This provides support for the delivery of caring messages through this type of intervention (delivered over time through secure messaging with the support of a coach or care manager). The rate of patients who actually reached the DBT skills site content (26/60, 43%) indicates a need for strategies to reduce barriers to DBT skills site participation, such as simplifying the invitation and consent process for patients. The steepest drops were between viewing the message and visiting the consent page (17/56, 30% of those remaining were lost), and between visiting the consent page and consenting to the DBT skills intervention (13/39, 33% of those remaining were lost; Figure 1). Although it is reasonable to hypothesize that those dropping off were concerned about loss of autonomy or stigma [55,56], participants eligible for this study had already made a significant suicidal disclosure in endorsing suicidal thoughts at a recent visit. Furthermore, while the consent video explicitly refers to suicidal thoughts, the invitation message did not. Indeed, patients did not know that was part of the reason they were approached until they reached the consent video. Notably, all patients in the program had already received care in the health system. It is certainly possible that some patients declined to participate because they were already satisfied with their care. Patients who gave consent to intervention participation appeared to engage, and some gave positive feedback about the content of the intervention.

Limitations

A limitation of our study was that the data analysis was limited to anonymized information regarding program participation. Health records data to identify potential participants were used under a waiver of informed consent, so we did not retain demographic, diagnostic, or other clinical information, including the total PHQ score. Although patients were identified as eligible based on their high severity of suicidal thoughts and all eligible patients were enrolled in the study, it could be that there were more and less severe patients within this group and that DBT skills intervention participation varied depending on the severity. Furthermore, participation among those invited may have been reduced by the need for a research consent process. We suspect that engagement would have been higher without this step between secure message invitation and the DBT skills site. In addition, we do not yet know whether the combination of elements of caring messages with brief DBT skills support will be effective, given that caring messages are intended to be nondirective. Finally, it is possible that those who received the invitation to the intervention felt singled out in some way, having had a visit recently where they disclosed suicidal thoughts. Indeed, qualitative research indicates that those who

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receive the PHQ-9 have significant concerns about how the information regarding the ninth item and suicide will be used [55,56]. Instead, the invitation might read, “As part of my job I reach out to many people we think might benefit from this program....” The key would be to not add too much text for patients to read, while remaining mindful of potential patient fears associated with suicide or mental health–related care (eg, loss of autonomy and psychiatric hospitalizations) [56,57]. Furthermore, our sample of engagement data was small (n=20). It would have been helpful to collect engagement data for all patients invited to participate in the intervention.

As noted by one participant, once one’s emotions reach a certain threshold, the DBT skills become more difficult to access. One limitation of this intervention is that the DBT skills content was not framed in terms of skills for day-to-day stressors versus skills for acute crises. Future interventions may benefit from tailoring additional skills to match the spectrum of emotional stress/crises [58].

Conclusions

This project addresses a number of the most important conceptual, methodological, logistical, and ethical challenges that hamper major advancement in the field of suicide prevention. Qualitative and quantitative data from this study were used to inform the design of a full-scale effectiveness trial (ClinicalTrials.gov: NCT02326883). This research, led by four health care systems within the Mental Health Research Network, is underway to determine its effectiveness [59]. In that trial, participants are randomly assigned to continued usual care, an outreach-based care management intervention, or a coach-supported, web-based DBT skills training program with elements of caring messages, based on the intervention developed and evaluated here.

The videos that were developed as part of this project that make up most of the DBT skills content are publicly available to both the researchers and the public as one piece of NowMattersNow.org [60]. Survey participants to this website have described reductions in suicidal thoughts and negative emotions while visiting the website [34]. Although brief web-based interventions cannot replace intensive tertiary interventions (eg, in-person DBT/CBT), they hold promise as a low-intensity, population-based intervention by ensuring that the right content is consistently delivered to individuals at high risk of suicide and suicide attempt at the time it is needed.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Consent “form” video.
[MP4 File (MP4 Video), 42479 KB - formative_v5i4e21127_app1.mp4]

Multimedia Appendix 2
Program landing page video.
[MOV File , 16688 KB - formative_v5i4e21127_app2.mov]

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Abbreviations

CBT: cognitive behavioral therapy
DBT: dialectical behavior therapy
EMR: electronic medical record
PHQ: Patient Health Questionnaire

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Original Paper

A Multiple Health Behavior Change, Self-Monitoring Mobile App for Adolescents: Development and Usability Study of the Health4Life App

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Abstract

Background: The link between chronic diseases and the Big 6 lifestyle risk behaviors (ie, poor diet, physical inactivity, smoking, alcohol use, sedentary recreational screen time, and poor sleep) is well established. It is critical to target these lifestyle risk behaviors, as they often co-occur and emerge in adolescence. Smartphones have become an integral part of everyday life, and many adolescents already use mobile apps to monitor their lifestyle behaviors and improve their health. Smartphones may be a valuable platform for engaging adolescents with interventions to prevent key chronic disease risk behaviors.

Objective: The aim of this paper is to describe the development, usability, and acceptability of the Health4Life app, a self-monitoring smartphone app for adolescents that concurrently targets the Big 6 lifestyle behaviors.

Methods: The development of the Health4Life app was an iterative process conducted in collaboration with adolescents and experts. The development process consisted of three stages: scoping the literature; end user consultations, which included a web-based survey (N=815; mean age 13.89, SD 0.89 years) and a focus group (N=12) among adolescents; and app development and beta testing. Following this development work, 232 adolescents were asked to rate the usability and acceptability of the app.

Results: The process resulted in a self-monitoring smartphone app that allows adolescent users to track and set goals for the Big 6 health behaviors, using in-app rewards and notifications to enhance engagement. The overall adolescent feedback was positive in terms of user-friendly design, content, relevance, and helpfulness. Commonly identified areas for improvement were to increase interactive features and display recorded health behaviors differently to improve interpretability.

Conclusions: The Health4Life app is a co-designed, self-monitoring smartphone app for adolescents that concurrently targets the Big 6 lifestyle behaviors. Adolescents rated the app as highly acceptable and usable. The app has the potential to efficiently and effectively modify important risk factors for chronic disease among young people and is currently being evaluated in a world-first trial of 6640 secondary school students in 71 schools across Australia.

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KEYWORDS

mHealth; mobile phone; chronic disease; adolescents; health promotion

Introduction

Background

Chronic diseases are the leading cause of death globally [1]. There are six key lifestyle risk behaviors linked to the development of chronic disease that often emerge during adolescence, highlighting adolescence as a potentially critical opportunity to intervene before these health behaviors become entrenched [2,3]. The key lifestyle behaviors are poor diet, physical inactivity, smoking, alcohol use [1,4,5], sedentary behavior (ie, sitting and recreational screen time) [6,7], and poor sleep (ie, long or short duration and poor quality) [8]. These *Big 6* risk behaviors have been found to commonly co-occur, which presents opportunities to adopt a multiple health behavior change approach [9]. Targeting multiple behavioral risk factors together, rather than in isolation, allows skills and knowledge learned in relation to one behavior to be transferred to other behaviors [10], resulting in improvements across multiple behaviors without additional effort [11]. To date, most chronic disease prevention and treatment approaches have been conducted among adults and have typically focused on changing single behaviors only, presenting a significant opportunity for the development of more effective and efficient prevention programs in adolescence [12].

Smartphones have become an integral part of everyday life, and many adolescents use mobile apps to monitor and improve their health [13,14]. In Australia, early adolescence and the transition from primary school to secondary school (which takes place when students are aged approximately 12 years) is a turning point for mobile phone ownership. Roughly 1 in 3 individuals aged 11 years, compared with three-fourth of those aged 13 years, own a mobile phone in Australia. This then increases to 91% for those aged 14 to 17 years, with 94% of those mobile phones being smartphones [15]. Mobile phone–based interventions have been shown to be effective in improving a range of risk factors associated with chronic diseases among adults, including physical inactivity, poor diet, sleep, overweight and obesity, alcohol use, smoking, and mental health problems [16-20], with similar evidence emerging among adolescents [21-26]. In addition, through mobile devices, individualized interventions can be provided inexpensively to a large number of people, including those who are geographically isolated, at a time and place when they are ready to engage [27]. Therefore, mobile phones may be an ideal platform for engaging adolescents with interventions to prevent key chronic disease risk behaviors. However, to the best of our knowledge, no mobile health (mHealth) tools that simultaneously target all of the Big 6 risk behaviors among adolescents currently exist [28].

Recently, we developed the Health4Life school-based program, a web-based program to concurrently address the Big 6 chronic disease risk factors among Australian secondary school students. The universal (ie, delivered to all students, regardless of risk) prevention program is based on the successful Climate Schools program [29-31], which uses interactive cartoon storylines about a group of teenagers and is based on the principles of social influence theory [32]. This includes providing accurate, relevant, and developmentally appropriate information; normative content; and resistance skills training. The Health4Life program adopts a multiple health behavior change approach and provides simultaneous education about the Big 6 via 6 web-based cartoon modules delivered in schools to students aged between 12 and 13 years (grade 7 in Australian secondary schools). More information about the development of this school-based program is given in a study by Champion et al [33]. Given that mobile phone–based interventions have previously demonstrated effectiveness in improving some of the Big 6 risk behaviors among adolescents [21-26,34], an accompanying smartphone app, the Health4Life app, was developed. The Health4Life app aims to extend the reach and reinforce the content of the school-based program as students progress from grades 7 to 9 and help engage and further encourage students to modify their behaviors via goal setting and self-monitoring—2 key evidence-based behavior change techniques (BCTs) [35-39].

The Health4Life app was based on our team’s previously developed and evaluated multiple health behavior change mobile-based tool named MyHealthPA [40]. MyHealthPA was developed to help people improve 4 of the Big 6 lifestyle risk behaviors (poor diet, physical inactivity, alcohol use, and smoking). MyHealthPA uses self-monitoring, goal setting, and provision of feedback via interactive progress graphs to help users improve their health behaviors. The design and delivery of MyHealthPA was informed by the Flat-Explicit Design Model [41], a model designed to reduce the cognitive effort required to effectively interact with digital health tools, increasing the ease of use among people with mental health problems. For example, the model recommends using a *flat design*, including no more than 2 levels past the initial page or screen, descriptive labels, and explicit instructions, rather than succinct and abstract labels, with text written at a low reading level. The MyHealthPA app was trialed among 28 young people aged between 19 and 25 years over an 8-week period [40]. Small improvements in fruit and vegetable consumption, level of physical activity, alcohol use, and mood were found between baseline, immediately postintervention, and 1 month follow-up [40]. However, several opportunities for improvement were also identified, including conversion to a native app format (as opposed to a responsive website optimized for mobile phones) [40].

The MyHealthPA tool provided the initial structure for the Health4Life app, and additional design elements were informed by the theoretical, design, and engagement framework of the Health4Life and Climate Schools programs [29,30,33,42]. The development was informed by the processes outlined later.

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Objectives

This paper aims to describe the co-design process and usability and acceptability testing of the Health4Life app.

Methods

Co-design

To assist with the conversion of the MyHealthPA tool to an app appropriate for adolescents that also complemented the Health4Life school-based program, we undertook an iterative development process. End users (adolescents) and experts (academics and clinicians with expertise in prevention, substance use, physical activity, exercise physiology, sleep, dietetics, mental health, eHealth interventions, and behavior change) were engaged repeatedly at key points in the process. The development process consisted of three key stages: stage 1, scoping of the literature; stage 2, end user consultations; and stage 3, app development and beta testing. Following this development work, the Health4Life app was included as an intervention component in the Health4Life trial (a large cluster randomized trial currently underway [43]), and we collected and analyzed information regarding the app's usability and acceptability among 232 initial users.

Stage 1: Scoping of the Literature

We conducted a series of nonsystematic, structured literature reviews to identify key BCTs to improve the Big 6 lifestyle risk behaviors among adolescents and successfully engage them with an mHealth app. The synthesized findings of each of these searches are briefly discussed later. Where possible, we drew findings from previously published systematic reviews.

Effective BCTs Among Adolescents

The key BCTs used within the MyHealthPA tool to improve users' health behaviors are self-monitoring and goal setting. Strong evidence for the efficacy of these BCTs among adults, including within mobile apps, exists [35-39]. To explore whether this evidence extends to adolescent populations, we conducted literature searches in PubMed. PubMed searches used terms, including self-monitoring, goal setting, health behavior, and adolescent or young people. We then explored whether evidence for other key BCTs among adolescents exists via a literature search using the following terms: BCTs and adolescent or young people.

Systematic reviews conducted by Rose et al [44], Brannon et al [34], and Willmott et al [45] found both self-monitoring and goal setting to be common components in behavior change interventions designed for adolescents. In a review of digital interventions to improve diet quality and physical activity among adolescents by Rose et al [44], they identified 11 studies that used goal setting and 14 that used self-monitoring and, of these, 6 used both strategies to encourage behavior change. Almost all the interventions that included goal setting showed significant improvements in adolescents' diets, physical activity, or both. Their findings also suggested that self-monitoring and goal setting are most effective when paired. Similarly, in their systematic review of the pediatric literature on BCTs, Brannon et al [34] found that self-monitoring and BCTs related to goal setting significantly predicted improvements in physical activity for adolescents.

Although goal setting has been shown to be an effective technique for behavior change in adults, and increasingly in adolescents, concerns remain regarding its feasibility and effectiveness among adolescents [46]. Setting an appropriate goal requires skills such as abstract reasoning, which only begins to develop during adolescence. One solution is to preset goals for adolescents participating in behavior change interventions. Although there is evidence that goal-setting interventions can significantly improve physical activity behavior, regardless of who prescribes the goal [47], it has been suggested that presetting adolescents' goals may limit their autonomy and decrease their commitment to that goal [46,48]. Instead, Shilts et al [46] suggested adopting a guided goal-setting approach in which adolescents select a broad goal area they would like to work on from a predefined list and are then presented with several minor related goals from which they can choose. This type of goal setting ensures the selection of appropriate goals in a way that empowers and respects adolescents' autonomy. Testing of this approach suggests that it is an effective method, with between 87% and 89% of adolescents who set eating or physical activity goals in this way, reporting that they made an effort to reach their goals [46].

Our review of the literature identified several BCTs (beyond goal setting and self-monitoring) that are commonly used in behavior change interventions (including mobile-based ones) designed for adolescents [19,49,50], including social support [34,51], prompts or cues [52-55], modeling [34], providing consequences for behavior [34,51], and feedback on behavior [51]. However, few studies have investigated their efficacy in actually changing health behaviors among adolescents.

Designing an Engaging Health App for Adolescents

A literature search in PubMed was conducted to identify the best way to encourage adolescents to engage with health apps. The search included the terms mobile app, smartphone, mobile phone, mHealth, digital, engagement, adherence, and adolescent or young people.

A total of 2 recent systematic reviews have investigated the efficacy of different strategies and features used to engage adolescents in digital health interventions [19,56]. Partridge and Redfern [56] found that key strategies for effective engagement included co-designing with adolescents, personalization or tailoring of interventions, and just-in-time adaptation allowing the provision of personalized support based on an individual's current context. A systematic review by Schoeppe et al [19] found that higher quality apps, in terms of functionality and user ratings, included more app features (such as educational information, social networking options, and gamification) and BCTs. However, this study also highlighted that more research is needed to discover which BCTs have a greater effect on engagement among this population.

Similarly, a recent review by Torous et al [57] identified five potential factors that contribute to low user engagement with mental health apps: (1) poor usability because of excessive burden of entering data, (2) lack of user-centric design because

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of poor involvement from the targeted population in development, (3) concerns regarding privacy, (4) a lack of trust because of unsubstantiated claims and lack of evidence, and (5) lack of easily accessible crisis support information.

Other potentially useful strategies for encouraging greater engagement with health apps among adolescents include providing awards or badges for completing app tasks and *streaks* (ie, completion of app tasks a number of days in a row) [58,59], providing funny or inspirational quotes or memes [60], and providing trigger or prompts to access the app. Many of these techniques have already been used in commercial apps to encourage engagement [57,61]. Although the actual efficacy of these strategies among adolescents is yet to be systematically tested, there are strong theoretical justifications for why their inclusion could improve adolescents' engagement with a health app.

Key Implications for App Development

Taken together, our scoping of the literature suggests that self-monitoring and goal setting (employing a guided goal-setting approach) are appropriate and effective BCTs for use among adolescents. Of a number of other potentially appropriate BCTs identified in a small body of literature [34,51-55], providing prompts and cues and feedback on behavior are likely the best suited for inclusion in a mobile-based tool such as the Health4Life app. This study also reinforces the appropriateness of employing an approach that uses peers to model health behavior changes [33,34,62].

The importance of involving adolescents in the development of any health app has emerged as a key consideration for promoting engagement with mHealth apps [56,57]. Similarly, this study suggests that allowing individual customization of apps and personalization of feedback [56], ensuring that the app is easy to use [57], providing prompts or reminders [52-55], providing rewards [19], providing inspirational quotes [60], employing multiple engagement and behavior change strategies [19], providing easy access to additional support [57], being evidence based [57], and providing transparency regarding privacy issues [57], all may be important for improving engagement with health apps among adolescents.

Stage 2: End User Consultations

To understand mobile phone usage among the target age groups and inform the development of a prototype design, a web-based survey was conducted. A focus group was then conducted to gain more in-depth information and feedback on the prototype design to ensure that the Health4Life app was appropriate and tailored to the needs of adolescents.

Web-Based Survey With Adolescents

Participants and Procedure

A total of 7 independent secondary schools in metropolitan regions of New South Wales and the Australian Capital Territory, Australia, were invited to participate in an anonymous web-based survey. Of the 7 schools, 3 (2 coeducational and 1 female-only school) agreed to participate. Schools distributed information and consent forms to the parents or guardians of their students of grades 7 to 9. Opt-out written or verbal parental consent and active written student consent were required (815/816, 99.9% consent rate). The students completed the survey during classes between August and September 2018. Participants were entered into the draw to win a Fitbit valued at Aus $450 (US $315). Ethics approval was obtained from the University of New South Wales Sydney Human Research Ethics Committee (HC180224).

Measures

The web-based survey assessed the demographic characteristics, including age, sex, and postcode, and the Big 6 health behaviors and included a series of bespoke and adapted items [63] to assess mobile phone use. Participants were asked if they owned a smartphone, when and how often they used their smartphone, and how often they used their phone to undertake different activities and to describe their school's policy regarding mobile phone use. Students were also asked to name their favorite health app and describe what they liked most about the app, including what motivated them to start using it and what features of the app they found most useful or helpful.

Analysis

Descriptive analyses were conducted using IBM SPSS Statistics 24 (IBM Corporation) to investigate sample characteristics and prevalence rates of mobile phone use. For open-ended responses collected, the sample was stratified by age and year group and a random subsample between 20% (163/815) and 25% (204/815) was selected to ensure balanced representation across age and year groups. These responses were qualitatively analyzed until data saturation was reached. Using an inductive approach [64], one author (LT) coded the responses and grouped them according to key themes.

Findings

A total of 815 students, including 687 (84.3%) females, 110 (13.5%) males, and 12 (1.5%) students who were identified as nonbinary or preferred not to disclose their gender, participated in the web-based survey. They were aged between 12 and 15.75 years (mean 13.89, SD 0.89 years). The Index of Community Socio-Educational Advantage (ICSEA) values for participating schools ranged between 1106 and 1182 [65]. The ICSEA values were calculated on a scale with a median of 1000 and SD of 100, with higher values indicating higher levels of educational advantage. Most students (725/815, 88.9%) owned a smartphone, whereas 6% (49/815) did not own a smartphone or were not sure if their phone was a smartphone. Table 1 displays the patterns of smartphone use reported by participants. Participants reported high frequencies of smartphone use overall but infrequent use during school hours. Table 2 shows the patterns of participants' smartphone use for a variety of activities. The most frequently performed activities included accessing the internet, using apps, and sending or receiving text messages.

When asked to list and describe their favorite health app on their smartphone, 472 participants listed 84 different apps as their *favorite health app*. The most frequently mentioned app was the iPhone *Health* app, which is one of the preinstalled apps on the iPhone, with 22.7% (107/472) of students identifying it as their favorite health app. This was followed by 15%

(71/472) of participants who identified the Fitbit app as their favorite, 9.5% (45/472) who listed Clue or Flo (menstrual cycle tracking apps), and 5.3% (25/472) who listed MyFitnessPal.

The key themes that emerged from the open-ended responses are listed in Table 3. When asked to describe their motivations for downloading and using these apps, participants primarily described a desire for knowledge or a desire to improve health and health behaviors that had motivated them to download the app. When asked about the features of their favorite app, participants described tracking features and providing guidance on health behaviors and issues to be the features they found most useful and helpful. However, a number of participants were unable to articulate the most useful features of their favorite health apps.

Table 1. Patterns of smartphone use among web-based survey participants who own a smartphone (N=815).

Patterns of smartphone use	Value, n (%)
Frequency of smartphone use (n=725)	
Several times an hour	104 (14.3)
Every hour	50 (6.9)
Several times a day	326 (45.0)
Every day	187 (25.8)
Several times a week	41 (5.7)
Once a week	14 (1.9)
Monthly or less	1 (0.1)
I do not use a smartphone	2 (0.3)
Use a smartphone during recess (n=725)	131 (18.1)
Use a smartphone during class (n=725)	45 (6.2)
Use a smartphone in between class (n=725)	77 (10.6)
Only use a smartphone on the way to or from school (n=725)	496 (68.4)
Do not use a smartphone during school hours (n=725)	166 (22.9)
Carry a smartphone during a school day (eg, in a pocket or bag; n=721)	
Always	205 (28.4)
Usually	127 (17.6)
About half the time	74 (10.3)
Rarely	142 (19.7)
Never	173 (24.0)
School permits mobile phone use by students at school (n=721)	62 (8.6)

Table 2. Frequency of smartphone use for specific activities (n=719).

Smartphone use for specific activities	Frequency of smartphone use for activities, n (%)				
	Daily	Weekly	Once or twice a month	Less than once a month	Never
Make or receive phone calls	339 (47.1)	275 (38.2)	63 (8.8)	31 (4.3)	11 (1.5)
Send or receive text messages	568 (79.0)	108 (15.0)	28 (3.9)	9 (1.3)	6 (0.8)
Access the internet	594 (82.6)	76 (10.6)	24 (3.3)	13 (1.8)	12 (1.7)
Use apps	589 (81.9)	81 (11.3)	27 (3.8)	10 (1.4)	12 (1.7)
Social networking (eg, Facebook or Twitter)	533 (74.1)	68 (9.5)	18 (2.5)	7 (1.0)	93 (12.9)
Send or receive email	234 (32.6)	209 (29.1)	116 (16.1)	68 (9.5)	92 (12.8)
Take a picture	304 (42.3)	293 (40.8)	78 (10.8)	32 (4.5)	12 (1.7)
Look for health or medical information or track your health and fitness	102 (14.2)	150 (20.9)	168 (23.4)	121 (16.8)	178 (24.8)
Entertainment (listen to music and watch videos)	519 (72.2)	131 (18.2)	28 (3.9)	24 (3.3)	17 (2.4)

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Table 3. Summary of key themes extracted from students’ open-ended responses.

Theme	Example
Motivations for downloading and using health apps	
A desire for knowledge	
Desire to better understand menstrual cycle (female respondents)	• “My doctors told me to track my period and I kept forgetting to write it on paper, but I saw a you-tuber use an app to track their period and decided to give it a go.” (Female, aged 12 years)
Desire to better understand one’s own health, health behaviors, and mental health, often to help change behaviors	• “MyFitnessPal provides every aspect from eating and weight health to physical health. I also needed an app which provided all of it so I had one place to store my health and progress.” (Male, aged 13 years) • “What motivated me to download this app and then use it was that I wanted to keep a record of my health level, and later to see if the level increased or decreased and why. This also motivated me to increase my health level and be involved with more sporting activities.” (Female, aged 12 years)
Desire to improve health and health behaviors	
Wanting to improve fitness, lose weight, get healthy, and improve sleep	• “Wanted to get more fit.” (Female, aged 12 years) • “Because I am very unactive and unfit.” (Female, aged 12 years)
Other motivations	• To be more organized (eg, with health appointments) • They only downloaded the app to assist a wearable device to function (eg, Fitbit app) • Others had recommended they download the app and use it • The app came preinstalled on their phone
Useful features of favorite health apps	
Tracking	
Tracking a wide range of health issues and behaviors perceived to be an attractive feature of health apps (eg, tracking steps; sleep; exercise sessions; the distance and speed of runs and walks; menstrual cycles; and food intake, including detailed calorie counting and mood)	• “It counts my exercise, my activity and my steps.” (Male, aged 14 years) • “You can enter what you eat in a day and it will tell you if you need to stop eating something or eat something.” (Female, aged 13 years) • “Allows me to track my feelings and health.” (Female, aged 14 years)
Providing guidance	
Most useful features of health apps described to be features that provided guidance on health issues and behaviors (eg, guidance on workout routines; healthy foods, including recipes and scanning food items; and how to improve mood)	• “The healthy recipes and the way I can scan food items to find out if they are healthy or not.” (Female, aged 13 years) • “The recommended workouts for my age.” (Male, aged 12 years) • “It has designed workouts that you can do and it shows you how to do them.” (Female, aged 13 years)
Other useful features	• Entertainment • Goal setting • Reminders to perform healthy behaviors • Allowing communication or competition with friends

Key Implications for App Development

The findings from the web-based survey found that almost all adolescent smartphone owners reported using their smartphones at least daily (667/725, 92%). Most also reported using mobile apps on a daily basis (589/725, 81.9%). However, only 35.1% (252/725) reported daily or weekly use of their smartphones for health purposes. Together, these results support the use of a smartphone app to engage adolescents; however, they highlight the need for co-design and end user feedback when developing health apps to maximize engagement and potential health benefits.

Students reported sending or receiving text messages and accessing social networking sites far more frequently than making or receiving phone calls. This suggests that text messages are a key form of communication for this group and highlights that using text-based approaches (eg, apps and SMS) to deliver remote interventions is likely to be more familiar and potentially more acceptable to adolescents than telephone call–based approaches.

A desire to better understand their own health behaviors, often to help improve health behaviors, has emerged as a key motivation for using health apps. In designing a health app for this population, providing ways for adolescents to receive personalized feedback about their own patterns of behaviors may be important. In line with this, the ability to track health behaviors in an app has emerged as a desirable feature.

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Finally, participants reported that very few of their schools permitted mobile phone use by students at school. The majority reported only using their smartphones on the way to or from school, although most did carry their phones with them during the school day. These insights have important implications for the design of apps and notification schedules for school-age adolescents. Although designing an app to collect ecological momentary assessments of health behaviors multiple times throughout the day may be a way to elicit a more accurate recording of health behaviors, these results suggest that such an approach would be unacceptable (encouraging students to break their schools' mobile phone policies) and not feasible for school-age students. Prompting data entry before or after school may be a more acceptable approach.

Focus Group

A focus group with adolescents was conducted to gain feedback and suggestions for app content and design.

Participants and Procedure

Participants were 12 adolescents recruited via personal networks. Active written consent was obtained from parents and participants before their participation in the focus group. Participants attended a 1.5-hour long face-to-face focus group in January 2019, which was loosely directed by one researcher (LT) with open-ended and prompting questions.

Participants were shown an example of how the app may display tracked health behaviors using a prototype design, before being asked to comment on the example. Participants were then asked to make suggestions for alternative ways to show this information, including by drawing their ideas. Participants were also asked for their thoughts and suggestions regarding how the goal-setting section of the app could function and be presented. The focus groups were audio recorded and transcribed. The participants received a JB-HiFi gift voucher of Aus $20 (US $15). Ethical approval was obtained from the University of New South Wales Sydney Human Research Ethics Committee (HC17852).

Analysis

The focus group data were transcribed by one researcher (BO). Using an inductive approach, comments and recommendations were grouped into themes by one researcher (BO), cross-checked by a second researcher (LT) and then used to inform refinements and modifications.

Findings

A total of 12 female adolescents aged between 11.1 and 14.9 years participated in the focus group. All participants lived in Sydney, Australia. Participants commented that all data entry features and progress graphs within the app should be clear and easy to use. They mostly agreed that tracked health behaviors should be individually displayed across a week using line graphs (as opposed to displaying all 6 behaviors of interest on a single graph) and that progress graphs should also contain detailed summary information about health behavior. Examples of ways in which participants suggested health behavior tracking could be displayed within the app are available in Multimedia Appendix 1.

Most participants emphasized the importance of making goal setting and achievement a rewarding experience, with the inclusion of *winning* an icon, badge, or emoji when reaching a goal. Many participants also preferred the inclusion of motivational comments or explanations as to why one should attempt to reach each health behavior goal. Participants discussed the idea of *competing* with friends by sharing their behavior tracking with others; however, the group disagreed about whether this would be beneficial or detrimental for adolescent users. Other comments included ensuring that goals are easy to input and that the goals suggested by the app are achievable and easy to fit into pre-existing schedules.

Key Implications for App Development

Beyond design ideas for the display of progress graphs within the app, key takeaway messages from the focus group included the need to display progress for each of the 6 health behaviors of interest separately and provide a detailed summary of user behaviors. The need for a simple-to-use interface and the importance of providing rewards within the app to engage adolescents were also reiterated.

Stage 3: App Development and Beta Testing

The findings from stages 1 and 2 were used to inform the development of the Health4Life app. Using the MyHealthPA tool for initial structure and content and incorporating key recommendations from the formative research described earlier, an external IT development company was engaged to produce a beta version of the Health4Life app. Graphic designs developed for the Health4Life school-based program (eg, cartoon characters, icons, or fonts) were used to ensure consistency between the 2 complementary programs.

Initial usability testing of the beta version of the app was first undertaken, and any technical issues identified were resolved before the app was reviewed. The reviewers consisted of academics and clinicians with expertise in adolescent health behavior change (n=6) and 4 adolescents within the teams' personal networks. Two of these adolescents had also participated in the focus group. The 2 other adolescents were males who were unable to participate in the focus group; however, the research team felt it was important to obtain the input of male adolescents. Reviewers provided feedback regarding the final content, usability, acceptability, and appeal of the program.

Key changes to the beta version suggested by reviewers included improvements in the way in which content was displayed within the app (eg, simplifying health behavior progress graphs, adding stars on the dashboard to indicate when users reported meeting recommended health behavior guidelines to help users easily track progress for the day and reinforce healthy behaviors) and minor content changes (eg, removing quotes from celebrities perceived not to be current enough to be of interest to end users and adding quotes from current Australian-based celebrities).

The Final Health4Life App

The resulting Health4Life app consisted of the following 6 sections (screenshots are shown in Figure 1).

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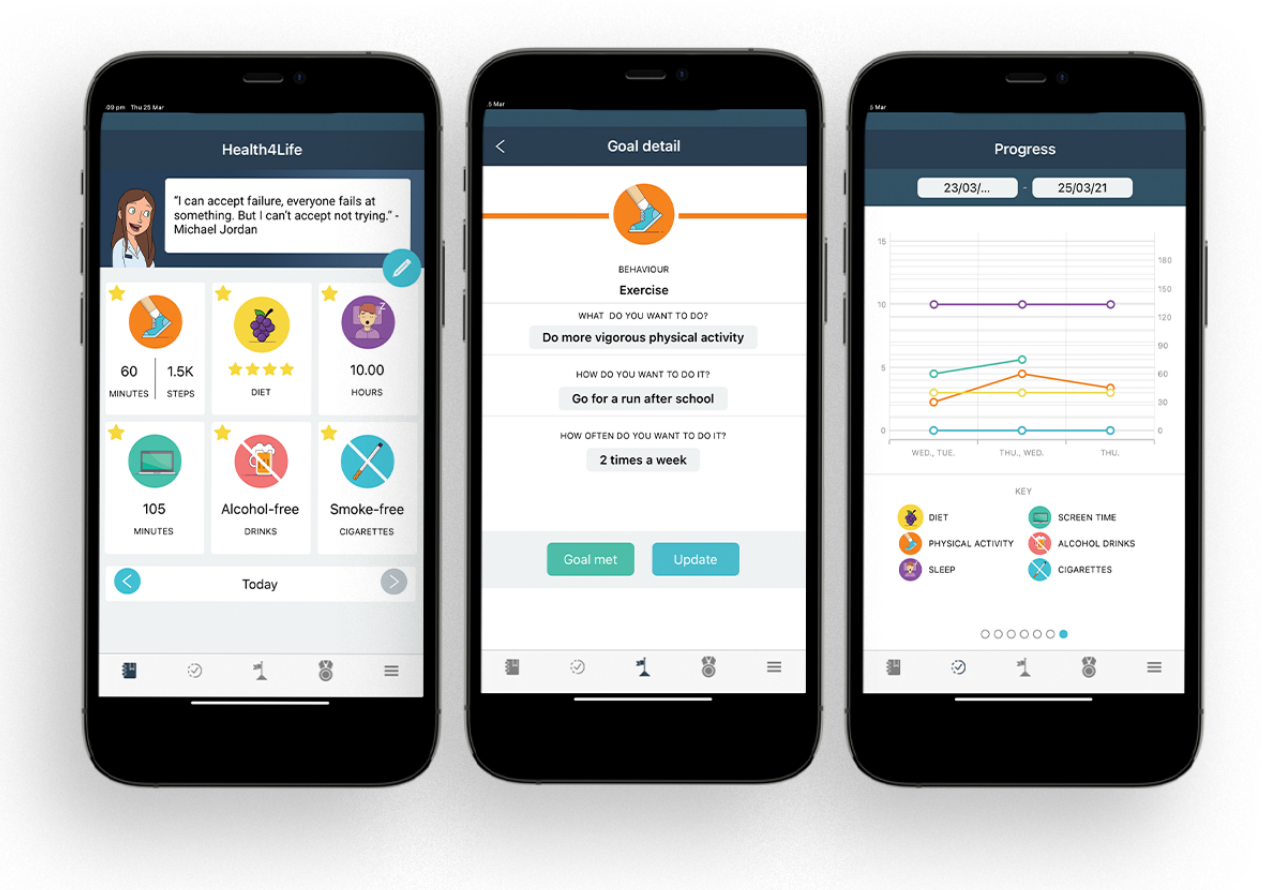

Figure 1. Selected screenshots of the Health4Life app.

"I can accept failure, everyone fails at something. But I can't accept not trying." - Michael Jordan

BEHAVIOUR: Exercise

WHAT DO YOU WANT TO DO? Do more vigorous physical activity

HOW DO YOU WANT TO DO IT? Go for a run after school

HOW OFTEN DO YOU WANT TO DO IT? 2 times a week

Dashboard

This page provides a simple and visual portrayal of the user's Big 6 health behaviors for the current day and a menu to access all other pages. When users report meeting the recommended guidelines for a particular behavior, a gold star appears next to the relevant health behavior. To promote peer-to-peer communication and education, users are prompted to select a *Health4Life Buddy* to help guide them through the app from the group of 6 core characters in the school-based program. On the dashboard their *buddy* presents different motivational celebrity quotes, tips, and prompts to log behaviors.

Diary

This page allows users to record their health behaviors and mood. For each behavior, users can click an icon to give them more information about what exactly they are being asked to enter (eg, what a serve of fruit is or a definition of recreational screen time). Textbox 1 describes the specific behaviors that the user can record.

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Textbox 1. Daily behaviors recorded within the Health4Life app.

Lifestyle risk behavior and specific behaviors recorded

- Physical activity
    - Minutes of moderate-to-vigorous physical activity
    - Steps (manual entry)
- Diet
    - Number of sugar-sweetened beverages
    - Serves of fruit
    - Serves of vegetables
    - Number of discretionary food items
- Sleep
    - Bedtime (the previous night)
    - Wake-up time (that morning)
    - Recreational screen time
    - Minutes of recreational screen time
- Alcohol use
    - If they have drunk any alcohol (yes or no)
    - Number of standard drinks of alcohol (including just a sip)
- Tobacco use
    - If they have smoked any tobacco (yes or no)
    - Number of cigarettes smoked (including just a puff)
- Mood
    - How they felt (5-point emoticon scale)

Progress

This section allows users to view their progress individually for each of the 6 health behaviors. Users are also provided with a summary of their behaviors, which highlights for how many days in the previous 7 days they have met the recommended guidelines for that behavior. A final progress graph displays all 6 behaviors together, allowing users to identify ways in which their health behaviors may be linked.

Goals

This section allows users to complete a guided goal-setting activity to set specific, measurable, achievable, relevant, time-bound (SMART) goals for any of the Big 6 behaviors. Users are prompted to first select the behavior they would like to set a goal for. They are then presented with 2 to 4 broad goal options: *What they would like to do* (eg, do more light physical activity, do more moderate physical activity). Upon selecting their broad goal, they were asked, “How would you like to do it?” and presented with up to 7 appropriate options for how they might achieve that goal (eg, go for a jog after school, dance to music, play a game like soccer, handball, or tag during lunch or recess at school) and prompted to select *How often they would like to do it?* (once a week, 2 times a week, 3 times a week, etc).

Rewards

This section allows users to view how many medals they have received and access information about what they need to do to earn medals for each health behavior. For each behavior, users can earn a bronze medal for meeting recommended guidelines for that behavior for 1 day, a silver medal for meeting the recommended guidelines for 3 days in a row, and a gold medal for meeting the recommended guidelines for that behavior for 7 days in a row.

Menu

In this section, users can access their profile and app settings along with the following:

- Resources: links and a brief description of web-based resources users could access for extra information and additional support to change their health behaviors and improve their mental health.
- Emergency: contact details for relevant chat and telephone help lines. Users are instructed to contact one of these services or contact emergency services if they are thinking about suicide or experiencing a personal crisis.

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- Help: link to a video tutorial on how to use the Health4Life app and details of how to get help with any technical issues using the app.

Usability and Acceptability Testing

Following the development work described earlier, access to the Health4Life app was provided to 3623 intervention condition students participating in the Health4Life trial. Students were provided with details on how to access the app via email (ie, downloading from the relevant app store), and teachers were asked to encourage students to download the app. After logging on to the app, students were sent daily reminder messages each evening, prompting them to record their health behaviors in the app. The Health4Life trial is a cluster randomized controlled trial currently being conducted among 6640 students from 71 schools across New South Wales, Western Australia, and Queensland, Australia (trial commenced in 2019; full trial details are given in the study by Teesson and Champion [43]).

Students at independent secondary schools in New South Wales that were allocated to the intervention condition in the Health4Life trial (7 schools in total; ICSEA values ranging between 1012 and 1139 [65]) were invited to complete a web-based questionnaire evaluating the Health4Life school-based program and the Health4Life app. Items related to the app aimed to generate information regarding the usability and acceptability of the app and included the System Usability Scale (SUS) [66], a valid and reliable industry standard tool for measuring the usability of digital tools [67]. Items were measured on a 5-point scale ranging from strongly disagree to strongly agree. Participants were also asked to name 1 good thing and 1 bad thing about the app or to give a reason for not downloading the app. These open-ended responses were coded and grouped into themes by one author (BO) until saturation was achieved.

Results

A total of 535 students (535/685, 78.1%) completed the questionnaire; of these, 232 (43.4%) reported downloading the app. Overall, students rated the Health4Life app favorably, with 58.2% (135/232) rating the app as either good or very good and only 6.9% (16/232) rating the app as poor or very poor. Approximately half of the participants (127/232, 55%) agreed or strongly agreed that the app would help people of their age to change their lifestyle behaviors (17/232, 7.3% disagree or strongly disagree), and 42.4% (98/232) reported that they would recommend the app to their friends (42/232, 18.1% maybe; 91/232, 39.2% no).

Responses to the SUS found that most students thought the Health4Life app was easy to use (124/232, 53.4%), that they would not need the help of a technical person to be able to use the app (135/232, 58.4%), that most people would learn to use the app very quickly (127/232, 54.7%), that they felt very confident using the app (122/232, 52.5%), that the app was not unnecessarily complex (106/232, 45.7%), and that they did not need to learn a lot before they could get going with the app (106/232, 45.7%). Some participants reported that the app was cumbersome to use (41/232, 17.6%), there was too much inconsistency within the app (33/232, 14.2%), or the features of the app were not well integrated (24/232, 10.3%). However, most responses were neutral for these items (143/232, 61.6%; 109/232, 46.9%; 126/232, 54.2%, respectively). Similarly, only 24.1% (56/232) of students reported agreeing or strongly agreeing that they would like to use the app frequently. The app received a total average SUS score of 59.5 (SD 14.1), representing *OK* usability [68].

Positive things about the app design identified by students included its esthetic design (eg, “It looks cool”), general structure of the app, and that it was easy to use (eg, “It was easy to understand”). However, negative aspects of the app’s design highlighted by students included its simplistic design and lack of advanced features (eg, “I found it a little bit basic for a fitness app, as I thought it would have more features”) and the design of the progress graphs (eg, “I would have liked my data and rating on my health to be displayed differently so it is easier to read”).

App features that students highlighted as positive included the mobile format (eg, “It is useful to use because it is on your phone or iPad”) and the ability to track multiple health behaviors (eg, “It tracks all the different parts to make sure you have a healthy lifestyle”), set goals, and the reminders sent (eg, “It gave me helpful notifications to use the app”). The ability to personalize the app and receive individualized feedback about health behaviors was also very well received (eg, “The app helps YOU discover YOUR habits and how to change them, with a supportive character. The overall app is very personalised”).

A common complaint from participants regarding the app’s features was the need to enter steps manually into the app, rather than being able to link to a step counter device (eg, “It could be connected to your phone…and it would count your steps and exercise”).

Participants also discussed that remembering their health behaviors over the course of the entire day can be difficult. Although some participants found reminders useful, others expressed that the reminders to use the app were annoying (eg, “it notifies me all the time and it is annoying”). From a technical side of things some participants also complained about the app sometimes freezing or not working properly (eg, “it can sometimes be a bit glitchy and/or freeze”).

Finally, among those participants who did not download the app, the top reasons for not doing so were not having a phone or enough phone storage, feeling like they did not need the app or the Health4Life school-based program was enough, not knowing that there was an app associated with the Health4Life school-based program, or not being informed how to download it (including that they were told by their teacher not to download the app or that they did not have to download it).

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Discussion

Principal Findings

This study aims to describe formative research that led to the development of the Health4Life app and the initial usability and acceptability testing. Scoping of the literature identified key evidence-based BCTs, such as self-monitoring, goal setting, and providing prompts and feedback on behavior that were incorporated into the app design. End user consultations revealed that most adolescents (725/815, 88.9%) owned a smartphone that they frequently used to access the internet, use apps for social networking, and send or receive text messages; however, health apps were less frequently used, highlighting the need for co-design to increase engagement. Key app features, such as progress graphs and rewards, were identified and incorporated into the app design. Together, these findings led to the development of the Health4Life app, a co-designed, self-monitoring smartphone app, for adolescents that concurrently targets the Big 6 lifestyle behaviors.

Initial acceptability and usability findings suggest that the Health4Life app is an easy-to-use tool with features that appeal to adolescents. Approximately half of the respondents included in our feasibility and acceptability testing rated the Health4Life app as *good* or *very good* and agreed that the app was easy to use and would help people like them to change their lifestyle behaviors. These positive perspectives were reiterated in many open-ended responses from the participants. However, only a quarter of participants reported that they would like to use the app frequently and most participants expressed neutral attitudes with regard to the app consistency and integration of features. Despite previous support for the effectiveness of mobile phone–based interventions for changing health risk behaviors [16-20], disparity between perceived acceptability of an app and actual use has been reported in previous mobile-based development and evaluation studies [40]. Co-design with young people and tools to promote active engagement are likely to be important components of any youth-based app.

Strengths and Limitations

Formative research that informed the development of the Health4Life app had several limitations. First, the reviews of the literature were not formal systematic reviews. Other useful features to incorporate into the Health4Life app may have been identified if a more comprehensive review of the literature was conducted. However, the features that were included in the app, to encourage either health behavior change or engagement (eg, self-monitoring, goal setting, personalized feedback, or rewards), have a strong theoretical and empirical evidence base to support their use. Another limitation was that the end user consultations only included students from metropolitan areas and involved mainly female participants, with no males participating in the focus group. Different perspectives and ideas for app content presentation may have been generated if more males and students from nonmetropolitan areas had been recruited. The full trial of the Health4Life program is currently underway and will allow us to evaluate the acceptability and effectiveness of the Health4Life app in a broader sample of gender-diverse adolescents (N=6640) [43]. Furthermore, because of limited time and resources, coding and grouping of qualitative data was completed by only one researcher.

Although very few participants reported negative views of the usability of the app, it is clear that there is some room for improvement, given the less-than-optimal average SUS total score obtained (59.2, which reflects a *D grading* and *OK* usability). Results from the SUS are displayed in Multimedia Appendix 2. However, similar scores have been reported for other mHealth apps with comparable features (eg, goal setting, rewards, and diaries for health behaviors) when reviewed by adolescents in several European countries [69]. It is also worth noting that the SUS score means that receiving all neutral responses will result in a score of 50 and *fail* grading. Our score, in part, reflects a high proportion of neutral responses received. Although these neutral responses may represent genuine neutral perspectives, research has shown that participants may use a midpoint response when they do not understand an item or if the item is ambiguous or socially undesirable [70]. In addition, questions offering neutral midpoints decrease response reliability and measurement quality in children and adolescents [71-75]. As such, the SUS responses from our sample of those aged 11 to 14 years may need to be interpreted with caution.

This formative research generated important insights into the development and implementation of health apps for adolescents. Additional customization with regard to the timing and frequency of reminder notifications may be important when trying to strike the right balance between enough reminders to effectively engage users and too many so that users are put off and choose not to access or disengage with the app. Participants in our initial examination of the feasibility and acceptability of the Health4Life app received a single notification via email, alerting them to the app and how they could access it. However, anecdotally, it emerged that a large proportion of students did not frequently check their school email addresses, which they were required to use as their primary email contact in the trial. Teachers were encouraged to mention the app to students and encourage them to download it and were provided with an example classroom activity they could conduct using the app. However, implementation of these activities was at the teacher's discretion and results from our feasibility and acceptability testing showed that many teachers did not mention the app to students or in some cases discouraged their students from downloading it. Alternative modes of communication (eg, SMS text messaging) or parental engagement may be needed to effectively reach most students outside of the school environment and working more closely with teachers to address any concerns they might have in encouraging their students to download and use an app like the Health4Life app.

Finally, the feasibility and acceptability of the app was tested only among a subsample of participants who were all from independent secondary schools in the metropolitan regions of New South Wales. The full trial of the Health4Life program will evaluate the effectiveness of the school-based program and smartphone app at targeting the Big 6 risk behaviors among this subsample and students from 2 other states, including independent, public, and Catholic schools in both metropolitan and regional locations. As such, it is one of the largest and most diverse samples of Australian adolescents. This will enable us

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to examine the ways in which users interact with the app, how different patterns of use or nonuse might influence health behavior change outcomes among users, and how this might differ for different types of users.

Conclusions

The Health4Life app is the first mobile app intervention specifically designed with, and for, adolescents to concurrently address the Big 6 risk behaviors. Designed in collaboration with adolescents and experts and adopting a multiple health behavior change approach, it has the potential to efficiently and effectively modify important risk factors for chronic diseases among young people.

As part of the Health4Life initiative, the Health4Life app is provided in conjunction with the Health4Life school-based program to all grade 7 students, regardless of their engagement in the Big 6 risk behaviors. To our knowledge, this is the first time such an app will be used to support a school-based program to simultaneously target the Big 6 lifestyle risk behaviors [28]. By reinforcing key learning from the school-based program outside of the classroom and allowing students to receive regular and individualized feedback about their own health behaviors, the Health4Life app has the potential to efficiently and effectively modify important risk factors for chronic disease among young people.

The next important step is to establish the effectiveness of the Health4Life intervention, including the Health4Life app. A cluster randomized controlled trial is currently underway in 71 schools across Australia to evaluate whether Health4Life is more effective than health education as usual in delaying the uptake of alcohol and tobacco use, reducing sedentary recreational screen time, reducing the decline in moderate-to-vigorous physical activity, reducing the consumption of sugar-sweetened beverages, and improving sleep [43].

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Example of focus group participants’ suggestions for displaying tracked behaviors in the app.
[DOCX File , 786 KB - formative_v5i4e25513_app1.docx]

Multimedia Appendix 2
System usability scale results.
[DOCX File , 16 KB - formative_v5i4e25513_app2.docx]

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Abbreviations

BCT: behavior change technique
ICSEA: Index of Community Socio-Educational Advantage
mHealth: mobile health
SUS: System Usability Scale

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Original Paper

A Modular Mobile Health App for Personalized Rehabilitation Throughout the Breast Cancer Care Continuum: Development Study

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Abstract

Background: Although many mobile health (mHealth) apps have evolved as support tools for self-management of breast cancer, limited studies have developed a comprehensive app and described the algorithms for personalized rehabilitation throughout the breast cancer care continuum.

Objective: This study aimed to develop a comprehensive mobile app and to describe an algorithm that adjusts personalized content to facilitate self-management throughout the breast cancer care continuum.

Methods: The development process of the modular mHealth app included the following 4 steps: (1) organizing expert teams, (2) defining evidence-based fundamental content and modules, (3) classifying user information for algorithms to personalize the content, and (4) creating the app platform and connectivity to digital health care devices.

Results: We developed a modular mHealth app service, which took 18 months, including a review of related literature and guidelines and the development of the app and connectivity to digital health care devices. A total of 11 functionalities were defined in the app with weekly analysis. The user information classification was formulated for personalized rehabilitation according to 5 key criteria: general user information, breast operation type, lymph node surgery type, chemotherapy and hormonal therapy use, and change in treatment after surgery. The main modules for personalized content included a self-monitoring screen, personalized health information, personalized exercise, and diet management.

Conclusions: The strength of this study was the development of a comprehensive mHealth app and algorithms to adjust content based on user medical information for personalized rehabilitation during the breast cancer care continuum.

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KEYWORDS

breast cancer; mobile health; rehabilitation; cancer continuum

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Introduction

Background

Breast cancer is the most frequently diagnosed cancer among women worldwide and in Korea. In 2019, there were an estimated 24,010 cases, suggesting an increasing trend [1]. Patients with breast cancer undergo a long course of diagnostic, treatment, and posttreatment procedures; long-term survivorship; and end-of-life stages [2]. Different treatments for breast cancer result in a series of treatment-related problems such as upper limb dysfunction, fatigue, and sleep disturbance [3-6], and these side effects induce short-term, long-term, and late effects [7]. Patients with breast cancer should be educated regarding self-management of their physical symptoms and functions and changing their behavior to promote a better quality of life [4,8]. Therefore, an accessible system is essential for the resolution of symptoms and health care concerns across the breast cancer care continuum.

From this viewpoint, mobile health (mHealth) apps in cancer care have emerged as an attractive technology for enabling symptom and disease management and promoting healthy lifestyles such as increasing physical activity [9-13]. An increasing number of mHealth apps for patients with breast cancer are being developed; these apps aid in establishing an association between patients and health care professionals [9,14-16]. Currently, approximately 600 mobile apps for patients with breast cancer are available in the iOS and Android markets [16]. The potential advantages of providing interventions using mHealth apps include ease of use, cost-and resource-effectiveness, and personalization during treatment [17]. It has positive effects on physical activity, weight loss, quality of life, functional fitness, and psychological factors (such as anxiety, depression, and distress) [18-22].

As the need for tailored intervention with mobile apps and wearable trackers among patients with breast cancer has increased [17,23], adjustment of the cancer treatment plan by considering the characteristics of individual patients has become important. However, a recent systematic review [9] revealed that most mobile apps focus on only providing relevant information or recording side effects during the treatment of breast cancer rather than providing personalized rehabilitation [22,24-26].

Objective

To the best of our knowledge, no studies have specifically focused on developing a comprehensive mHealth app for providing personalized content during the breast cancer care continuum, although several studies have examined the feasibility or effects of interventions that use an app during treatment. Therefore, we developed a modular mHealth app that can be personalized according to surgery type and treatment modality during the breast cancer care continuum. This study aimed to describe algorithms for personalizing the content of the app to support self-management and address the development process.

Methods

Development Process

Stage 1: Expert Team Organization for App Development

For app development, an expert team was organized, which was comprised of a multidisciplinary research team and development team. The research team included a breast surgeon, 2 physical and rehabilitation medicine physicians, 2 physical therapists, 2 exercise experts, and 2 nutritionists. The development team consisted of app developers and service programmers. The development team (2 professional developers and 2 service planners) had experience in developing an mHealth app for chronic disease management, pregnancy, and patients with stomach, colon, and prostate cancers. The app design team included 2 designers who had extensive expertise in designing applications for cancer patients.

Stage 2: Evidence-Based Fundamental Content and Modules

This app was developed for Korean women with breast cancer, and it aimed to promote health care from the postoperative period to the end of treatment. To clarify the actual content and modules of the app for breast cancer, the research team exchanged mutual opinions through regular meetings and sorted the content. The content and modules were included after sufficient discussion and review of the relevant research experience. The final decisions on the app's content and modules were determined by a consensus of all experts. A total of 11 functionalities was included in this app to help users manage the side effects of their diseases and treatments, comorbidities, and lifestyle choices with a weekly analysis function (Table 1).

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Table 1. Functionality and key characteristics of the mobile app.

Functionality	Key characteristics (evidence-based)
Expert consultation	Provides consultations related to exercise and nutrition using text messages, voice recordings, and images; health care professionals respond to the questions within 24 hours.
Self-monitoring (today's to-do list)	Allows users to self-check their treatment-related symptoms; allows users to self-assess their physical activity, calorie consumption, sleep, and stress information.
Personalized health information and education	Offers health information and education on exercise, nutrition, and disease (updated every Monday in webzine form); offers health information and education according to surgery, treatment type, side effects, and comorbidities.
Personalized exercise management	Offers aerobic exercise with the goal of a specific heart rate and exercise time according to the user's health information; offers an arm and shoulder exercise program with a video consisting of four steps according to the user's information (surgery and treatment type) and exercise journal.
Physical activity management	Recommends target step intensity (normal, brisk, and run), calories, heart rate, and step count (eg, 5000 steps and 200 kcal).
Diet management	Provides daily guidelines for each food group: Users can record the foods ingested during breakfast, lunch, dinner, and refreshments for a day using speech recognition and text input; recommends nutritional intake according to comorbidities.
Sleep management	Allows users to track total sleep times, sleep efficacy, REM[a] sleep time, NREM[b] sleep time, and sleep quality using a smart band.
Comorbidity management (weight, blood pressure, blood glucose)	Allows users to use a journal format and Bluetooth-enabled smart device: The target blood pressure and blood glucose levels are indicated; allows users to track their weight, blood pressure, and blood glucose level.
Stress management	Allows users to track their stress level (categorized as good, normal, low, and high) based on heart rate variation analysis.
Medication and smoking management	Provides an alarm sound at the time when users should take their medications, allowing them to track their medication intakes; provides an alarm sound to prompt users to record their daily smoking status.

[a] REM: rapid eye movement.

[b] NREM: non-rapid eye movement.

To offer evidence-based information, the following resources were used for the app: the American College of Sports Medicine Exercise Prescription Guidelines for Cancer Survivorship; exercise program for patients with breast cancer [8,27-29]; neurophysiological mechanisms of sleep [30-34]; Korean Society for the Study of Obesity guidelines [34,35]; Korean Society of Hypertension guidelines [36]; and Korean Diabetes Association guidelines [37].

Stage 3: Classification of User Information for the Algorithms for Personalized Content

To provide personalized content, we discussed and sorted the representative treatment course after surgery for breast cancer according to the aim and scope of the app. The following information was included in the algorithm for personalized content (Figure 1): general user information, breast surgery type, axillary surgery type, treatment using chemotherapy and hormonal therapy, and treatment change after postoperative period (total of 5 years). This classification complied with the National Comprehensive Cancer Network Guidelines for patients with breast cancer [38] and reflected the treatment process of breast cancer patients in Korea. At the end of the review and discussion, the content was finally classified into a total of 34 treatment courses.

General user information included the following: name or nickname, sex, birth date, height, weight, chronic diseases (eg, hypertension, diabetes, and hyperlipidemia), current food intake (eg, vegetables, fruit, fish, meat, and rice), and smoking status. To utilize personalized content, users input breast surgery type, lymph node surgery type, surgery date, hospital discharge date, and current treatment (eg, chemotherapy, radiation therapy, and hormonal therapy), including general user information.

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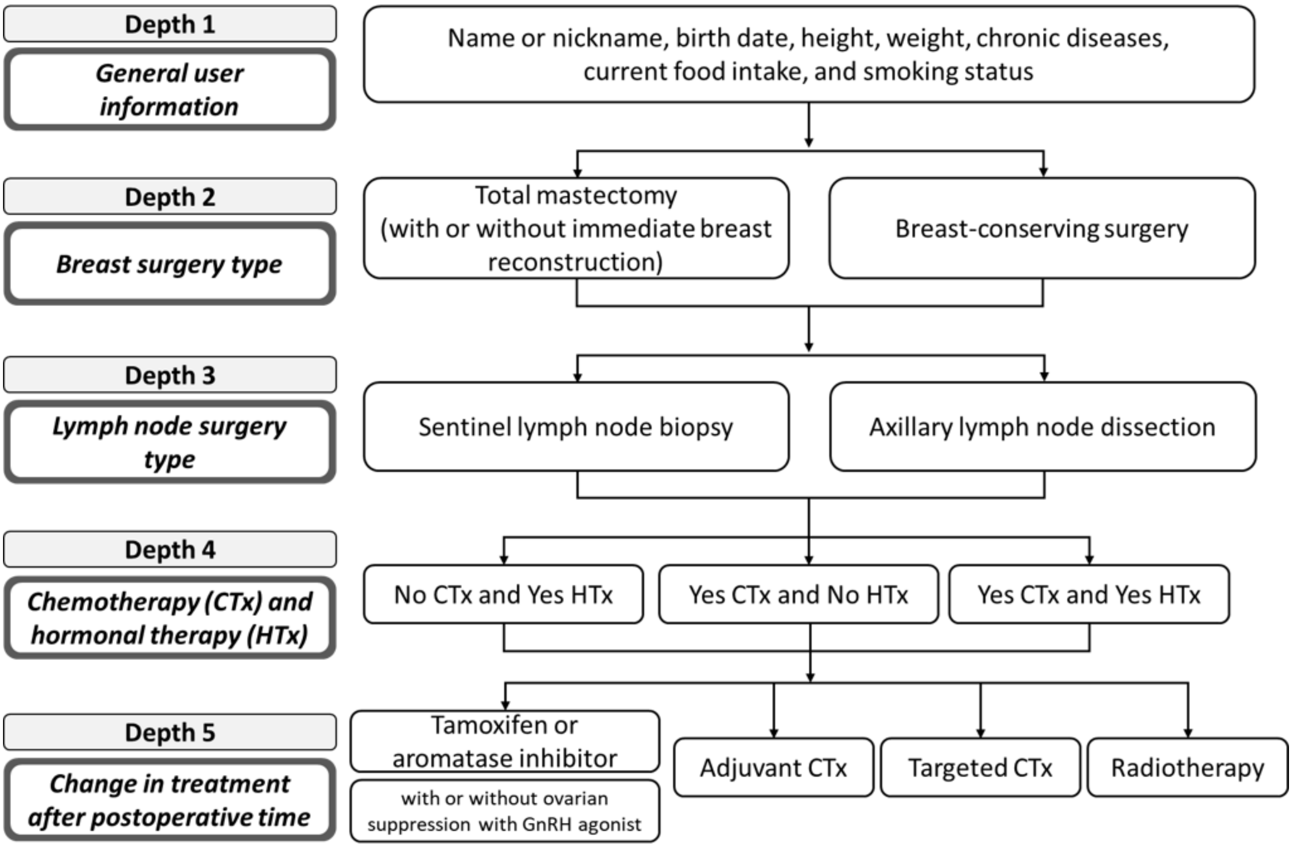
Figure 1. Classification system of user information for the algorithms for personalized content.



Stage 4: Creation of the Modular mHealth App Platform and Connectivity to Digital Health Care Devices

This app was developed for use on both Android and iOS platforms and can transfer data via connection with Bluetooth-enabled wearable smart devices. Health care professionals can use a web-based open architecture management (OAM) program to monitor all data, including those on app service use and wearable or smart devices.

The wearable device includes a DoFit smart band worn on the wrist (NF-B20, Medi Plus Solution, Seoul, South Korea), which allows the measurement of physical activity, stress level, heart rate, and sleep information through a built-in 6-axis accelerometer, gyroscope, and photoplethysmography sensor. Energy expenditure and physical activity intensities were analyzed on the basis of heart rates and step counts. Stress level is provided on the basis of heart rate variation analysis of heart rates collected during daily activities. Moreover, the smart device linked to the app includes a blood pressure gauge (UA-651BLEm, A&D Medical, Tokyo, Japan), glucose monitor (GM01AAB, i-SENS, Seoul, Korea), and scale (XMTZC04HM, Xiaomi Corporation, Beijing, China). The Korean certification test verified the appropriate level of radiation exposure from health care devices.

In order to use data from this platform and digital health device and for use of personal information and information from mobile and wearable devices, consent is obtained while joining this service. Data generated from the platform are protected through protection of personal information and storage of data in our service platform server after deidentification of the data.

Results

We required 18 months to review the database, related literature, and guidelines as well as to develop and launch the 11 functionalities, connectivity with a digital health care device, monitoring program, and app testing. Figure 2 presents the service flow of the app. The overall service flow of the developed app is as follows: The user creates an account (subscription information and personal health record data) and enters medical care information (breast surgery type, type of surgery to remove lymph nodes, and postoperative treatment). On the basis of the treatment information, the first algorithm is applied, and the user case is classified. Personalized guides are provided for exercise, side effect education, and nutrition. The second algorithm analyzes the program usability and whether the implementation follows management guidelines and then personalizes the guide. By interworking with health care devices such as smart bands and the establishment of the OAM system for data monitoring, the service platform enables patient-health care expert communication.

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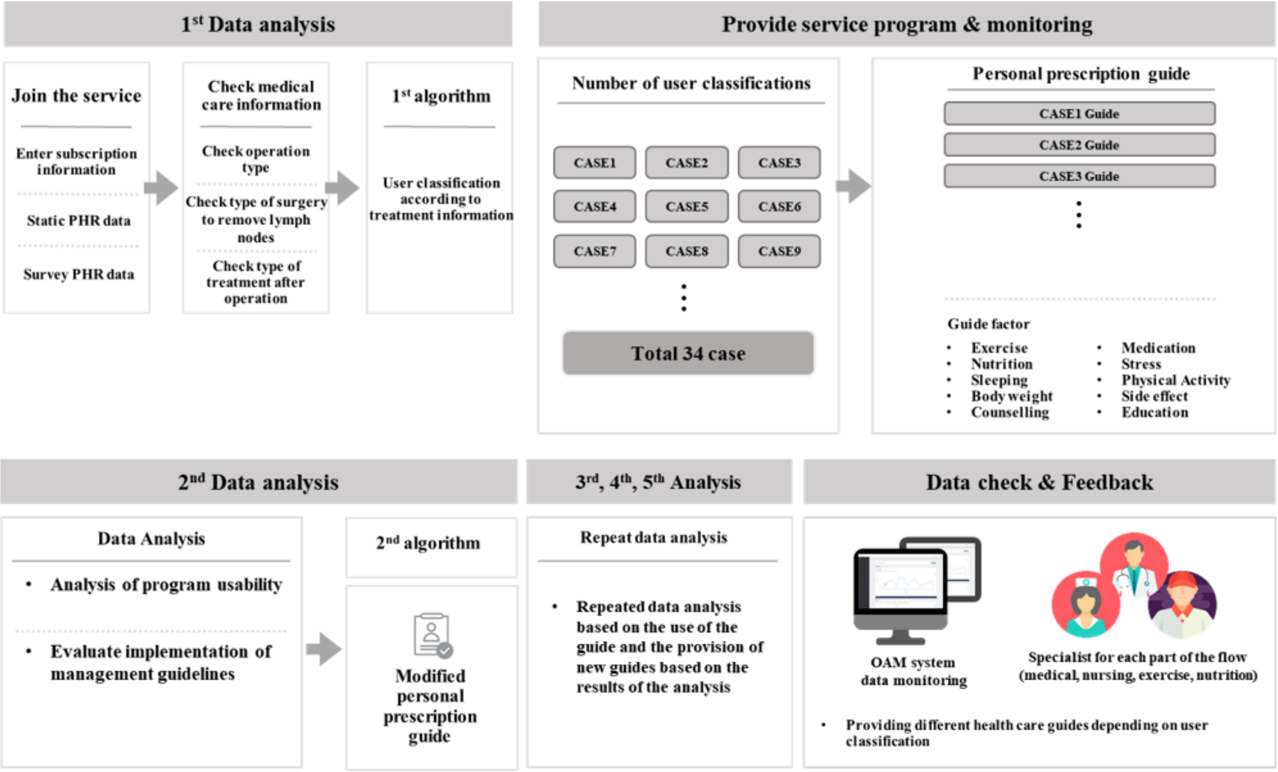
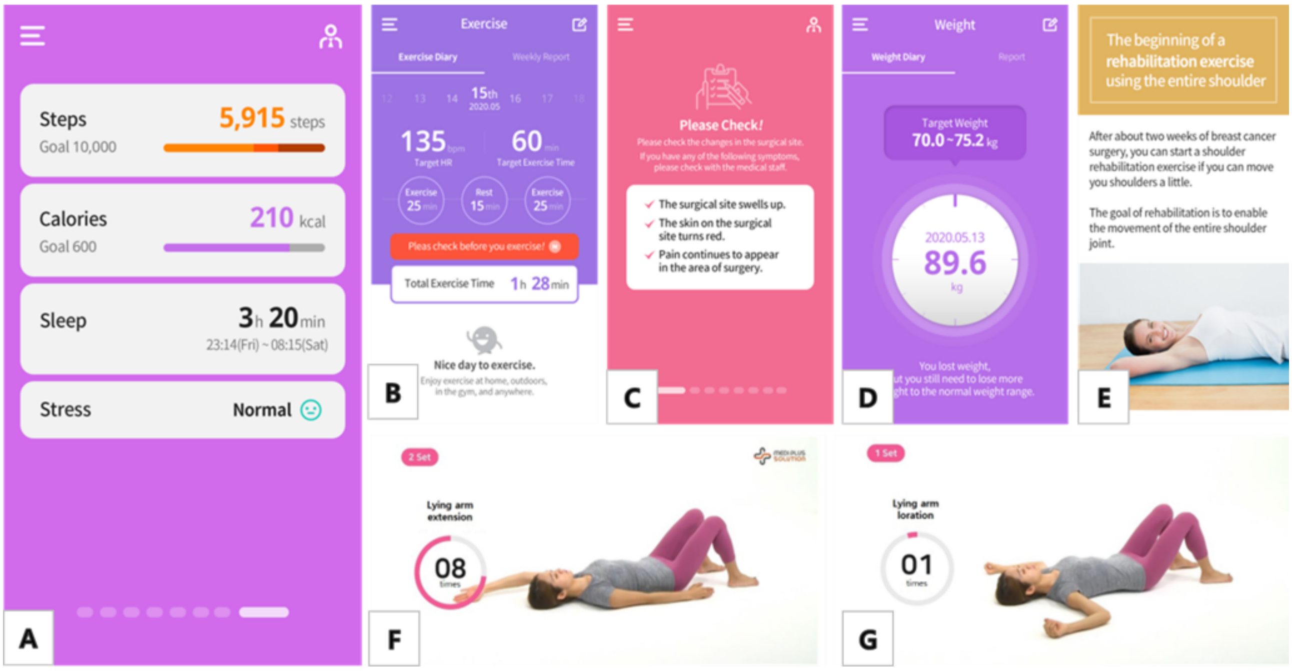
Figure 2. Service flowchart of the development of the modular mobile health (mHealth) app for personalized rehabilitation. OAM: open architecture management; PHR: personal health record.



Key Modules for Personalized Content Based on Classification of User Information

Figure 3 shows screenshots representing the app's functionality. According to the classification of user information algorithms for personalized content, if a user enters their information, the app provides personalized content and goals on the self-monitoring screen, including personalized health information, aerobic exercise, arm and shoulder exercises, and nutrition management.

Figure 3. Screenshots of the representative app functionality: (A) self-monitoring, (B) exercise management, (C) main (today's to-do list), (D) weight management, (E) personalized education and information, and (F) arm and (G) shoulder exercises.



Nice day to exercise.
Enjoy exercise at home, outdoors, in the gym, and anywhere.

Please check the changes in the surgical site.
If you have any of the following symptoms, please check with the medical staff.

- ✓ The surgical site swells up.
- ✓ The skin on the surgical site turns red.
- ✓ Pain continues to appear in the area of surgery.

You lost weight, ut you still need to lose more ght to the normal weight range.

The beginning of a rehabilitation exercise using the entire shoulder

After about two weeks of breast cancer surgery, you can start a shoulder rehabilitation exercise if you can move you shoulders a little.

The goal of rehabilitation is to enable the movement of the entire shoulder joint.

Self-Monitoring Screen (Today's To-Do List)

Once the user information is entered, the self-monitoring components are displayed by priority at login. The treatment-related symptom checklist is displayed as treatment changes occur. For example, if a patient with breast cancer initiates chemotherapy, medical caution related to side effects

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is shown on the main screen, and users are prompted to check their health conditions when they log in. After the treatment is completed, the monitoring screen changes according to the user's comorbidities. If the user has a chronic disease, the management screen is displayed as a priority. On the self-monitoring screen, the last screen displays a brief graph showing step count, calories, sleep details, and stress level, regardless of health status.

Personalized Health Information

Information on health condition, managing side effects, and medical precautions are displayed in 3 categories (disease, nutrition, and exercise). The information is adjusted according to user health information such as surgery date, treatment type, and chronic disease and updated every Monday. From 1 to 5 weeks postoperative, the user is offered relevant management information. If users input treatment information such as chemotherapy, radiotherapy, and hormonal therapy, this functionality will describe the side effects, nutrition, and exercises needed during treatment. Chronic disease and wellness management information is provided after the treatment is completed.

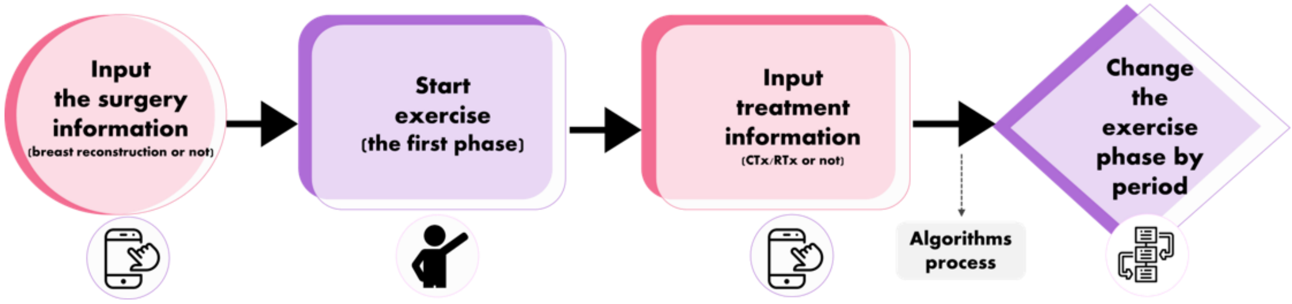
Personalized Exercise

Arm and Shoulder Exercise Program

The exercise program was developed by rehabilitation experts based on the aforementioned studies in stage 2. This home-based video exercise program consists of 4 stages that gradually progress from active-assisted to arm strengthening exercises.

The rehabilitation experts designed algorithms specific to surgery and treatment types. The changes occur automatically, and the start time of each stage differs according to surgery and treatment type. These details include immediate breast reconstruction, chemotherapy, and radiotherapy. The process of applying the algorithm for the shoulder and arm exercise program is shown in Figure 4.

Figure 4. Process of applying the personalized arm and shoulder exercise program. CTx: chemotherapy; RTx: radiation therapy.



Aerobic Exercise for Breast Cancer

According to the user's treatment information, the target heart rate and exercise time are automatically adjusted in accordance with the American College of Sports Medicine guidelines [39]. The initial baseline is set according to the treatment information that the user inputs at sign-up. As the week progresses, an algorithm determines the heart rate goal and gradually increases the exercise time. For instance, when chemotherapy information is entered, the target heart rate in this stage is immediately changed to control the exercise intensity; the same change occurs when chronic disease information is entered.

Depending on the estimated rate of perceived exertion after exercise termination, the exercise goal and duration are increased, decreased, or maintained. If the user records "hard" more than twice per week or "very hard" only once per week, the exercise phase is lowered. In addition, heart rate is measured in real time using a smart band during aerobic exercise. If the user's heart rate exceeds the target, an alarm will sound to notify the need to adjust the exercise intensity.

Diet Management

The algorithm for calorie intake is calculated using the original intake per food group, body mass index, and age that the user inputs at sign-up. This module recommends a meal plan, including food groups and intake based on the Korean diet. Furthermore, users can check whether they are consuming well-balanced food types and amounts through a graph that indicates "lacking" in gray, "appropriate" in green, and "excessive" in red. At the bottom of the diet management screen, the recommended nutrition plan changes depending on the presence or absence of chronic diseases. For instance, consumption of protein and fat is displayed for users who have undergone surgery from week 1 to 5 and who have no chronic diseases. If the user has diabetes, essential nutrients are adjusted to include carbohydrates and fat. This functionality allows users to compare their intake and recommended dietary allowance. There are restrictions on adjusting diet plans depending on the user's dietary preferences (eg, vegetarian) or taboo foods (eg, religious diet).

Discussion

Principal Findings

In this study, we documented the process of developing a modular mHealth app to provide personalized content based on surgery type, treatment process, and chronic disease(s). This study specified the algorithm used to modify the content by surgery and treatment types and according to the analysis of user health records. In addition, to improve the motivation and benefits of using the mHealth app [40,41], we used assistant technology (ie, smart band) and professional support for monitoring and providing real-time feedback (ie, OAM program) during app use.

The key feature of the developed app is that it is not limited to specific treatment groups such as those treated with

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chemotherapy or radiotherapy and is a comprehensive self-management tool available during the breast cancer care continuum. To cover the characteristics of diverse users and provide personalized content, 34 user cases were classified according to surgery information and treatment process. A previous research study [41] developed an information-centered app that consisted of 5 modules according to the information needs of women with breast cancer during treatment based on interviews and discussion with experts. They included 8 information items — stages of diagnosis, adjuvant chemotherapy, operation, chemotherapy, radiation therapy, endocrine therapy, targeted therapy, and rehabilitation. However, the focus of our study was not simply providing information but providing personalized content with a comprehensive self-management tool during the breast cancer care continuum according to the different surgery types, treatments, and chronic diseases.

With regard to the development of a comprehensive app, most modules were consistent with those from previous research [42] that provided the framework, which consisted of 8 themes, including information related to treatment, physical activity (exercise and rehabilitation), emotions (mental support, music therapy, and sufficient sleep), diet, health records, social resources, experience sharing, and expert consulting. The aforementioned study investigated the needs information through focus group interviews with women who completed different therapies or received long-term hormonal therapies. In this study, according to a review of a previous study and discussions with a multidisciplinary team, 11 modules were developed covering health information and education, self-monitoring, exercise and physical activity management, diet, sleep, comorbidity, stress, medication and smoking management, and expert consultations. Particularly, our study differs from previous studies in that the content of some modules in this developed app was adjusted primarily according to the user's characteristics (eg, type of surgery and treatment) and can be changed according to comorbidities and diseases. Some discrepancies between our results and those of previous studies may be due to differences in culture, development approach, and target user.

Limitations

Although this study aimed to develop an app that offers comprehensive and personalized health management content during the breast cancer care continuum, some concerns need to be addressed at a later stage. This app has limitations in adjusting content based on the factors that need to be considered for highly personalized mHealth interventions such as symptom burden, weather, and treatment cycle. To date, electronic medical record data have not been directly linked with the app. To obtain personalized content, users must update their health and treatment information directly in the app. If this concern is resolved, it may be beneficial for users to use the app. Moreover, long-term engagement with and adherence to the comprehensive mHealth-supported intervention must be investigated, and additional analysis of needs and satisfaction according to user characteristics will be required.

Despite these limitations, this is an important first step in realizing a comprehensive and personalized, rehabilitation-based mHealth app for patients with breast cancer during the breast cancer care continuum.

Conclusion

This app was developed to facilitate the comprehensive and personalized rehabilitation of patients with breast cancer throughout the treatment course using algorithms to deliver personalized content and change the user information accordingly and to motivate and monitor patients using a digital health care device that tracks the user's information and communication with health care experts. This study enlisted algorithms to provide personalized content and describe the functionality of the comprehensive app for patients with breast cancer. In the future, its efficacy and clinical effectiveness as a management solution should be evaluated through clinical management, continuous upgrades based on the latest guidelines, and user feedback.

Acknowledgments

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Authors' Contributions

JY and JK wrote the manuscript with support from JH and YK. All authors designed the project and developed the theoretical framework for the app development. JK developed the overall app. All authors discussed the results and commented on the manuscript. JH directed and supervised the project.

Conflicts of Interest

None declared.

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Abbreviations

mHealth: mobile health
OAM: open architecture management

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Original Paper

Feasibility and Acceptability of a Smoking Cessation Smartphone App (My QuitBuddy) in Older Persons: Pilot Randomized Controlled Trial

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Abstract

Background: Although many smoking cessation smartphone apps exist, few have been independently evaluated, particularly in older populations. In 2017, of the 112 commercially available smoking cessation apps in Australia, only 6 were deemed to be of high quality, in that they partially adhered to Australian guidelines. Mobile health (mHealth) apps have the potential to modify smoking behavior at a relatively low cost; however, their acceptability in older smokers remains unknown. Rigorous scientific evaluation of apps is thus urgently needed to assist smokers and clinicians alike.

Objective: We conducted a pilot randomized controlled trial to evaluate the feasibility of a large-scale trial to assess the use and acceptability of a high-quality smoking cessation app in older smokers.

Methods: Adult inpatient and outpatient smokers with computer and smartphone access were recruited face to face and via telephone interviews from Metropolitan Hospitals in Brisbane, Australia. Participants were randomized 1:1 to the intervention (requested to download the “My QuitBuddy” smoking cessation app on their smartphone) or the control group (provided access to a tailored smoking cessation support webpage [Quit HQ]). The My QuitBuddy app is freely available from app stores and provides personalized evidenced-based smoking cessation support. Quit HQ offers regular email support over 12 weeks. No training or instructions on the use of these e-resources were given to participants. Outcomes at 3 months included recruitment and retention rates, use and acceptability of e-resource (User Version of the Mobile App Rating Scale [uMARS]), changes in quitting motivation (10-point scale), and self-reported smoking abstinence.

Results: We randomized 64 of 231 potentially eligible individuals (27.7%). The mean age of participants was 62 (SD 8). Nicotine dependence was moderate (mean Heaviness of Smoking Index [HSI] 2.8 [SD 1.2]). At 3 months the retention rate was (58/64, 91%). A total of 15 of 31 participants in the intervention arm (48%) used the app at least once, compared with 10 of 33 (30%) in the control arm. uMARS scores for e-resource use and acceptability were statistically similar (*P*=.29). Motivation to quit was significantly higher in the intervention arm compared with the control arm (median 6 [IQR 4-8] versus 4 [IQR 4-5], respectively, *P*=.02). According to the intention-to-treat analysis, smoking abstinence was nonsignificantly higher in the intervention group (4/31 [13%], 95% CI 4%-30%, versus 2/33 [6%], 95% CI 1%-20%; *P*=.42). The estimated number needed to treat was 14.

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Conclusions: Internet and mHealth smoking cessation resources appear acceptable to a minority of older smokers. Smokers who engaged with the allocated e-resources rated them equally, and there were trends toward greater uptake, increased motivation, and higher abstinence rates in the app group; however, only the change in motivation reached statistical significance (median score 6 versus 4, respectively, *P*=.02). This results of this pilot study suggest that apps may improve quit outcomes in older adults who are willing to use them. Further research into user–app interactions should be undertaken to facilitate improvements in app design and consumer engagement. These favorable trends should be explored in larger trials with sufficient statistical power.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12619000159156; http://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=376849&isReview=true

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KEYWORDS

mHealth; mobile apps; motivation; smartphone; smoking cessation; tobacco smoking

Introduction

Globally, 6 million people die from tobacco use annually, accounting for 11.5% of deaths worldwide and an economic cost of US $1 trillion [1]. Despite smoking prevalence falling in most economically developed countries [2], important efforts to reduce prevalence are ongoing [3]. With an estimated 6.8 billion active mobile phones worldwide, patient-facing smartphone apps offer novel opportunities to modify health behavior at low cost. With little or no clinician input they may represent a powerful new platform to help smokers quit [4,5]. Multiple smoking cessation apps exist; however, only few have been independently evaluated in clinical populations. Thornton et al [6] reviewed all free, commercially available smoking cessation apps in Australia, and only 6 of 112 apps were deemed high quality, at least partially following Australian treatment guidelines. Haskins et al’s [7] systematic review identified only 6 smoking cessation apps with peer-reviewed scientific support. Only 2 (4%) of the top 50 suggested by leading app stores had any scientific support. In addition, most app trials have been small, resulting in imprecise effect estimates. A meta-analysis of 8 randomized controlled trials (n=3543) found a clinically, but nonstatistically significant change in the rate of abstinence compared with usual care (pooled relative risk 1.15, 95% CI 0.85-1.57) [8].

No trials so far have assessed older populations; mean age ranges in published trials vary from 24.9 to 54.3 years [8]. Older populations are important as they represent heavier tobacco users and perhaps harder-to-treat smokers who may be less fluent in, or have limited access to, information technology (IT) [9,10]. Thus, there is an urgent need for data in this cluttered and poorly regulated market across all population subgroups, especially in older smokers.

My QuitBuddy, one of the most popular apps with over 200,000 downloads [11], was released in 2012 by the Australian Department of Health and is in the top 10 recommended smoking cessation apps in iOS and Google Play stores. Although deemed high quality, it lacks evaluation in a randomized controlled trial [6].

We therefore designed the eQUIT study to assess the feasibility, use, and acceptability of the My QuitBuddy smoking cessation app in adult smokers. A secondary outcome was to estimate the treatment effect size to inform power calculations for larger trials.

Methods

Study Design and Participants

eQUIT was a randomized controlled trial of smoking cessation e-resources. Current smokers aged over 18 who owned an internet-enabled smartphone and a computer were eligible. Smokers currently using a smoking cessation app were ineligible. Recruitment was limited to 1 participant per household. Control arm participants were instructed to not download any smoking cessation apps during the study period. Screening and mixed methods recruitment (face to face/telephone) were via smoking cessation clinics and inpatient and outpatient respiratory clinics (Multimedia Appendix 1). We also included enrollees in the International Lung Screen Trial (ILST) [12] in the Metro North Hospital and Health Service, Brisbane. Potentially eligible adult smokers were identified from clinics by the research team and from the ILST study database. Potentially eligible participants were asked questions to determine their eligibility (smartphone and computer ownership, concurrent app use). If eligible, participants were invited to provide informed consent which they could accept or decline. While recruitment was open to all adults, we primarily targeted older smokers, as clinical patients with chronic disease seen in hospital respiratory and cardiac clinics tend to be older; additionally, all participants undergoing lung cancer screening in the ILST were aged between 55 and 80 (an eligibility criterion of the ILST).

The trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12619000159156) and approved by the hospital human research ethics committees.

Smoking Cessation e-Resources

Participants in the control arm received an access link to a smoking cessation webpage hosted by the Queensland State Department of Health (Quit HQ) [13]. Quit HQ allows registration for a 12-week program of support emails containing health advice, motivational stories, and Quitline links.

Participants in the intervention arm received the link to download the My QuitBuddy app from app stores (Figure 1) [11]. My QuitBuddy motivates users across 4 functional domains: rational (health benefits, cost savings); emotional

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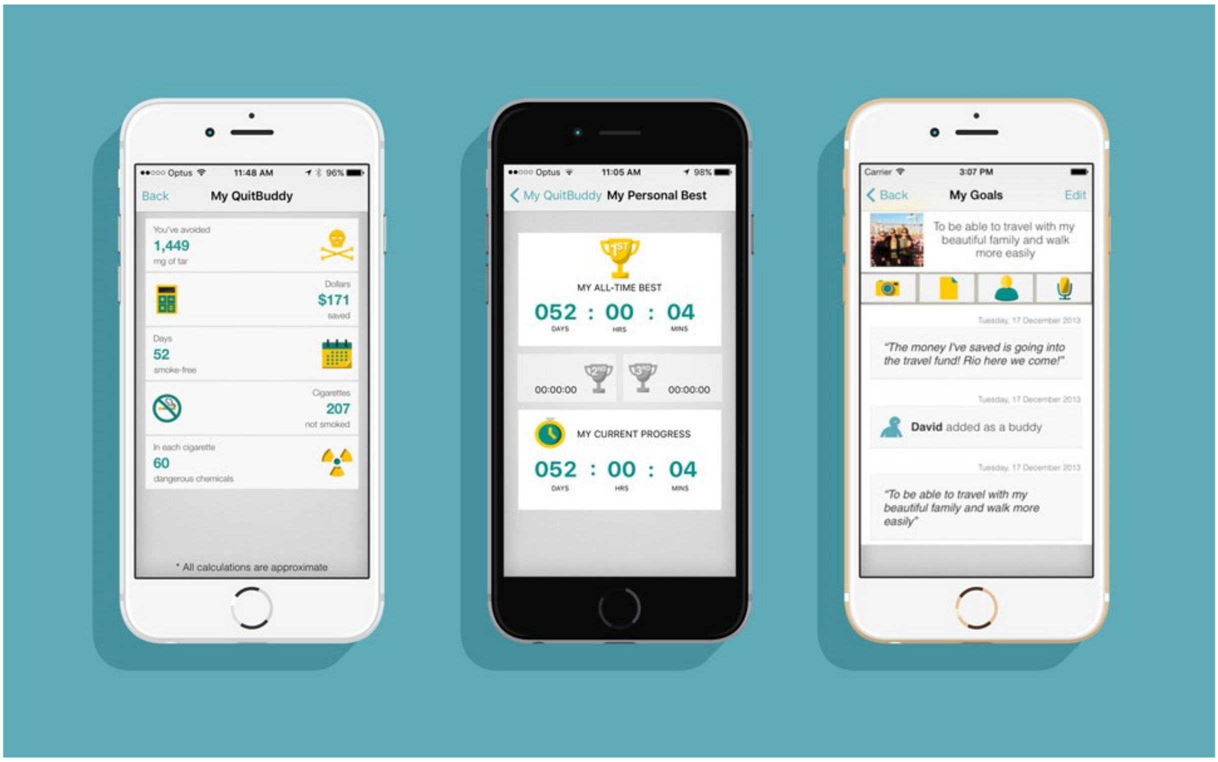
(positive influence of family and friends); social (community forums); and gamification (playful interactions producing serious outcomes). Both e-resources utilize similar educational content, motivational techniques, and direct links to Quitline. However, the app provides more personalized support in real time.

Figure 1. Screenshot My QuitBuddy app.



* All calculations are approximate

To be able to travel with my beautiful family and walk more easily

"The money I've saved is going into the travel fund! Rio here we come!"

David added as a buddy

"To be able to travel with my beautiful family and walk more easily"

Randomization

Randomization codes, stratified by hospital and grouped in blocks of 6, were centrally generated by a computer [14]. Allocation was concealed using sequentially numbered opaque envelopes.

Participants were randomized 1:1 after written consent and baseline questionnaires were completed. Participants were provided with a download link to the respective e-resource (thus not blinded). No training in e-resource use was given to simulate "real life" more closely. Participants were instructed to engage with the e-resource at their own discretion and use any standard-of-care smoking cessation interventions provided by their primary care provider.

Data Collection

Participants completed questionnaires at baseline and 3 months after randomization. Questionnaires were collected by telephone, in person, post, or email.

Baseline data included demographics; smoking history; smoking-related disease; motivation to quit (10-point scale, ranging from 1 [I enjoy smoking so much I will never consider quitting] to 10 [I have quit and I am 100% confident that I will never smoke again]) [15]; and generic health-related quality of life [16] (5-level EQ-5D [EQ-5D-5L], with higher scores indicating worse health status, EQ-5D Visual Analogue Scale [EQ-VAS] score [16], and self-reported overall health, ranging from 100 ["best possible" health] to 0 ["worst possible" health]). IT proficiency was rated by frequency of simple tasks (internet shopping and banking) and self-rated IT confidence (visual analog scale 0-100, with higher scores indicating higher confidence). Nicotine dependence was assessed using the HSI [17].

Outcome assessment was unblinded; however, subjective assessment was minimized by using a standard questionnaire. Self - reported smoking abstinence at 3 months was defined as smoking less than 5 cigarettes in the previous 12 weeks [18]. Visits to general practitioner and cessation intervention received (5As; "Ask, Advise, Assess, Assist, and Arrange") [19] were recorded. Participants rated the e-resource using the User Version of the Mobile App Rating Scale (uMARS), a 20-item measure with 4 objective quality subscales (engagement, functionality, aesthetics, and information quality); a subjective quality subscale; and a perceived impact subscale. Higher scores indicate better quality rating [20]. As far as we are aware, there are no validated tools that can be used across every type of internet or app resource. As we wanted to compare responses using the same tool across both conditions, we chose uMARS because (1) uMARS questions appear equally relevant to webpages as they do for apps, thus the same questionnaire could be administered to all participants; (2) the uMARS tool did not require substantial alteration for website users (wherever the term "app" appeared in the tool, we changed the wording to "app/webpage"; the questions themselves did not require any adjustment); (3) uMARS has been very well validated in many settings and the focus of this study was to evaluate an app as the experimental condition, rather than webpage as the control condition.

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The scheduled in-app and email reminders of both the intervention and control e-resources were individualized by the participants if and when they first engaged with their allocation. This information was not collected by the research team. Up to 10 attempts to contact participants to complete questionnaires were allowed during follow-up as per protocol.

Sample Size Justification and Statistical Analysis

As a feasibility study, formal sample size calculation was not required. However, we estimated the sample size required at around 10% of the number required for a statistically powered study. Assuming less than 20% loss to follow-up, a sample size of 64 would inform our aims of determining feasibility and acceptability [21,22].

Intention-to-treat analysis was performed, assuming nonresponders were smokers. Continuous measures were summarized using mean or median and compared using Student *t* test (for normally distributed data) or Wilcoxon rank-sum test (if data are not normally distributed). Categorical variables were compared using the Fisher exact test. Analyses were performed using the Stata Software (version 15; StataCorp). *P* values less than .05 were considered statistically significant.

Data Sharing Statement

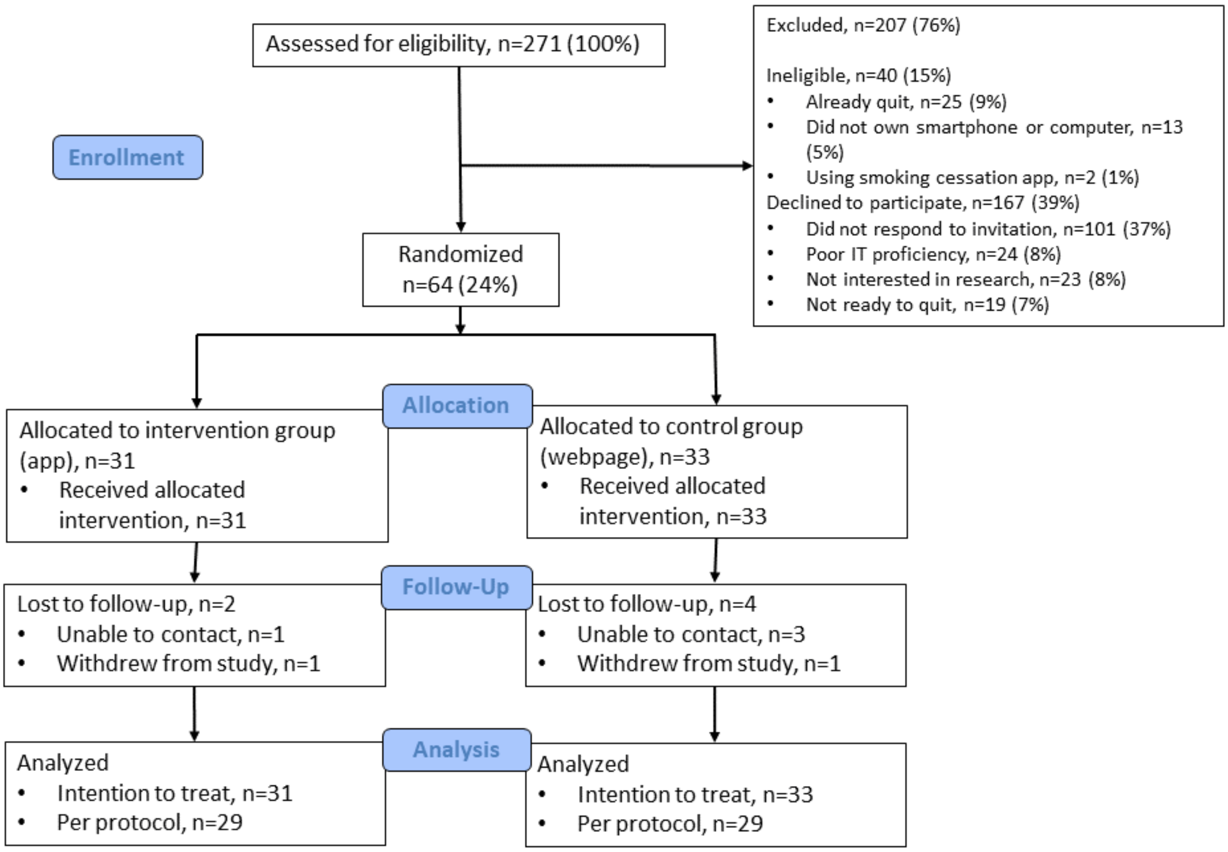
Anonymized data that support the findings of this study are available on request from the corresponding author, subject to ethical review. The data are not publicly available due to privacy and ethical restrictions.

Results

Recruitment

Between the April 4 and May 23, 2019, 271 inpatient and outpatient smokers were screened for eligibility (Figure 2). Of the 231 potentially eligible individuals, 64 (27.7%) were randomized. A total of 31 were allocated to the intervention arm and 33 to the control arm. Reasons for non-enrollment are outlined in Figure 2.

Figure 2. eQUIT consort.



Baseline Data

Baseline characteristics are presented in Table 1. Overall, 29/64 (45%) participants were female, and 34/64 (53%) participants had completed tertiary-level education. The mean age was 62 (SD 8), and only 4 participants were under the age of 50. Participants smoked a median of 15 cigarettes per day. Average nicotine addiction was moderate and similar between groups (mean HSI was 2.5 and 3.0, *P*=.18). Median motivation to quit was 4, equating to the statement “I sometimes think about quitting but have no specific plans to quit.” Nearly all participants (60/64, 94%) reported previous quit attempts. Only the history of chronic obstructive pulmonary disease was statistically significantly higher in the control arm (9/33 [27%] vs 1/31 [3%], *P*=.013).

Health-related quality of life was good. Proficiency in IT tasks appeared quite high; over one-half of the group used internet banking every week, and over one-half used internet shopping regularly. Self-rated IT confidence was high (median 75 out of 100).

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Table 1. Baseline demographic data.

Demographics	Intervention arm (My QuitBuddy app; n=31)	Control arm (Quit HQ Webpage; n=33)	*P* value
Age (years), mean (SD)	61 (9)	63 (8)	.52[a]
Gender (female), n (%)	11 (35)	18 (55)	.14[b]
Education, n (%)			.10[b]
Grade 12 or less	13 (42)	11 (33)	
Completed high school	5 (16)	1 (3)	
Tertiary/vocational/post graduate level achieved	13 (42)	21 (64)	
History of asthma, n (%)	4 (13)	9 (27)	.22[b]
History of chronic obstructive pulmonary disease, n (%)	1 (3)	9 (27)	.013[b]
History of bronchitis, n (%)	0 (0)	2 (6)	.49[b]
History of emphysema, n (%)	9 (29)	11 (33)	.79[b]
History of heart disease, n (%)	3 (10)	5 (15)	.71[b]
History of cancer, n (%)	3 (10)	5 (15)	.71[b]
Heaviness of Smoking Index[c], mean (SD)	2.5 (1.5)	3 (1.0)	.18[a]
Cigarettes per day, median (IQR)	20 (10-20)	15 (10-20)	.74[d]
At least one prior quit attempt, n (%)	29 (94)	31 (94)	>.99[b]
Motivation to quit, median (IQR)	4 (4-6)	4 (4-5)	.86[d]
Health-related quality of life[e], median (IQR)			
Anxiety/depression	0 (0-1)	0 (0-1)	.63[d]
Mobility	0 (0-1)	0 (0-1)	.50[d]
Pain/discomfort	1 (0-1)	0 (0-1)	.20[d]
Self-care	0 (0-0)	0 (0-0)	.65[d]
Usual activities	0 (0-1)	0 (0-0)	.07[d]
EQ-5D Visual Analogue Scale score	70 (50-85)	80 (70-90)	.14[d]
Online banking frequency, n (%)			.84[b]
Never	7 (23)	6 (18)	
Occasional to regular use	7 (23)	10 (30)	
Every week	17 (55)	17 (52)	
Online shopping frequency, n (%)			.59[b]
Never	13 (42)	12 (36)	
Occasional to regular use	18 (58)	19 (58)	
Every week	0 (0)	2 (6)	
Information technology confidence, median (IQR)	80 (60-85)	70 (50-90)	.77[d]

[a] From independent *t* test.

[b] From Fisher exact test.

[c] Higher score indicates greater addiction.

[d] Wilcoxon rank-sum test.

[e] Measured using the EuroQol-5D instrument.

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Outcomes

Of the 64 participants randomized, 58 (91%) completed a follow-up questionnaire at 12 weeks. An equal number of participants in each arm completed the study per protocol (29/31 [94%] and 29/33 [88%]), respectively.

e-Resource engagement was higher in the intervention arm: 15/31 (48%; 95% CI 32%-70%) participants in the intervention arm used the resource (app) at least once, compared with 10/33 (30%; 95% CI 18%-54%) participants in the control arm (*P*=.29). uMARS ratings of e-resource across 7 subscales did not differ significantly between intervention and control arms, with weak evidence for a higher functionality rating for the app (*P*=.07 to *P*=.51). Both e-resources had a median star rating of 3 out of 5 stars (Table 2).

In total, 42 participants (from both intervention and control arms) had visited their primary care provider at follow-up, and they equally utilized pharmacotherapy (Table 2). In both arms, provision of the more "active" parts of the 5As intervention was similar ("assist" and "arrange").

Table 2. Distribution of responses at follow-up by the study arm.

Response	Intervention arm (My QuitBuddy app; n=29)	Control arm (Quit HQ Webpage; n=29)	*P* value
Smoking abstinence, n (%)	4 (14)	2 (7)	.67[a]
Heaviness of smoking index, mean (SD)	2.0 (1.5)	2.2 (1.3)	.50[b]
Motivation to quit, median (IQR)	6 (4.0-8.0)	4 (4.0-5.0)	.02[c]
Cigarettes per day, median (IQR)	10 (2-20)	12 (6-20)	.31[c]
Ever-use of e-resource, mean (SD)	15 (52)	10 (34)	.29[a]
e-Resource star rating, median (IQR)	3 (3-4)	3 (3-4)	.24[c]
User Version of the Mobile App Rating Scale, mean (SD)			
Engage	2.7 (0.9)	2.4 (1.0)	.50[b]
Function	3.7 (0.9)	2.9 (1.3)	.07[b]
Aesthetics	3.5 (0.7)	3.1 (0.9)	.17[b]
Information	3.9 (0.8)	3.7 (1.2)	.51[b]
Quality	3.3 (0.9)	3.0 (1.1)	.43[b]
Subjective quality	2.9 (1.2)	2.3 (1.2)	.15[b]
Impact	3.4 (1.1)	2.9 (1.4)	.33[b]
Pharmacotherapy, n (%)			
Varenicline	5 (17)	5 (17)	>.99[b]
Bupropion	1 (3)	0 (0)	>.99[b]
Nicotine patches	6 (21)	7 (24)	>.99[b]
General practitioner follow-up, n (%)			
Visited general practitioner	22 (76)	20 (69)	.77[a]
Ask/advise/assess	11[d] (50)	14[e] (70)	
Assist/arrange medication counselling/follow-up	9[d] (41)	8[e] (40)	

[a] From Fisher exact test.

[b] From independent *t* test.

[c] Wilcoxon rank-sum test.

[d] N=22.

[e] N=20.

Quit motivation was significantly higher in the intervention arm than in the control arm (median score 6 versus 4, respectively, *P*=.02), equating to the following statements: "I plan to quit in the next 6 months" and "I sometimes think about quitting but have no specific plans to quit," respectively. Mean cigarettes smoked per day decreased by half in the intervention arm, although this was not statistically significant (*P*=.31).

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Using per-protocol analysis, 4/29 (14%; 95% CI 4%-32%) participants in the intervention arm and 2/29 (7%; 95% CI 1%-23%) in the control arm reported quitting at 3 months (*P*=.67). In the intention-to-treat analysis, the respective proportions were 4/31 (13%; 95% CI 4%-30%) and 2/33 (6%; 95% CI 1%-20%). The relative risk of quitting smoking in the intervention arm was 2.1 (95% CI 0.4-10.8; *P*=.42). The number of participants needed to treat for 1 successful quitter was 14 [23]. The number needed to treat was calculated as the inverse of the absolute risk reduction.

Discussion

Principal Findings

We conducted a pilot randomized controlled trial to assess the uptake, use, and acceptability of the My QuitBuddy app in an adult population compared with a webpage presenting resources for quitting smoking. The app appeared reasonably acceptable to smokers. Although both e-resources received similar ratings for engagement, functionality, aesthetics, and information quality, we found a trend toward greater uptake of the app, which may reflect greater convenience and immediacy of a smartphone platform. While participants in both arms appeared equally well supported by their primary care physicians, we observed a clinically and statistically significant increase in motivation to quit among users of the app at 3 months, and a nonstatistically significant, but clinically very significant, halving of mean daily cigarette consumption and doubling in self-reported quit rate. These results suggest tangible benefits for smokers using the app. Although this pilot trial was underpowered to detect small differences in outcomes, the observed trends are encouraging and worth pursuing in a larger trial. Even if the absolute difference in quit rate is small, potential benefits at the population level could be enormous, considering the reach of smartphones. For example, Phase 1 of the Australian National Tobacco Media Campaign in 1997 reduced national smoking prevalence by 1.4%, resulting in health care savings of AUD 740.6 (US $572.08) million [24].

Digital Literacy and Access

Digital technology to help smokers is not a panacea and certainly not a replacement for traditional cessation services. An important caveat is that not all Australians are digitally literate or have digital access. The Australian Digital Inclusion Index (ADII) assesses digital inclusion across the dimensions of access, affordability, and digital ability [25]. Scores above 65 indicate high levels of digital inclusion, scores between 45 and 65 indicate moderate levels of digital inclusion, and scores below 45 indicate low levels of digital inclusion. The national average ADII score has improved over the past 4 years, from 52.7 in 2014 to 56.5 in 2017, mainly driven by increases in access and digital ability, with smaller improvements in affordability. However, there are clear divides across the social spectrum. In 2017, the average ADII score was 41.1 in low-income households compared with 68.1 in high-income households, 42.9 in those aged 65 years and older, and 49.5 in Indigenous Australians. Inclusion is also higher in cities (ADII score 58.6) than in rural areas (ADII score 50.7), although this gap has slightly narrowed since 2015 [25]. Importantly, these less digitally included groups also have the highest smoking rates. A survey of disadvantaged Australian smokers found similar themes; internet use was negatively associated with older age, heavier smoking, and lower income [10].

Comparison With Prior Work

Our study thus provides important new insights into a hitherto unstudied group. To date, all intervention trials of smoking cessation mobile health (mHealth) apps have targeted younger (<50 years old) populations [8]. By contrast, the mean age of our population was 62. All participants appeared confident with IT use, as they reported often using online banking and, less frequently, online shopping, and they had higher-than-average education. Although most invitees did not respond and did not provide a reason to decline enrollment, we did uncover evidence of the digital divide; of the 40 invitees who were ineligible, 13 (33%) did not own a smartphone or a computer. This figure is similar to that reported in the study by McCrabb et al [10], in which 28% of socially disadvantaged smokers did not have any internet access. We did not target Indigenous Australians in this study; besides, only (1/64, 2%) of our participants self-identified as Indigenous Australian, and we therefore cannot comment on app acceptability in this group. A pilot study that evaluated the use of a smoking cessation app in Indigenous Australians, which was limited by a small sample size, found low use of the trial app; however, participants valued social media interaction and distraction elements, such as games in apps [26]. The My QuitBuddy app contains these features, and may thus prove acceptable to smokers among Indigenous Australians. Future work with Indigenous Australians is much needed as smoking prevalence in this group is 2.8 times more than that of non-Indigenous Australians, and is responsible for roughly twice the disease burden (17%) [27].

Limitations

This pilot study examined the feasibility of running a larger statistically powered randomized controlled trial. The favorable trends toward better quit outcomes support the need for a larger trial. An important factor we observed was that only about one-quarter of invited individuals consented to be randomized. A large proportion of people did not respond to the invitation. Although perhaps one-third of nonrespondents may be affected by digital access/literacy issues, we believe a major limitation could have been our hospital telephone systems, which do not display caller ID, thus increasing the chance of the researcher's call being blocked. In the future, we would prioritize SMS text messages and email invitations over phone calls. Nevertheless, once recruited, participants seemed motivated and the 91% (58/64) retention rate is acceptable. Another limitation often discussed in smoking cessation trials is biochemical verification of smoking status self-reported by participants. We did not feel that a hospital visit specifically for biochemical verification was practical. Attempts at remote biochemical testing have been made with limited success. For example, return-of-post cotinine tests and personal exhaled carbon monoxide monitors, evaluated in pilot studies, led to disappointing (25%-50%) returns and would probably be impractical in large, pragmatic studies of mHealth apps [28,29].

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Future Work

A unique difference that mHealth apps offer, which traditional smoking cessation interventions are unable to realistically deliver, is the proximity and longevity of smoking cessation support. Apps remain on the smartphone until deletion, potentially providing daily motivational support for years. This is important because nicotine addiction is a chronic relapsing-remitting disease. Pharmacotherapy and counseling are generally used for a finite period and show a significant loss of effect over time. It is conceivable that once a smoker quits, abstinence is better maintained when using an app. A 12-month follow-up period may be able to test this hypothesis.

Future studies could evaluate the effectiveness of individual app components for smoking cessation. Participant surveys only scratch the surface of this question. Passive collection of real-time “backend” data will give insights into how and when users interact with the app, how this varies by demographics, and how this may change over time. Future trials, with suitable data protection and ethical consideration, should capture these important data to inform improvements in app design.

Conclusions

mHealth apps are an emerging technology that hold great promise for behavior change as an adjunct to standard cessation services. Apps may have a role in older smokers, but the evidence base is weak and needs urgent attention. Our pilot study suggests that apps are acceptable to a sizeable minority of older smokers, but that they may improve smoking cessation outcomes in those who engage with them. As older generations become increasingly IT literate, and if digital equality can be improved, it is possible that the acceptability of apps will increase. The encouraging findings from this pilot study remain to be tested in a larger, statistically powered trial.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT-eHEALTH checklist (V1.6.1).
[PDF File (Adobe PDF File), 527 KB - formative_v5i4e24976_app1.pdf]

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Abbreviations

ADII: Australian Digital Inclusion Index
ILST: International Lung Screen Trial
IT: information technology
uMARS: User Version of the Mobile App Rating Scale

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Original Paper

Mobile Health Intervention Promoting Physical Activity in Adults Post Cardiac Rehabilitation: Pilot Randomized Controlled Trial

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Abstract

Background: Cardiac rehabilitation (CR) is an exercise-based program prescribed after cardiac events associated with improved physical, mental, and social functioning; however, many patients return to a sedentary lifestyle leading to deteriorating functional capacity after discharge from CR. Physical activity (PA) is critical to avoid recurrence of cardiac events and mortality and maintain functional capacity. Leveraging mobile health (mHealth) strategies to increase adherence to PA is a promising approach. Based on the social cognitive theory, we sought to determine whether mHealth strategies (Movn mobile app for self-monitoring, supportive push-through messages, and wearable activity tracker) would improve PA and functional capacity over 2 months.

Objective: The objectives of this pilot randomized controlled trial were to examine preliminary effects of an mHealth intervention on group differences in PA and functional capacity and group differences in depression and self-efficacy to maintain exercise after CR.

Methods: During the final week of outpatient CR, patients were randomized 1:1 to the intervention group or usual care. The intervention group downloaded the Movn mobile app, received supportive push-through messages on motivation and educational messages related to cardiovascular disease (CVD) management 3 times per week, and wore a Charge 2 (Fitbit Inc) activity tracker to track step counts. Participants in the usual care group wore a pedometer and recorded their daily steps in a diary. Data from the 6-minute walk test (6MWT) and self-reported questionnaires were collected at baseline and 2 months.

Results: We recruited 60 patients from 2 CR sites at a community hospital in Northern California. The mean age was 68.0 (SD 9.3) years, and 23% (14/60) were female; retention rate was 85% (51/60). Our results from 51 patients who completed follow-up showed the intervention group had a statistically significant higher mean daily step count compared with the control (8860 vs 6633; P=.02). There was no difference between groups for the 6MWT, depression, or self-efficacy to maintain exercise.

Conclusions: This intervention addresses a major public health initiative to examine the potential for mobile health strategies to promote PA in patients with CVD. Our technology-based pilot mHealth intervention provides promising results on a pragmatic and contemporary approach to promote PA by increasing daily step counts after completing CR.

Trial Registration: ClinicalTrials.gov NCT03446313; https://clinicaltrials.gov/ct2/show/NCT03446313

(JMIR Form Res 2021;5(4):e20468) doi:10.2196/20468

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KEYWORDS

physical activity; cardiac rehabilitation; digital health; mobile app; wearable device; mHealth

Introduction

Background

Cardiovascular disease (CVD) is the leading cause of mortality, affecting 43.7 million older adults aged 60 years and over [1]. After a cardiac event such as myocardial infarction, coronary revascularization, or valve procedure, Class 1A national performance measures recommend that patients be referred to cardiac rehabilitation (CR) [2-4]. CR programs, which consist of supervised exercise training, behavioral activation, and psychosocial support [4,5], promote physical activity (PA) and other health behaviors that reduce secondary events and mortality [6]. Upon graduation from a typically 12-week CR program, patients are encouraged to continue these same levels of physical activity (PA) indefinitely [7]. However, numerous studies have shown that most patients fail to maintain the recommended levels of PA and instead return to a sedentary lifestyle [8].

Maintaining PA after CR is particularly important in older adults to gain and maintain the critical benefits of improved physical function (balance, gait, strength, and endurance) [9]. PA maintenance after CR is linked to reduced adverse geriatric outcomes such as falls and mobility impairment [9], thereby increasing susceptibility to adverse secondary cardiac events, functional decline, and depression [5]. Compared with other groups, older adults benefit from extended education on safety of exercising independently and motivation to maintain PA. Thus, more targeted interventions for older adults on promoting PA maintenance after CR completion are clearly needed.

As smartphone ownership increases across age groups worldwide [10], mobile technology has become more integrated with health care, and use of mobile health (mHealth) apps has become feasible for even the most novice users [11]. Health apps can be effective adjuncts for the management of chronic conditions [12] and have a positive impact on long-term behavior change [13]. Therefore, we sought to determine whether an mHealth intervention with a wearable activity tracker, mobile app, and text messages could promote PA maintenance after CR completion. The aims of the Mobile4Heart pilot randomized controlled trial (RCT) were to examine preliminary effects of an mHealth intervention on group differences in PA (step counts) and functional capacity measured by the 6-minute walk test (6MWT) and group differences in depression and self-efficacy to maintain exercise after CR. We hypothesized that the intervention group would have higher levels of PA, greater functional capacity, less depression, and higher self-efficacy compared with the control group after 2 months of using supportive technology to maintain PA.

Theoretical Framework

Behavior change in PA has been more successful with theory-based interventions [14] such as social cognitive theory (SCT) [15,16]. We applied the tenets of SCT to develop the intervention components and explain the mechanism of behavior change in PA maintenance after completing CR. SCT is one of the most commonly used behavioral change theories in PA research [17,18] and posits that human behavior is a triadic and reciprocal interaction of one’s personal (cognitive and affective), behavioral (actions and reactions), and environmental (social and physical) factors [19]. Our intervention components include the 3 major SCT constructs: (1) self-efficacy (one’s perception of their ability to perform a particular behavior); (2) self-regulation (ability to exert control over their behavior, cognitions, and environment); and (3) social support (emotional, instrumental, or informational help from a social network). SCT represents a causal model in which self-efficacy affects human behavior through other mediating processes such as mastery of self-regulation and building social support [20-23]. In the context of our intervention (Table 1), using the proposed mHealth technology is closely related to SCT constructs as it is proposed to build self-efficacy, self-regulation skills, and perceived social support, thus leading to PA maintenance.

Table 1. Social cognitive theory components.

Social cognitive theory construct	mHealth intervention	Control
Self-efficacy	Mobile app (Movn)	Paper-and-pencil diary
Self-regulation	Fitbit Charge 2	Pedometer
Social support	2 telephone calls plus tailored motivational text messages	2 telephone calls

Methods

Ethical Approval

This study was approved by the institutional review boards at the John Muir Medical Center (recruiting) and University of California San Francisco (sponsoring).

Study Sample and Participants

Between February 2018 and January 2019, 109 patients at 3 community CR centers were screened for eligibility. A total of 60 participants were included and randomized (using computer-based randomization) to the intervention group or usual care (control) group (Figure 1). Participants were included in the study if they were at least age 18 years, had a history of CVD, owned a smartphone or tablet, and were within 2 weeks of completing CR. Exclusion criteria included cognitive impairment, lack of English proficiency or literacy, or unstable clinical conditions (eg, unstable arrhythmias, uncontrolled hypertension, active infection, second or third degree heart block).

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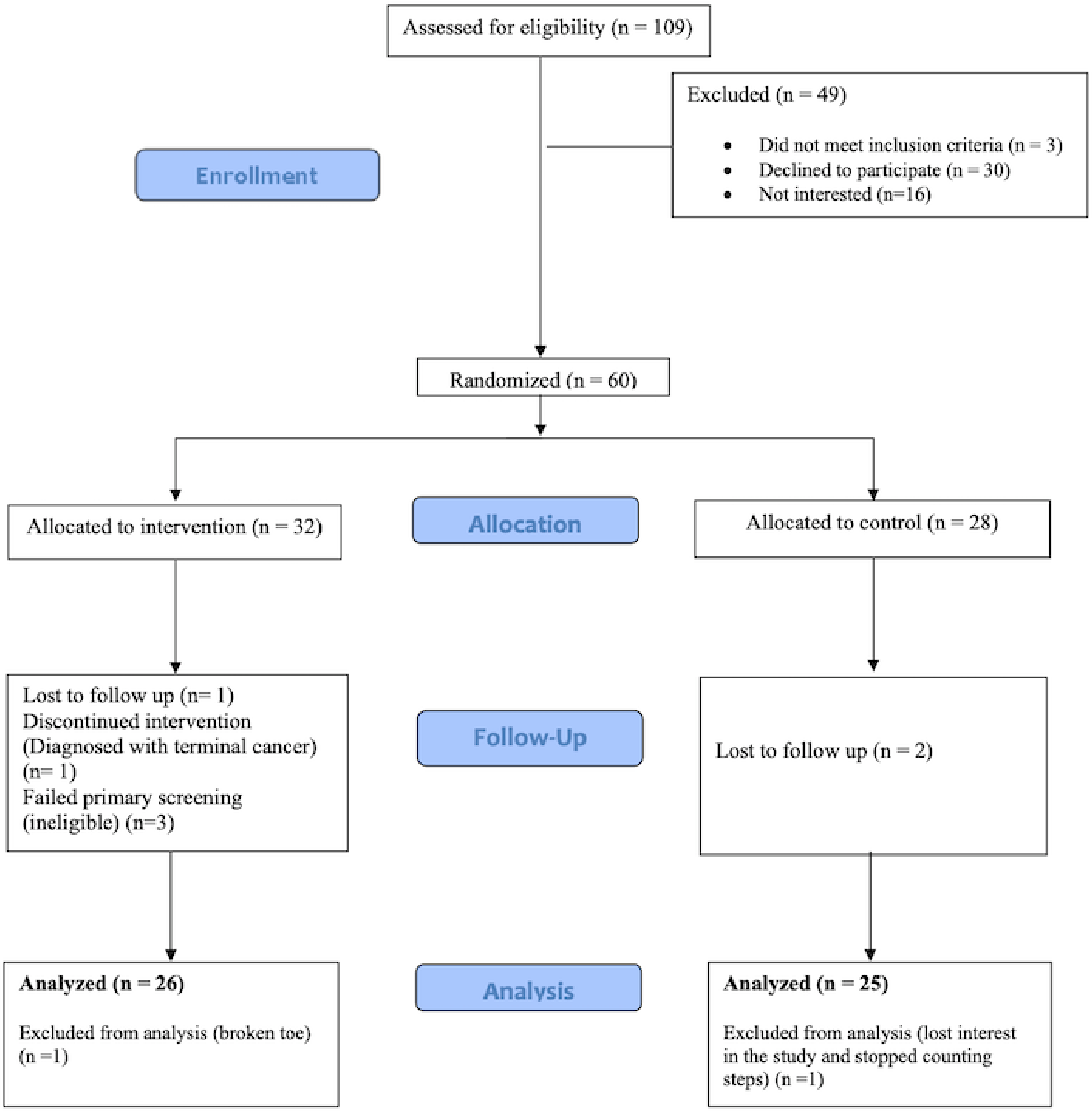
Figure 1. Consolidated Standards of Reporting Trials screening and recruitment diagram.



Study Design and Intervention

We conducted a pilot RCT with 2 arms. The intervention group received (1) a Charge 2 (Fitbit Inc) to record step counts, (2) a Movn mobile app to record exercise, and (3) push-through motivational PA prompts and educational messages related to CVD management. Messages were sent from the study team through the Movn app as a push notification 3 times per week on random days between 9 AM and 6 PM to provide positive feedback and additional motivation for PA. These 1- and 2-way messages were based on the American Heart Association Simple 7 principles [24] and prompted participants to engage in PA, keep healthy eating habits, or track their medication use.

Additionally, participants could use the Movn app to record daily weight, blood pressure, heart rate, medication use, and other exercise (eg, swimming, biking) not captured by the Fitbit device. Every time they chose to record any of these other measures, they were prompted to complete this information through a push notification from the app. Finally, mHealth participants had the ability to report any cardiovascular symptoms through the Movn app. If the participant reported shortness of breath or chest pain, a message prompted them with a button to call 911. The study team triaged participant entries once a day.

Participants in the control group were provided a basic pedometer (Walking 3D, IceFox) and paper-and-pencil diary to record daily step counts. They were asked to fasten the pedometer around their waist or to place it in their pants pocket during all waking hours.

All participants received a phone call (or text message if in the intervention group) 3 days following enrollment to answer any questions regarding the study and verify adherence to the assigned regimen. After 1 month of participation, participants received a follow-up phone call or text sent by the study staff.

Procedures

Participants in the intervention group wore the Charge 2 on their wrist during all waking hours. Fitbit devices use a 3-axis accelerometer and translate movement into digital measurements when attached to the body providing information about the frequency, duration, intensity, and patterns of movement to determine the number of steps taken, distance traveled, calories burned, and sleep quality [25]. For the purpose of this study, only the number of steps was collected.

Participants from the intervention group downloaded the Movn rehab mobile app and Fitbit app to their smartphone, the latter being used to wirelessly sync and view step counts. To protect patients' information, a generic email account and initials were generated by the study staff to register the participants on both Movn and Fitbit apps. The study team provided technical support to participants as needed.

Outcome Measures and Data Collection

Two study staff met with all enrolled participants for the baseline visit within 2 weeks of completing CR. A standardized script was used as a checklist to ensure all components of enrollment were covered. All participants provided written informed consent before participation. Cognitive assessment was conducted for each participant using the Mini-Cog test [26-28]. Participants scoring positive for cognitive impairment on the Mini-Cog test were considered a screen failure. Once eligibility was determined, participants completed paper questionnaires about sociodemographic characteristics, mobile phone use, exercise self-efficacy, quality of life, self-reported PA, and depression. Participants then completed the 6MWT. A 60-meter corridor in the CR building was designated in which to perform the 6MWT. The wall was premarked with 30 meters for the one length of the corridor and patients were asked to walk back and forth as many times as possible over 6 minutes. Two cones were placed at both ends of the long corridor. Patients were allowed to take breaks if needed while the timer kept going. Vital signs were collected just before and after the test including blood pressure, heart rate, and oxygen saturation. Upon completion of the baseline questionnaires and 6MWT, patients were informed as to which study group they were randomized.

Upon completion of the 2-month study period, participants returned for a follow-up visit. At this visit, participants completed the following questionnaires about exercise self-efficacy, quality of life, self-reported PA, and depression. All participants performed the 6MWT. For participants in the control group, they also submitted their step diary. As compensation for time spent in the study, participants in the intervention group chose between keeping their Charge 2 or receiving $100 in the form of gift cards. Participants in the control group received $100 in gift cards.

This pilot study assessed the feasibility of supporting older adults using an mHealth intervention through successes in screening, recruitment, and retention. Acceptability was measured using a satisfaction questionnaire. In addition, we conducted individual interviews with 7 participants from the intervention group to obtain additional feedback that will be reported in a future publication.

The outcome of step counts was collected from the intervention group using Fitabase [29]. Fitabase is a comprehensive data management platform, stored in a cloud format, designed to support all data collection from the Fitbit device [29]. Data were automatically collected once the Fitbit activity trackers were synced with the Fitbit app. For the control group, steps data were collected from the diaries provided to the participants during study enrollment.

To determine functional capacity, 6MWT data were collected at baseline and 2-month follow-up for all participants [30-34]. Self-report data measuring psychosocial variables and PA were collected at baseline and follow-up.

We assessed participants for change in depressive symptoms and exercise self-efficacy from baseline to 2 months. The Patient Health Questionnaire (PHQ)–9 is a self-report instrument for depressive symptoms (Cronbach α=0.88); higher scores on the PHQ-9 (range 0 to 27) correspond with greater depressive symptom severity [35,36]. The Exercise Self-Efficacy Scale (EXSE) was used to determine participant confidence in their ability to exercise in the future; higher scores (range 0% to 100%) indicate higher self-confidence to exercise (Cronbach α=0.92). We also examined these variables as covariates related to PA and functional capacity.

Statistical Analysis

Descriptive statistics and outcomes are presented as means with standard deviations for continuous variables (or medians and interquartile ranges [IQR] if skewed) and proportions (%) for categorical variables. *P* values for baseline tests were calculated from 2-sample *t* tests (or Wilcox rank-sum test if skewed) or chi-square tests.

We analyzed the primary outcome of step count difference between the two groups over 60 days fitting linear mixed-effects models with the step count for each day [37] in R version 3.6.0 (The R Foundation for Statistical Computing) [38]. For a more precise estimate of the treatment effect, we used a stepwise procedure to include potential covariates impacting the outcome (age, gender, working status, college or higher education, relationship status, depression, self-efficacy, and self-reported PA), including only terms that were significant in the model. The 2-sided significance level was established a priori at an alpha of .05. We employed an intention-to-treat analysis approach.

We tested the functional capacity outcome of the standardized change score in 6MWT from baseline and 2 months also using linear mixed models, with the same approach. The covariate association of depression and self-efficacy for step count difference and 6MWT were also considered to be secondary questions of interest.

Since our analysis included a small amount of missing data for the covariates (education missing on 8%, all other covariates <4%), our analyses used multiple imputation by chained equations, using 5 imputations [39]. Results differed very little compared with complete case analysis.

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Results

Characteristics of Study Participants

Figure 1 displays the screening and recruitment results of 60 participants according to the CONSORT (Consolidated Standards of Reporting Trials) guidelines. Table 2 outlines the characteristics of our sample that included 51 participants for the final analysis. The two groups did not differ significantly at baseline on any of the sociodemographic characteristics. Participants were aged 49 to 89 (mean 68.0) years. The majority were male (46/60, 77%) and identified as white (45/60, 75%). In addition, there were no group differences in self-reported baseline PA (high defined as exercising 150 minutes or more per week). Primary diagnoses for enrollment in CR included ischemic heart disease (eg, percutaneous coronary intervention, coronary artery bypass surgery, angina, and myocardial infarction; 49/60 [82%]), valvular heart disease (eg, aortic valve replacement, mitral valve replacement, etc, 6/60 [10%]), heart failure (3/60, 5%), and structural heart disease (eg, myxoma, aortic dissection, 2/60, 3%).

Table 2. Baseline sociodemographic data of enrolled participants (n=51).

Characteristic	Intervention (n=26)	Control (n=25)	*P* value
Age, mean (SD)	66.7 (8.6)	66.8 (8.7)	.97
Female, n (%)	6 (23)	5 (20)	.79
Hispanic or Latino, n (%)	1 (4)	2 (8)	.70
White race, n (%)	19 (73)	22 (88)	.37
Married, n (%)	23 (88)	19 (76)	.19
Employed, n (%)	10 (38)	13 (52)	.33
College graduate, n (%)	18 (69)	16 (64)	.92
Physically active, n (%)	20 (63)	16 (57)	.50
PHQ-9[a], median (IQR)[b]	1 (0, 3)	2 (0, 3)	.53
EXSE[c], median (IQR)	10 (9.9, 10)	9.9 (8.4, 10)	.07
6MWT[d] (meters), mean (SE)	430 (112)	429 (97)	.96
Causes for enrollment in cardiac rehabilitation, n (%)			
Ischemic heart diseases	19 (73)	22 (88)	.19
Heart failure	4 (15)	1 (4)	.18
Valvular heart disease	2 (8)	1 (4)	.58
Structural heart disease	1 (4)	1 (4)	.98

[a] PHQ-9: Physical Health Questionnaire for depression.

[b] IQR: Interquartile range.

[c] EXSE: Exercise Self-Efficacy Scale.

[d] 6MWT: 6-minute walk test.

Feasibility and Acceptability

We screened an average of 3 individuals per week and were successful in recruiting 60 individuals over 11 months. We enrolled 60 individuals; however, 9 withdrew or were lost to follow-up (4 from the intervention group and 5 from the control group), representing 15% (9/60) attrition. We also measured overall acceptability by administering a satisfaction questionnaire at the end of study with overall high satisfaction scores for the Movn app and Fitbit device (4.5 and 4.86 out of 5, respectively) but lower scores for the push messages (3.14 out of 5).

Physical Activity Outcome: Mean Daily Step Counts

Over the 2-month period, the intervention group showed a statistically significant higher mean daily step count compared with the control group (8860 vs 6633, respectively; or a covariate-adjusted difference of 2192 steps (95% CI 344 to 4040 steps, *P*=.02; Figure 2). This result was adjusted for age only, as the other covariates (race, working status, college education, depression, and exercise self-efficacy) were not significantly different when included in both univariate and multivariate linear models. The unadjusted difference in mean step counts was similar (difference of 2223 steps, 95% CI 138 to 4308 steps, *P*=.04). We also tested for any difference over time but found no significant change over the 2-month period (β=3.7 steps per day, 95% CI –3.1 to 10.6, *P*=.29).

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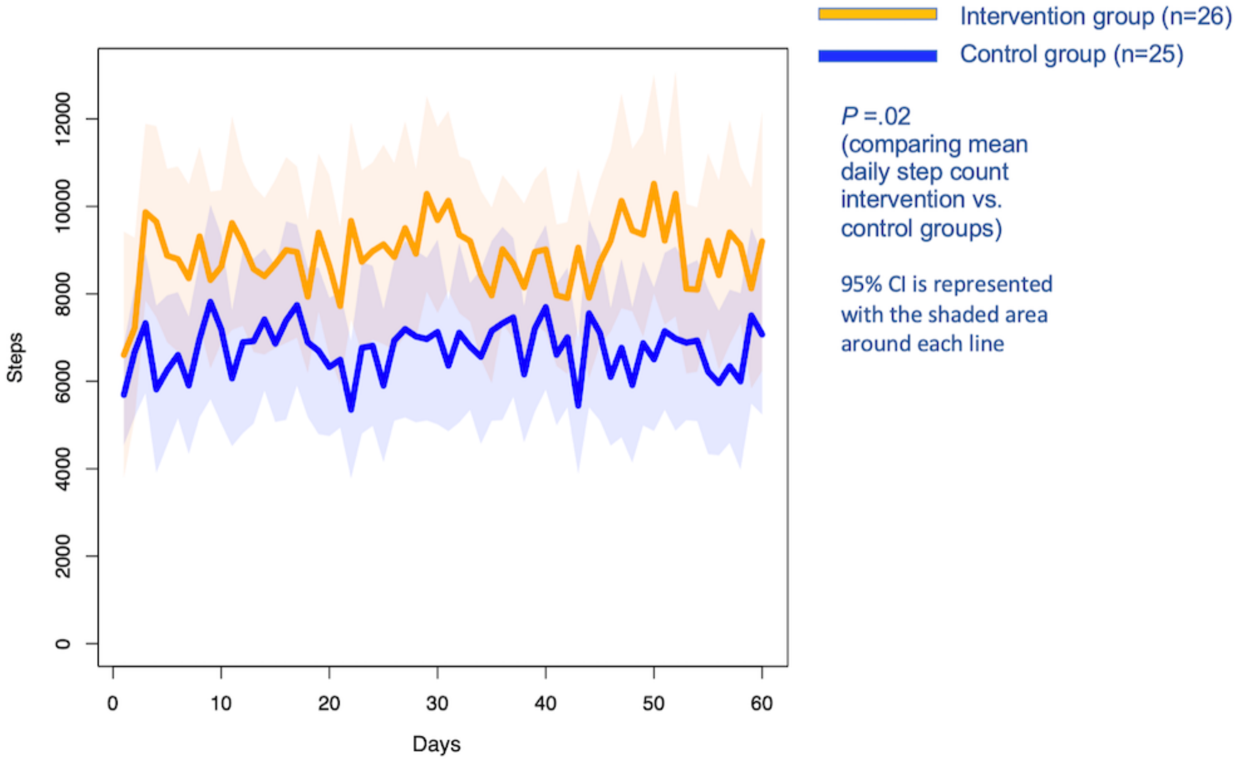
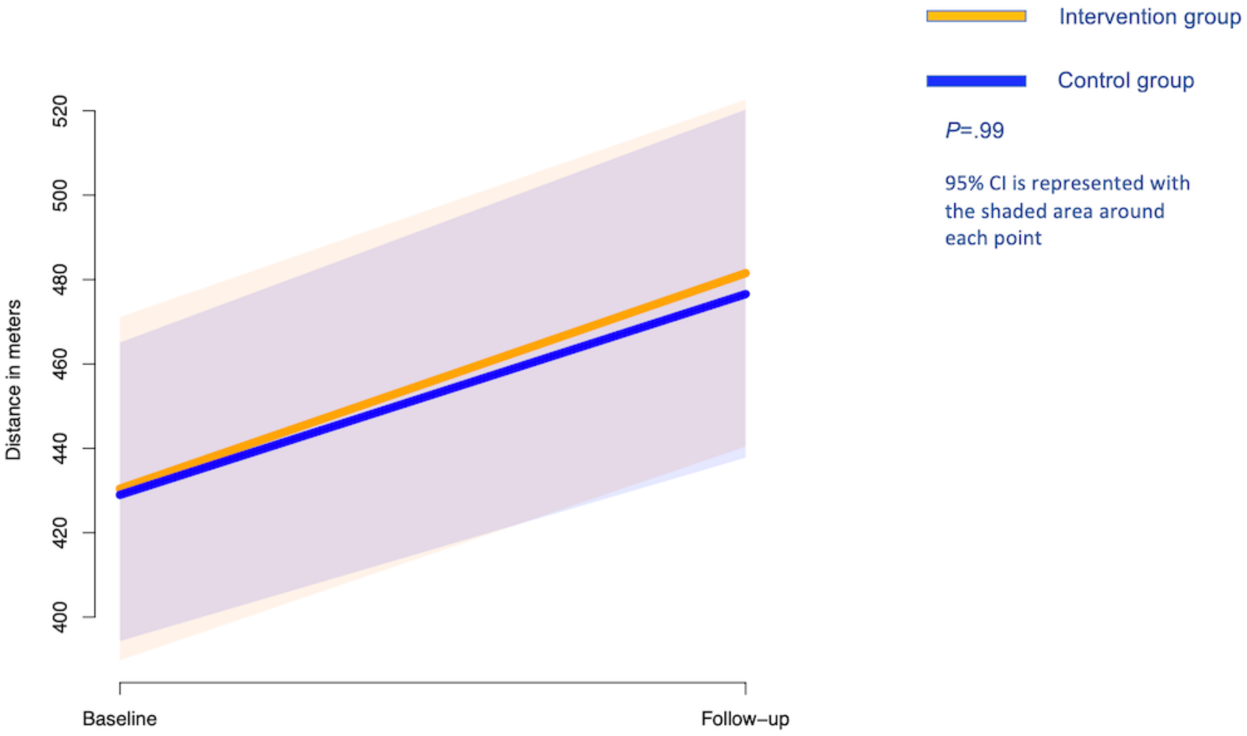
Figure 2. Mean daily step counts over 60 days.



Functional Capacity Outcome

There were no statistically significant differences between the groups at follow-up in the other outcome measures evaluated (Figure 3). After 60 days of follow-up, mean 6MWT distance increased by 61 meters in both intervention and control groups, but there was no significant difference between the two groups (0.4 meters, 95% CI 44.7 to 45.4 meters, *P*=.99). In this analysis, we adjusted for age, gender, and college or higher education in our final multivariate model. However, there was a main effect of time (an increase of 138 steps from baseline to after 60 days of follow-up (95% CI 77 to 199), or 2.3 steps per day, (95% CI 1.3 to 3.3), *P*=<.001), after adjusting for the same covariates.

Figure 3. Change in exercise capacity over 60 days.



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Depressive Symptoms and Exercise Self-Efficacy Outcomes

Total scores for depressive symptoms and exercise self-efficacy were examined from baseline to 2 months. We also examined these variables as possible covariates related to the PA and 6MWT results. There was no significant association between depressive symptoms and exercise self-efficacy with step counts or distance walked in the 6MWT for either group in univariate or multivariate analyses (Table 3).

Table 3. Association of depression (Physical Health Questionnaire for depression) and exercise self-efficacy (Exercise Self-Efficacy Scale) with step count and 6-minute walk test.

Covariate	Intervention	Control	β_{Steps}[a] (95% CI)	P_{Steps}[b]	β_{6MWT}[c,d] (95% CI)	P_{6MWT}[e]
PHQ-9[a,f], n (%)	27.0 (90.0)	24.0 (85.7)	2390 (172, 4952)	.07	116 (–60, 292)	.21
EXSE[b,g], n (%)	7.0 (25.9)	14.0 (50.0)	–1051 (–2998, 895)	.29	50 (–43, 142)	.30

[a] Score <5 meaning no depressive symptoms.

[b] Score <10 meaning lower than maximum exercise self-efficacy.

[c] 6MWT: 6-minute walk test.

[d] Adjusted for age and group assignment.

[e] Adjusted for age, group assignment, and baseline versus follow-up, gender, and education.

[f] PHQ-9: Physical Health Questionnaire for depression.

[g] EXSE: Exercise Self-Efficacy Scale.

Discussion

Principal Findings

Maintenance of exercise during the critical time period immediately after discharge from CR has been shown to predict future health behaviors and outcomes [24]. Our pilot study provides a contribution to the literature by examining the outcomes of an mHealth intervention that incorporates a mobile phone app. The intervention included a mobile phone app to deliver push-through messages and notifications plus an activity tracker to maintain PA in a vulnerable, older patient population who experienced an adverse cardiac event requiring CR. This mHealth intervention that deployed multiple technologies was deemed feasible with a high retention rate in both study groups (85%) and attested to participants' motivation to remain active and apply the knowledge they learned during CR. Participants also reported high satisfaction with the technology used in this study, including reminders to walk at least 250 steps every hour in times of inactivity.

Preliminary effects of the intervention were promising, with higher average daily step counts for the intervention group over 2 months of follow-up than those assigned to a control condition (pedometer + paper-and-pencil diary). Participants in the intervention group walked, on average, 2192 more daily steps than the control group. Our other outcomes of functional capacity, self-reported depressive symptoms, and exercise self-efficacy were not significantly different between groups. However, this study highlights the potential benefits of using a mobile app that was specifically designed for CR and a wearable device to promote PA after CR discharge among adults with CVD who had a mean age of 66.7 (SD 8.6) years in the intervention group. These promising data suggest that patients who participate in CR may benefit from the use of mobile technology after CR discharge to maintain PA, which is strongly associated with improved clinical outcomes such as less morbidity and mortality [40].

For optimal health cardiovascular outcomes, the American Heart Association and World Health Organization recommend 150 minutes of moderate-intensity aerobic PA per day for 5 days per week [41], which is about 7000 to 8000 steps per day. Studies suggest that 7500 steps per day are recommended for secondary prevention in patients with coronary artery disease to improve lipid profiles, muscle endurance, BMI, and waist circumference [42,43]. Other studies show that compared with <6000 steps per day, older adults with 8000 to 10,000 steps per day (equivalent to 20 to 30 minutes per day at an intensity >3 metabolic equivalents) have improved cardiovascular and musculoskeletal function [44]. Although this general recommendation may be a good starting point to improve PA for the target population in this study, the dose-response relationship between PA and health status may not be sufficient to reach optimal health status after a cardiac event or account for those with conditions such as heart failure or arthritis that may limit mobility. Moreover, there is no agreement between experts about the exact number of steps needed per day for tertiary prevention in older patients with CVD, and thus more research is needed for this at-risk population [45,46].

Limitations

While this study showed promising PA outcomes for adults after CR, there are important limitations to consider. First, the accuracy of most commercially available activity tracking devices is unclear although studies found high positive correlation and agreement between Fitbit devices and the Actigraph accelerometer as well as pedometers and the Actigraph device [47-50]. Accuracy of step counts from most PA devices is based on gait patterns collected from healthy volunteers [51,52]. Second, this study used different activity tracking devices for the intervention group (Fitbit wrist band) and control group (waist-level or pocket pedometer). As the primary intervention was a wearable activity tracker, providing the control group with Fitbit devices would have imposed the risk of diluting the intervention effect. Studies have shown that positioning of the tracker on the body could alter the sensitivity

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of the device and subsequently influence the number of captured steps [53,54]. Third, this pilot study included a small sample size with a 2-month duration, not allowing for conclusive results that are fully powered or long-term results on PA maintenance after CR. Fourth, the final sample was lacking in racial and gender diversity with a majority of white, male participants who tend to have higher PA than other racial groups [55,56], which limits the generalizability of this study results. Fifth, it is possible the control group showed a change in behavior by walking more steps than their baseline due to wearing a pedometer that provided a form of feedback about their PA [57,58]. Last, we proposed the chosen mHealth technology (Movn app, Charge 2, text messages) supported the building of theory-based constructs of self-efficacy and self-regulation from SCT that would promote behavior change. However, we acknowledge that the use of a pedometer may have supported self-regulation, although we hypothesized to a lesser degree due to the limited interaction with the pedometer as compared with the Fitbit device.

Comparison With Prior Work

Previous studies have reported that participants who used tracking tools to self-monitor PA reported significantly increased long-term adherence to regular exercise, which translated into better overall quality of life and reduction in risk factors [59-62]. Therefore, there have been several approaches to achieve this level of self-monitoring. To date, there have been few RCTs examining multiple technology-based interventions to sustain PA after completing CR (eg, text messages, online classes, and online social support groups) among the older adult population [63]. Many of these interventions were not tailored to participants' individual goals and needs but instead involved general messaging and feedback. Key factors associated with successful interventions include personalized messages with tailored advice, high engagement (2-way text messaging, higher frequency of messages), and use of multiple modalities [64]. Interventions that do not included tailoring could lead to loss of motivation and high attrition. PA interventions should focus on active engagement of participants through tailored physical fitness goals, tracking their performance [63,65,66], and 2-way communication about their progress.

Conclusion

Participants of CR receive little to no support during the transition from CR to community/home-based PA and need an organized support mechanism to maintain PA [39]. This pilot study showed an mHealth intervention using a wearable device and mobile phone app can increase PA with daily step counts in patients who complete CR. This intervention presented a pragmatic and contemporary approach for adults to promote PA after completing CR. This study provides support for a full-scale RCT with a longer intervention and monitoring period to assess trends in PA after CR as a result of applying mHealth technology for self-monitoring after CR. Future research will implement more tailored coaching for older adults. Our findings provide evidence for using mHealth to enhance patient self-management and demonstrate strong potential to promote PA maintenance through education, recording goals, tracking PA, and receiving tailored feedback.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT-EHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 291 KB - formative_v5i4e20468_app1.pdf]

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Abbreviations

6MWT: 6 minute walk test
CONSORT: Consolidated Standards of Reporting Trials
CR: cardiac rehabilitation
CVD: cardiovascular disease
EXSE: Exercise Self-Efficacy Scale
IQR: interquartile range
mHealth: mobile health
PA: physical activity
PHQ-9: Patient Health Questionnaire
RCT: randomized controlled trial
SCT: social cognitive theory

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Original Paper

Chatbot-Based Assessment of Employees' Mental Health: Design Process and Pilot Implementation

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Abstract

Background: Stress, burnout, and mental health problems such as depression and anxiety are common, and can significantly impact workplaces through absenteeism and reduced productivity. To address this issue, organizations must first understand the extent of the difficulties by mapping the mental health of their workforce. Online surveys are a cost-effective and scalable approach to achieve this but typically have low response rates, in part due to a lack of interactivity. Chatbots offer one potential solution, enhancing engagement through simulated natural human conversation and use of interactive features.

Objective: The aim of this study was to explore if a text-based chatbot is a feasible approach to engage and motivate employees to complete a workplace mental health assessment. This paper describes the design process and results of a pilot implementation.

Methods: A fully automated chatbot ("Viki") was developed to evaluate employee risks of suffering from depression, anxiety, stress, insomnia, burnout, and work-related stress. Viki uses a conversation style and gamification features to enhance engagement. A cross-sectional analysis was performed to gain first insights of a pilot implementation within a small to medium–sized enterprise (120 employees).

Results: The response rate was 64.2% (77/120). In total, 98 employees started the assessment, 77 of whom (79%) completed it. The majority of participants scored in the mild range for anxiety (20/40, 50%) and depression (16/28, 57%), in the moderate range for stress (10/22, 46%), and at the subthreshold level for insomnia (14/20, 70%) as defined by their questionnaire scores.

Conclusions: A chatbot-based workplace mental health assessment seems to be a highly engaging and effective way to collect anonymized mental health data among employees with response rates comparable to those of face-to-face interviews.

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KEYWORDS

chatbot; conversational agent; online; digital health; mobile phone; mental health; workplace; work stress; survey; response rate

Introduction

On average, people typically spend one-third of their lives at work. Thus, the workplace is one of the key environments that can affect quality of life, and emotional and physical well-being. Generally, work is considered to be good for mental health with involuntary joblessness being a well-recognized risk factor for mental health problems, including depression [1]. However, stressful work conditions can also contribute to the development of mental health problems [2]. Causes of common mental health problems such as depression and anxiety are complex and may include traumatic life experiences or inherited traits but can also

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be a reaction to work-related stress. The Dunedin Study found that high-demand jobs were associated with the onset of depression and anxiety in people with no prior history of diagnosis or treatment for either disorder [3]. Generally, work-related stress is considered to be a consequence of the organization and management, skills and competencies of employees, and the support they receive [2].

Besides serious consequences for an individual’s mental health and associated direct medical costs, stressful working conditions have indirect costs though reduced productivity due to absenteeism and presenteeism. A recent World Health Organization–led study estimated that depression and anxiety disorders cost the global economy US $1 trillion each year in lost productivity [4]. The implementation of cost-effective and feasible interventions could therefore have a significant impact on the individual, organization, and economy [5].

To minimize the impact of workplace risk factors, adequate policies and intervention programs should be implemented. To determine the appropriate interventions, the current mental health of employees and possible sources of work-related stress must first be assessed. There are specific measures that are commonly used to evaluate different mental health conditions and work-related risk factors, such as the Patient Health Questionnaire-9 (PHQ-9) [6]; Depression, Anxiety and Stress Scale-21 (DASS-21) [7]; and Job Satisfaction Survey (JSS) [8]. Traditionally, these questionnaires are self-administered in person or over the telephone with a health professional who facilitates completion, offering encouragement or clarification as needed. Both approaches yield similar results [9]. It is also possible to complete the scales online, using a webpage or smartphone app to display the questions and collect user responses. This method has been shown to be feasible in both clinical [10] and workplace [11] settings, albeit with relatively low response rates (34%) [11]. Symptom scores reported via a smartphone app strongly correlate with those reported through traditional paper-and-pen methods, although symptoms reported via smartphone were on average 3 points higher [12].

Engagement varies widely among digital health programs and smartphone apps [13]. According to a recent review, low engagement can occur when apps are not designed with the user in mind or do not solve the problem the user cares most about [14]. A lack of interactive or engaging features can also increase the risk of survey fatigue where users become tired and do not finish the survey [14]. Guided self-help interventions have been shown to have greater adherence than nonguided interventions [15]. This suggests that human support could improve engagement; however, this limits scalability. Chatbot-driven conversational surveys could offer an alternative by automating this encouragement and interaction. Chatbots have been shown to have significantly greater engagement and higher-quality responses than typical online surveys [16,17], and the relative anonymity offered by such an approach could be of additional value to employees.

Chatbots, or conversational computer programs, simulate human conversation. Features include word-classification processes, natural language processing, and artificial intelligence in addition to simple keyword scans and databases linking common phrases and predefined responses, which help the chatbot tailor the answers to a specific user input. Most chatbots are accessed via websites or mobile apps, or can be integrated into virtual assistants as a conversational component of a system, which can also control external devices or manage basic tasks such as emails or to-do lists. Chatbots tend to be represented by an animated character, in some cases an embodied “human” conversational agent who uses and responds to verbal and nonverbal communication such as hand gestures or body posture.

Many interactions between organizations and customers are already bot-driven, enabling companies to respond to more people at a faster and cheaper rate than if they use human customer service representatives. Besides being a cost-effective and feasible method of communication, chatbots are capable of generating a believable and dynamic dialogue. This has the potential to enhance engagement rates, using the chatbot to successfully guide and motivate users. Compared to typical online surveys, this may result in a higher level of engagement [16] and greater symptom disclosure [17]. However, to our knowledge, no system of this nature currently exists for assessing workplace mental health in Brazil.

This paper describes the chatbot design process and results of a pilot implementation in a workplace setting. The aim of this study was to explore whether a text-based chatbot is a feasible way to engage and motivate employees to complete a workplace mental health assessment so as to provide important insights for the employee and organization.

Methods

Design

This study was a pilot implementation of a chatbot-based mental health assessment performed in a real-world workplace setting, based on a cross-sectional analysis.

Sample

The sample comprised employees of an industrial plant in São Paulo, Brazil, with a total of 120 employees, who participated in the assessment between October and November 2019. These employees work at the recycling plant (n=52); in reverse logistics operations (n=40); or in the office in administration, information technology, or human resources roles (n=28).

Approval

All participants provided consent as part of the onboarding process. They agreed for their anonymized data to be used for research purposes and for the aggregated data to be shared with the organization. Data are stored securely and are password-protected.

The company’s Board of Directors approved the use of the routinely collected data for analysis and publication after having been briefed about the assessments and privacy requirements.

Research based on aggregate user data with no possibility of individual identification does not require approval of the Research Ethics Committee (CEP/CONEP) in Brazil.

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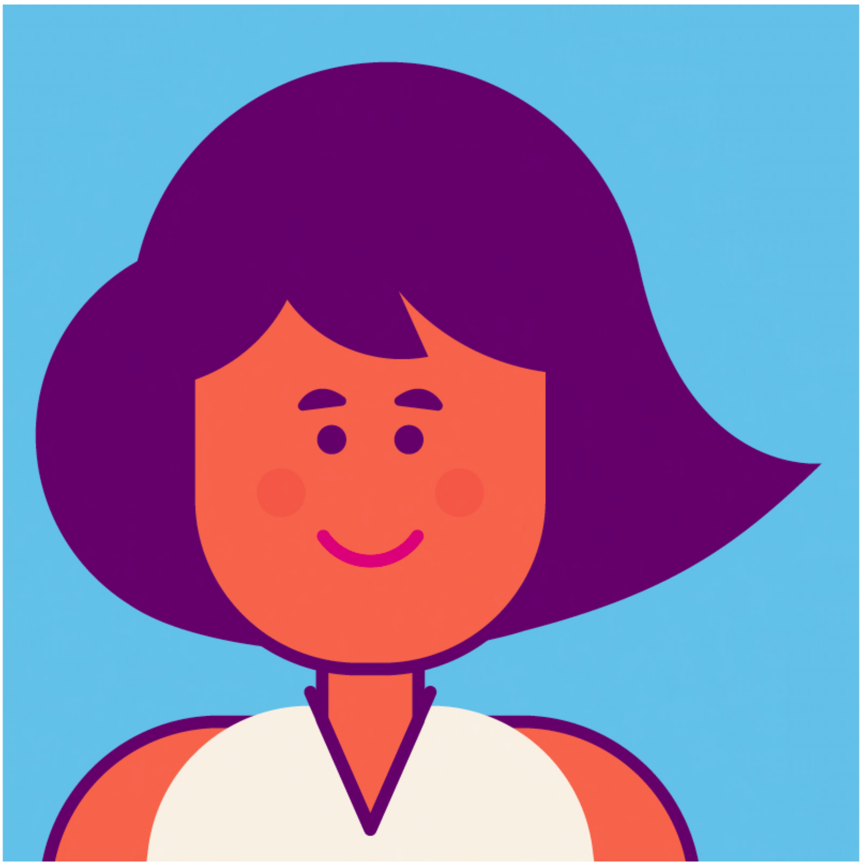
Chatbot Development and Testing

The chatbot was designed to assess employees' mental health in a cost-effective and engaging way. This requires a specific developing platform, clinically validated content, and an adequate visual presentation, as well as a clear purpose and a well-defined personality. A key component for reaching this goal is the user experience (UX), which is used to help connect the chatbot with users and build a shared experience. The first step was to analyze the needs, characteristics, and behaviors of the target user group. Based on these insights, the chatbot avatar "Viki" (Figure 1) was created, along with a specific language and conversation style. The UX team performed focus groups and telephone interviews with potential users to verify if the chatbot fits with their expectations and needs. For example, they were asked if the objective was clear, if the length of the checkup was accurate, whether they had any difficulties in completing the checkup, how they rated their experience of communicating with the chatbot, and how they would describe Viki. The data obtained from these interviews were used to refine the chatbot.

Figure 1. The chatbot avatar Viki.



The chatbot is built on ruby and javascript, and was created by the team at TNH Health. The checkup assessment is rule-based, with the next steps determined by user responses. As part of the design process, decision trees were defined, and all possible user journeys were mapped and analyzed. Decision trees enabled the chatbot to provide the right responses and information based on the user's inputs (ie, to customize the conversation). For example, if the user responds that they want to know more about depression, the chatbot delivers further information about the topic. If the user prefers to continue without knowing more about the topic, the chatbot takes them to the next topic. Building a decision tree creation tool with all of the necessary settings for interactions and data organization allowed the chatbot to be updated in an agile way without needing a new system release, which was deemed to be crucial to the development.

Given known challenges in engagement, gamification features were added to address this issue. Gamification is defined as "the use of game design elements in nongame contexts" [18], with features such as levels, challenges, points, progress, feedback, story, and reward [19]. The most important features utilized in this design were story and feedback. For the story, Viki guides users through the assessment process, presented as an expedition around an iceberg (Figure 2). The iceberg represents issues relating to mental health and is divided into different sections: stress, anxiety, depression, burnout, and work-related stress. Insomnia is additionally presented if the user scores positive to the question "I had trouble falling or staying asleep" or "sleeping too much" in the depression block.

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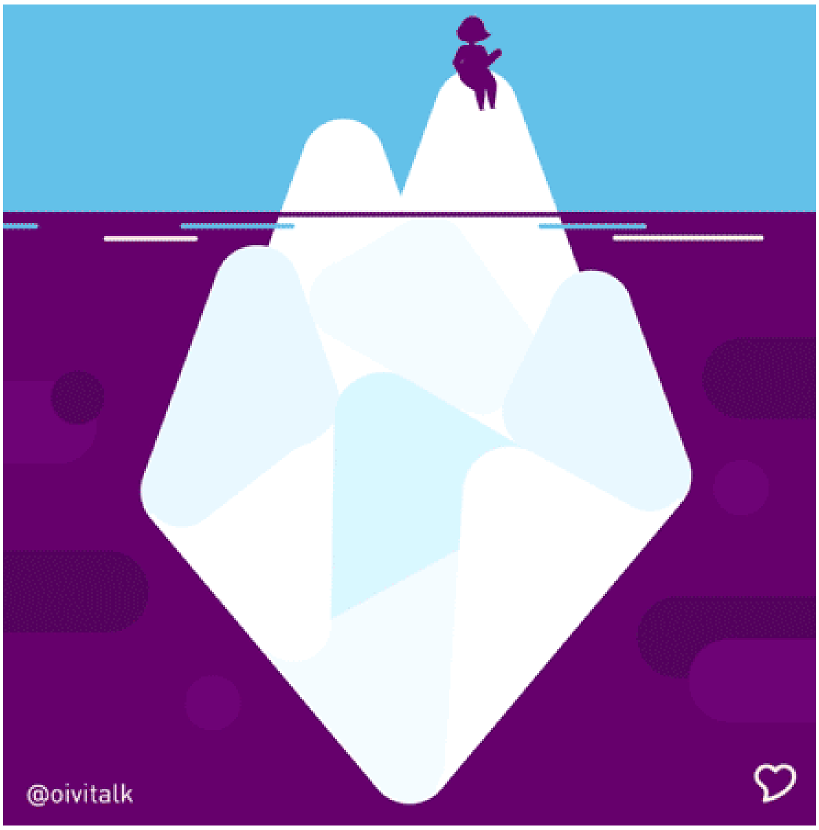
Figure 2. The iceberg story.



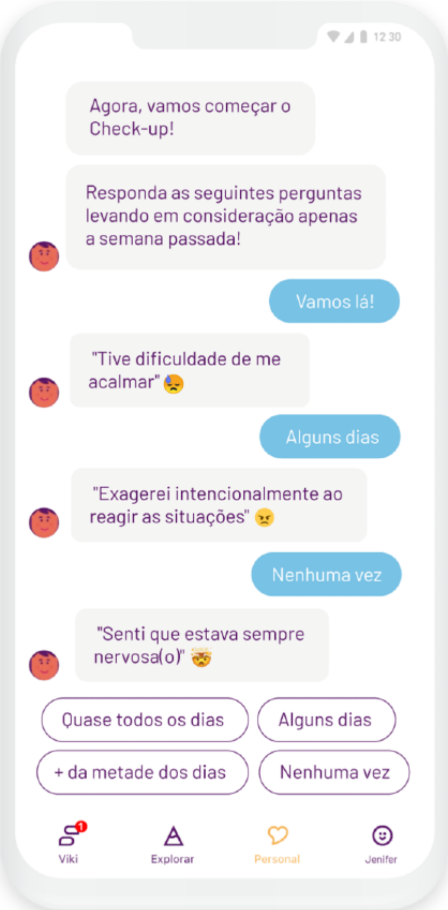
During the conversations, more and more of the iceberg, and thus the key topics, becomes visible to the user. Each section consists of an introduction to the topic and a standardized questionnaire. The questionnaires are delivered in a conversation format, with Viki asking a question and the user selecting their answers from predefined responses using the standard options for each questionnaire (Figure 3). The next question is only presented once the user selects their answer. This is displayed on a rolling screen with approximately three responses visible at a time. The user can go back and change their answer if they want, but there is no functionality included to skip a question. During the checkup, besides the questions for the different scales, Viki also offers messages of encouragement. These messages are designed to keep the participant motivated and engaged, matching the methods real human interviewers use. An example of such a message is “We are almost done, you are doing very well!” All communication is text-based, written in Brazilian Portuguese.

The entire assessment takes approximately 15 minutes. Responses are captured automatically and stored within a secure database. The user issue of nonresponse was discussed in the design process and the team agreed that a limit of 24 hours should be set. The user can pause at any time during the assessment, but if they do not complete the assessment within 24 hours the system will reset and data are overwritten. This ensures that all questionnaire data are collected within a specific time period.

Immediately after completing the assessment, participants receive personalized feedback and recommendations. Participants are reminded that the results do not offer a diagnosis, but may indicate the presence of an emotional problem. In the case of a serious risk identified (ie, very high risk for anxiety or depression or suicide risk detected during the assessment, or via key words typed by users), the conversation follows a safety protocol that includes referral to the care network or, if necessary, to emergency services.

Aggregated and anonymized data are presented on a dashboard and in an organization report to the company’s management. This allows oversight of the assessment process in real time (eg, response rate, distributions of mental health outcome categories of already assessed employees), and offers valuable insights to the organization, identifying issues and recommending actions such as further campaign actions in case of a general low engagement of the employees and planning of target-oriented interventions for specific departments or positions based on the mental health outcome distributions.

Figure 3. Screenshot of the mental health checkup.



Agora, vamos começar o Check-up!

Responda as seguintes perguntas levando em consideração apenas a semana passada!

Vamos lá!

"Tive dificuldade de me acalmar" 😞

Alguns dias

"Exagerei intencionalmente ao reagir as situações" 😠

Nenhuma vez

"Senti que estava sempre nervosa(o)" 🤯

Quase todos os dias

Alguns dias

+ da metade dos dias

Nenhuma vez

Participants are informed within the terms of use, which they are asked to agree to at the beginning of the checkup, about the anonymized sharing of their data with the company. To preserve anonymity, no name or other personal identification data are included on the dashboard or in the report, and departments or sections with less than 8 people were pooled into larger groups.

The usability and technical functionality of the chatbot and dashboards were tested prior to launching with users (with internal staff and organization employees). The only issue raised during this testing was how the chatbot would react to any unexpected free text entered by the employee during the assessment. Therefore, the settings and natural language understanding were adjusted to enable smooth running of the chatbot while adhering to risk protocols.

Mental Health Outcomes

The checkup includes the following questionnaires to cover the topics of anxiety, depression, stress, burnout, and work-related stress. Insomnia was added for users who did not answer the question about difficulties with sleeping with “Not at all” in the previously applied PHQ-9. All questionnaires were translated and validated in Brazilian Portuguese, with good psychometric properties [20-25]. No changes were made to question order or wording. The Generalized Anxiety Disorder-7 scale is a 7-item self-report scale used to assess anxiety symptoms over the past 2 weeks (eg, “How often have you been bothered by feeling afraid something awful might happen?”). Responses range from 0 (not at all) to 3 (nearly every day). Total scores are divided into four categories: none (0-4), mild (5-9), moderate (10-14), and severe (15+) symptoms [26]. The PHQ-9 is a 9-item self-report scale that evaluates symptoms of depression over the past 2 weeks (eg, “How often have you been bothered by feeling down, depressed, or hopeless?”). Responses range from 0 (not at all) to 3 (nearly every day). Total scores are divided into five categories: none (0-4), mild (5-9), moderate (10-14), moderately severe (15-19), and severe (20+) symptoms [6].

The DASS-21 is a 21-item self-report questionnaire consisting of three scales to measure depression, anxiety, and stress [27]. The stress subscale consists of 7 items and the user is asked how much each statement applied to them in the past week (eg, “I found it difficult to relax”). Responses range from 0 (did not apply) to 3 (applied very much or most of the time). Total scores are doubled and divided into five categories: normal (0-14), mild (15-18), moderate (19-25), severe (26-33), and extremely severe (34+) levels of stress [7].

The Insomnia Severity Index (ISI) is a 7-item self-report questionnaire assessing the nature, severity, and impact of insomnia. Responses range from 0 (no problem) to 4 (very severe problem). Total scores are categorized as: absence (0-7), subthreshold (8-14), moderate (15-21), and severe (22-28) insomnia [28].

The Oldenburg Burnout Inventory is a 16-item self-report scale with two dimensions: exhaustion and disengagement from work

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(eg, “There are days when I feel tired before I arrive at work”). Answers range from 1 (strongly agree) to 4 (strongly disagree) [29]. For analysis, the following categories were used: very low (0-15), low (16-30), high (31-45), and very high (46+) risk of burnout.

The JSS questionnaire is based on a two-dimensional theoretical model created by Robert Karasek that relates two aspects at work, demands and control, to the risk of illness. A third dimension, support, was later added by Theorell [8] as a protective factor to guard against work-related stress. A 15-item short form of the questionnaire was used to assess work-related risk and protective factors in this pilot (eg, “Does your work demand too much effort? Do you have a choice in deciding how you do your work?”). Scores range from 1 (almost never/totally agree) to 4 (frequently/totally disagree). Categories used for analysis were normal (0-15), slightly increased (16-30), increased (31-45), and extremely increased (46+).

Recruitment and Implementation

As the first stage of implementation, the mental health assessment was presented to the managers of each department of the company. Subsequently, an internal multichannel information campaign was used to present the assessment to employees and educate them about the importance of mental health. Viki was introduced as part of this campaign, using a variety of online and offline channels (email, intranet, banners, and leaflets). This psychoeducative action aimed to reduce stigma and motivate employees to consider looking at their own mental health, as well as to generate trust in the product.

All employees were then emailed a weblink with an invitation to complete the checkup to obtain feedback on their scores. No financial incentive was offered, and employees were informed that the checkup was anonymous and voluntary. They were told that it would take up to 15 minutes, and no stipulations were made regarding whether to complete the checkup at work or at home. It could be completed via cell phone or computer.

When employees click the link, they first pass through an authentication process where they register and enter their company code (which helped to identify the participants of this specific company survey within the whole user population) and agree to the terms and conditions. Viki then begins the checkup.

Statistical Analysis

Descriptive statistics are used to summarize sample characteristics, baseline symptoms, and completion rates. Only complete datasets were included in this analysis, and duplicates were not possible due to the registration process used. The Checklist for Reporting Results of Internet E-surveys was used for data reporting [30].

Results

Sample and Engagement

Of the 120 eligible employees, 98 employees started the assessment (81.7% initiation rate) and 77 completed it (79% completion rate). This response rate enabled data to be obtained for 64.2% (77/120) of the organization’s workforce. Data collection was performed within 4 weeks. More than half of those responding did so within the first week of the campaign.

Of the 77 employees completing the checkup, the majority were men (45/77, 58%), white (40/77, 52%), and aged between 25 and 44 years (55/77, 71%), reflecting the demographics of the organization’s workforce. The majority of respondents were in occupations of plant and machine operators and assemblers (n=21, 27%) or technicians and associate professionals (n=19, 25%).

Implementation

During implementation, we noticed differences in the speed of rollout, and considered if the motivation and conviction at a management level could be a factor in engagement. As a preventative measure to maximize engagement, we contacted department managers to emphasize the benefits of the checkup and to troubleshoot any potential issues. No issues were identified, but some managers reported they would ensure that they pass on this information to their teams. The informal feedback received from the lead of the project was that the campaign had been well received and they felt that the chatbot added value. This evidence is of course more anecdotal as it did not form part of the data analysis.

Mental Health Risks

Overall, the sample scored in the low ranges on the majority of the questionnaires (see Table 1). Scores were higher in the area of work-related stress, with equal control and demand reported alongside lower support. On the PHQ-9, 44% (34/77) of users reported difficulties with sleep and therefore also completed the ISI for insomnia.

For those with symptoms, the majority of respondents scored in the mild range for anxiety (20/40, 50%), mild range for depression (16/28, 57%), subthreshold level for insomnia (14/20, 70%), and moderate level for stress (10/22, 46%) as defined by the questionnaire scores. For burnout, most of the respondents scored in the low-risk category (50/74, 68%), whereas the majority scored in the increased-risk category for job-related stress (53/77, 69%).

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Table 1. Scores and outcomes for each questionnaire measure.

Measure	Respondents (n)	Mean (SD)	Assessment category
Anxiety (GAD-7[a])	77	6.21 (4.56)	Low
Depression (PHQ-9[b])	77	4.40 (5.21)	None
Stress (DASS-21[c])	77	11.09 (7.13)	Normal
Insomnia (ISI[d])[e]	34	9.26 (5.66)	Subthreshold
Burnout (OLBI[f])	77	27.68 (8.38)	Low
Occupational stress (JSS[g])	77	32.38 (3.55)	Increased
Control	77	12.32 (1.99)	Increased
Demand	77	12.19 (1.72)	Increased
Support	77	7.86 (2.40)	Increased

[a] GAD-7: Generalized Anxiety Disorder-7.

[b] PHQ-9: Patient Health Questionnaire-9.

[c] DASS-21: Depression, Anxiety and Stress Scale-21.

[d] ISI: Insomnia Severity Index.

[e] Completed only if sleep was identified as an issue.

[f] OLBI: Oldenburg Burnout Inventory.

[g] JSS: Job Stress Scale.

Discussion

Principal Findings

The chatbot-based assessment was successfully implemented in the workplace, suggesting that a chatbot could be a feasible way to engage employees in completing a workplace mental health assessment. There was a 79% (77/98) completion rate, obtaining questionnaire responses from 64.2% (77/120) of the workforce. This compares favorably to face-to-face data collection methods. For example, the São Paulo Megacity study reported a response rate of 81% [31] and epidemiological studies reported a response rate of 70% using the same method of data collection [32]. The completion rate in this analysis is 25% higher than that of results found in a telecommunication company using a web-based screening for depression [11], and is also clearly higher than that of other online surveys where rates below 10% are common [33]. A previous study reported a similar completion rate (78%) using a smartphone app to administer up to three survey sessions per day in a sample of psychiatric outpatients. However, this involved a smaller sample and the participants were financially compensated, which may influence motivation [12]. It would be interesting to further explore the impact of the different components of implementation to ascertain the factors that are most integral for success, such as the chatbot or the onboarding process. An online tool and distribution method could be particularly pertinent in an era of remote working.

The majority of users obtained low scores on all of the questionnaires. However, many users did report symptoms at a moderate or severe level. The proportions scoring at this level for depression (20/77, 26%) and anxiety (12/77, 16%) are higher than the estimated prevalence rates of anxiety disorders (9.3%) and depressive disorders (5.8%) found in the general population of Brazil [34], although these rates do vary considerably depending on the method of data collection and the measure used [35]. Prevalence rates are typically higher in women than in men [35], which is interesting given that this sample predominately comprised men. The risk of burnout identified is similar to levels found in other professional groups such as health workers [36] and teachers [37]. High demand was often reported in combination with a low degree of perceived control, which are both risk factors for burnout. This combination is considered to be the most critical in terms of a negative impact on individual mental health. The presence of anxiety, depression, and insomnia could also impact organizational productivity through absenteeism and presenteeism [2,11], which requires further exploration.

The fact that some people reported symptoms shows the importance of addressing mental health issues within the workplace. It would be interesting to determine whether these people have ever sought professional help or support for these difficulties. Insights gained from the assessment could be used to identify individual- and organizational-level strategies that could be implemented to improve mental health, and potentially productivity, within the workplace.

Limitations

The questionnaire measures have not yet been validated for use in a chatbot format with gamification. As this pilot showed that implementation is feasible, the next step is to complete a validation study to assess the effect of using this method on the psychometric properties of the questionnaires. Establishing validity is required before conclusions can reliably be drawn regarding the mental health of the workplace.

Although the chatbot could successfully obtain data for 64% of the workforce, there are no data for those who did not participate or for those who dropped out during the assessment. It would

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be interesting to compare sociodemographic characteristics and baseline symptoms between the groups. For example, previous research indicates that being male, with a lower educational level, and comorbidity of depression with anxiety can increase the risk of dropout and nonengagement [38]. Such insights could be used to adapt the chatbot or onboarding process to make it more appealing to the less-engaged group. Taking age and gender into account has been found to enhance use of digital mental health programs [39].

As this was a cross-sectional data analysis, we do not know if the high response rate will be sustained over time. There is the possibility that the response rate was inflated due to the novelty of the approach, which has been suggested to be a general characteristic of mobile health interventions [40]. Longitudinal research could explore this issue, which could assist in the development of UX with chatbots over time. Additionally, as the system used for output generation (responses to the user's input) is fixed (based on predefined decision trees), the conversation opportunities are currently limited. A larger amount of conversational data gained over time will be necessary to train the chatbot and make it intelligent in a more autonomous way. This would also allow for free text interpretation, for example.

Without controls, it is unclear if the results are due to the specific sample, their workplace, or the method of data collection, which may facilitate higher levels of disclosure [11]. After validating the questionnaires for use in this format, it would be important to repeat this exercise with different workplaces to ascertain if the results are generalizable to other populations, particularly considering issues of gender, age, work type, and level of education. It would be important to replicate the implementation in a workplace with more gender balance and a larger sample size. A usability questionnaire would further strengthen the validity of the results.

Further research is planned, which will include comparison with traditional paper-and-pen methods and web-based forms. These studies will also include repeat measurement following the implementation of remedial measures to ascertain their impact. We would also like to explore, using implementation science, the factors and processes involved in successful implementation of the chatbot within the workplace since there are many variables involved.

Conclusions

The creation of healthy workplaces and adequate mental health policies must be based on a comprehensive needs assessment. Face-to-face assessments are not anonymous or scalable, and online surveys are often limited by low response rates. A chatbot offers a fully automated digital solution, incorporating gamification features to engage and motivate employees to complete a workplace mental health assessment. The chatbot was found to have response rates comparable to those of face-to-face interviews, suggesting that this could be a feasible way to collect such data. To further verify this new solution, a validation study comparing it with other formats such as face-to-face interviews or online surveys, as well as including a feasibility and satisfaction analysis, would be the next logical step.

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Authors' Contributions

IH made substantial contributions to the conception and design of the work, and completed analysis of the results. All authors contributed to the writing, review, and approval of this manuscript for publication.

Conflicts of Interest

IH, KD, and MK work for TNH Health, the company that developed the chatbot and provided funding for this publication. KC and HC declare no conflicts of interest.

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Abbreviations

DASS-21: Depression, Anxiety and Stress Scale-21
ISI: Insomnia Severity Index
JSS: Job Stress Scale
PHQ-9: Patient Health Questionnaire-9
UX: user experience

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Original Paper

A Mental Health–Informed Physical Activity Intervention for First Responders and Their Partners Delivered Using Facebook: Mixed Methods Pilot Study

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Abstract

Background: First responders (eg, police, firefighters, and paramedics) are at high risk of experiencing poor mental health. Physical activity interventions can help reduce symptoms and improve mental health in this group. More research is needed to evaluate accessible, low-cost methods of delivering programs. Social media may be a potential platform for delivering group-based physical activity interventions.

Objective: This study aims to examine the feasibility and acceptability of delivering a mental health–informed physical activity program for first responders and their self-nominated support partners. This study also aims to assess the feasibility of applying a novel multiple time series design and to explore the impact of the intervention on mental health symptoms, sleep quality, quality of life, and physical activity levels.

Methods: We co-designed a 10-week web-based physical activity program delivered via a private Facebook group. We provided education and motivation around different topics weekly (eg, goal setting, overcoming barriers to exercise, and reducing sedentary behavior) and provided participants with a Fitbit. A multiple time series design was applied to assess psychological distress levels, with participants acting as their own control before the intervention.

Results: In total, 24 participants (12 first responders and 12 nominated support partners) were recruited, and 21 (88%) completed the postassessment questionnaires. High acceptability was observed in the qualitative interviews. Exploratory analyses revealed significant reductions in psychological distress during the intervention. Preintervention and postintervention analysis showed significant improvements in quality of life (P=.001; Cohen d=0.60); total depression, anxiety, and stress scores (P=.047; Cohen d=0.35); and minutes of walking (P=.04; Cohen d=0.55). Changes in perceived social support from family (P=.07; Cohen d=0.37), friends (P=.10; Cohen d=0.38), and sleep quality (P=.28; Cohen d=0.19) were not significant.

Conclusions: The results provide preliminary support for the use of social media and a multiple time series design to deliver mental health–informed physical activity interventions for first responders and their support partners. Therefore, an adequately powered trial is required.

Trial Registration: Australian New Zealand Clinical Trials Registry (ACTRN): 12618001267246; https://anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12618001267246.

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KEYWORDS

physical activity; PTSD; social media; first responders; mental health; families; online; exercise

Introduction

Background

First responders, including police, firefighters, and paramedics, are regularly exposed to traumatic events. This repeated exposure puts them at an increased risk of experiencing psychological distress and poor mental health [1]. Overall, 1 in 3 first responders report having high or very high levels of psychological distress [2], whereas 1 in 10 first responders experience posttraumatic stress disorder (PTSD) [3]. Consequently, first responders are more than twice as likely to report having suicidal thoughts and are 3 times more likely to have a suicide plan than the general population [2].

First responders are also at an increased risk of poor physical health because of a number of occupational risk factors. Regular exposure to high-pressure situations, shift work, and physical inactivity contribute to high rates of cardiovascular disease and its risk factors, including hypertension and obesity [4]. Notwithstanding the physical demands of the role, obesity and hypertension remain significant problems among first responders [5-7]. The risk of physical health comorbidities is compounded in those with poor mental health [8,9]. For example, PTSD is a risk factor for obesity, diabetes, and metabolic syndrome [10-14]. Urgent efforts are needed to prevent and treat physical and mental health issues in this underserved population.

There is strong evidence showing that exercise and physical activity can help prevent and treat common mental disorders experienced by first responders (eg, depression, anxiety, and PTSD) while simultaneously improving physical health outcomes [15]. Physical activity has been shown to improve mood, reduce symptoms of depression and anxiety, improve sleep quality, and reduce alcohol dependence [15-18]. Improvements in mental health symptoms have also been seen in people with PTSD when delivered in addition to usual care [19].

Physical activity also has great potential as a preventative strategy. A review of existing studies suggests that regular physical activity is associated with a reduction in 17% of incident cases of depression [16]. This should be considered among populations at an increased risk of psychological injuries, such as first responders. Given that poor mental health is a risk factor for physical inactivity [20] and that physical activity levels decrease more steeply over time with increasing PTSD symptoms [21], early intervention and prevention strategies are critical for protecting long-term physical and mental health [8,9].

Despite the well-documented mental health and cardioprotective benefits of increased physical activity, there is limited research exploring ways to engage at-risk populations such as first responders in preventative or treatment-based exercise programs. Social media provides a unique opportunity to overcome barriers related to accessing care experienced by first responders, including issues related to stigma toward mental illness [22] and geographical barriers. Importantly, web-based platforms offer a cost-effective [23] and scalable opportunity to deliver mental health–informed physical activity interventions to the first responders living in regional and remote settings. Social media also promotes social connectedness, which is fundamental to exercise adherence and long-term behavioral change [24]. Facebook groups have previously been used effectively to deliver behavior change interventions in both the general population and in people with serious mental illness [25,26]. To our knowledge, no previous studies have tested Facebook as a means of increasing physical activity levels in first responders.

In developing programs to improve the physical and mental health of first responders, it is also important to consider the people who support them, including spouses, family members, and friends. Informal caregivers (eg, spouses and family members) are more likely to have depression, sleep problems, stress, and physical health conditions [27,28]. Carers, therefore, need access to support and programs to improve their mental health and well-being. Given the strong impact of social connections on health outcomes [29], particularly among dyads, the inclusion of nominated support partners is likely to be mutually beneficial.

Objectives

This study aims to assess the feasibility, acceptability, and preliminary effectiveness of using a private Facebook group to deliver a physical activity intervention for first responders and their selected support partners. This study also aims to assess the feasibility of applying a novel interrupted time series design to determine whether this methodology would be a feasible substitute for a control group in an adequately powered trial. Exploratory analysis aimed to identify associated changes in mental health symptoms, sleep quality, quality of life, physical activity, and social support. We hypothesized that the program would be feasible, and participants would increase their physical activity with subsequent positive effects on mental health outcomes.

Methods

Design

An interrupted time series design was pilot tested. This methodology was used to detect whether the intervention had a significantly greater effect than the underlying secular trend [30,31]. Consecutive observations of the Kessler-10 (K10) every 2 weeks for a baseline period of 5 weeks were interrupted by the intervention to determine whether the series' slope or level changed following the intervention. Participants, therefore, acted as their own control. This methodology was tested to inform the practicality of applying it to an adequately powered trial and replacing the need for a randomized controlled trial

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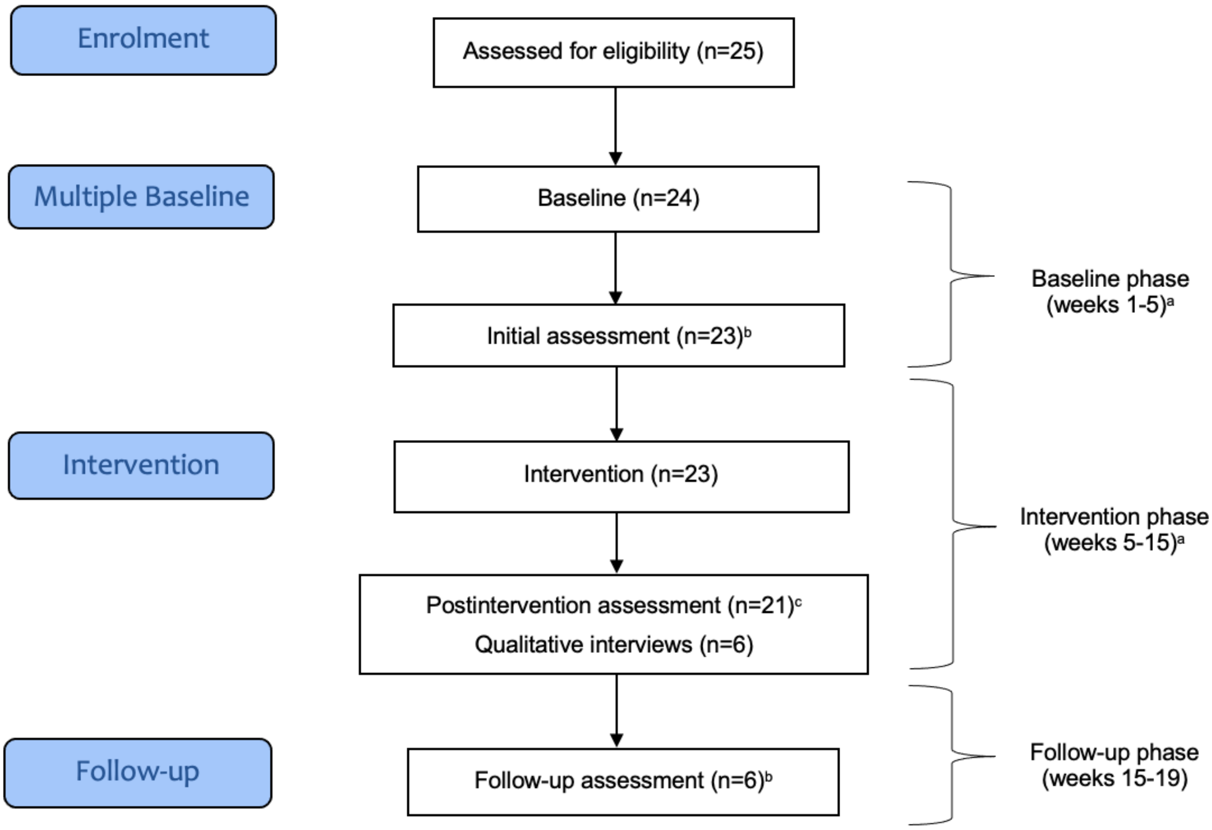
(RCT). A flow chart of the study design and assessment time points is shown in Figure 1.

This study was approved by the University of New South Wales Human Research Ethics Committee (HC180561) and prospectively registered (ACTRN12618001267246). All participants provided informed consent.

Figure 1. Flow of participants through the trial. [a]Kessler-10 (assessed every 2 weeks); [b]Depression Anxiety and Stress Scale-21, Pittsburgh Sleep Quality Index, Assessment of Quality of Life-6D, Simple Physical Activity Questionnaire, Posttraumatic Stress Disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders, fifth edition (first responders only), and social support and exercise survey; [c]Depression Anxiety and Stress Scale-21, Pittsburgh Sleep Quality Index, Assessment of Quality of Life-6D, Simple Physical Activity Questionnaire, Posttraumatic Stress Disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders, fifth edition (first responders only), social support and exercise survey, and feasibility questionnaire.



Participants

Participants were recruited between August and September 2018 through *Behind the Seen*, a not-for-profit community initiative that aims to increase awareness and reduce stigma toward mental health issues faced by first responders and their families. The *Behind the Seen* facilitators posted the study advertisement on their Facebook page, which has a following of 25,000 people. Convenience sampling was used to recruit participants who met the following criteria: former or current first responders, aged between 18 years and 65 years, and who were currently physically inactive, which is defined as engaging in less than 150 minutes of moderate-to-vigorous physical activity (MVPA) per week [32] and was assessed using a physical activity vital sign questionnaire [33]. Participants also needed to be able to communicate in English and have internet access. Participants were eligible to participate if they answered *no* to all the questions in the Exercise Sports Science Australia Prescreening Tool [34].

First responders nominated support partners to participate in the program. This was defined as any person with close personal relationships with them, for example, partners, family members, caregivers, or friends. The support partner was required to be aged between 18 years and 65 years and be medically cleared to exercise. First responders or support partners who scored >30 in the K10 (indicative of very high levels of psychological distress) and who were not receiving treatment or whose medications had changed in the past 4 weeks were excluded and referred to a local health professional.

Intervention

Participants were enrolled in a 10-week physical activity program delivered via a private Facebook group, which was set up for the purpose of the study. All participants commenced the program at the same time, which ran from October 2018 to January 2019. The facilitators of the group were exercise physiologists who provided education and facilitated discussions on different predetermined topics weekly, including goal setting, overcoming barriers, reducing sedentary behavior, and

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improving diet. A full description of the topics and example posts is provided in Table 1. All aspects of the program were codeveloped with the facilitators of the community organization (Behind the Seen), who have lived experience of both working as a first responder and living with PTSD. The facilitators posted 2-4 times per week and encouraged participants to post photos, ask questions, and share their journey on the Facebook group. The facilitators monitored the group daily from Monday to Friday and provided encouragement in the form of likes and comments in response to participants' posts. The content and features of the program were co-designed with lived experience personnel and were based on behavior change techniques, including shaping knowledge, self-monitoring, and social support [35]. Content was posted weekly in the form of information, exercise demonstration videos, links to existing web-based resources, step count competitions, and discussion questions. Each participant was given a physical activity tracking device (Fitbit Flex 2) to monitor their activity levels. Participants were instructed on the different Fitbit functions, for example, how to track the intensity of their exercise and set goals using the phone app. Facilitators also set up group challenges using the Fitbit phone app, for example, the highest step count between first responders and support partners.

Table 1. Facebook group facilitator content.

Week	Topic	Content
1	Welcome	• Participants were asked to introduce themselves (eg, occupation) and mention why they joined the group • Instructions were provided on Fitbit activity trackers
2	Goal setting	• How to write a SMART[a] goal. For example, participants were encouraged to increase their step count from the last week by 5%-10% • Participants were asked to write goals (short term, long term, and one with the support person) and post them on the Facebook group • Benefits of self-monitoring and ways to do it (eg, Fitbit and training diaries)
3	Benefits of physical activity	• Link between physical and mental health explained • Physical and mental health benefits (eg, improved mood, sleep, and decreased anxiety and stress) • Video links and factsheets provided
4	Barriers	• Participants were asked to vote on their biggest barriers to getting active (eg, lack of time, low motivation, and low mood) • Discuss strategies to overcome barriers and ask participants to share their suggestions and ideas
5	Support	• Information provided on how to be a helpful support person (practical support, effective communication, and exercising together) • Information provided on social support for increasing motivation
6	Sedentary behavior	• Risks associated with sedentary behavior (eg, increased mortality risk) • How to increase incidental activity, including ways to incorporate physical activity into everyday life • Minimize time spent sitting and encourage breaking up long periods of sitting
7	Aerobic exercise	• Australian guidelines (150 min of moderate-to-vigorous physical activity) • Finding an exercise you enjoy
8	Resistance exercise	• Australian guidelines (strength training at least two times per week) • Exercise safety (eg, the importance of a warm-up) • Videos of simple workouts (eg, squats and push-ups against a wall) • The importance of progression and ways to do it (eg, using the FITT[b] principle)
9	Healthy eating	• The healthy eating pyramid • Creating a healthy food environment (eg, shopping and cooking together and eating meals without distractions)
10	Review	• How to maintain an exercise program • Community programs discussed (eg, gyms and community runs) • Review of goals • Celebration of progress

[a] SMART: specific, measurable, achievable, realistic, and timely.

[b] FITT: frequency, intensity, time, and type.

Data Collection

Data were collected from both the first responder and their support partner via web-based self-report questionnaires, Fitbit data, and one-on-one Skype interviews. Data from all self-report questionnaires were gathered through the MetricWire platform, a phone app.

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Measures of Feasibility and Acceptability

A manual calculation of the sum of posts, likes, comments, and views was performed to define Facebook group use, as has been similarly defined in previous research [36]. Feasibility was assessed based on participant retention, measured in 2 ways: first, the number of participants who remained in the group until program completion, and second, the number of participants who completed all of the postintervention assessments.

Acceptability was assessed postintervention using a 14-item feasibility and acceptability questionnaire developed for a private Facebook group [37]. Responses were answered on a 7-point Likert scale (strongly disagree to strongly agree). Acceptability was assessed using qualitative interviews. Participants were invited to participate in a 20-minute one-on-one semistructured interview via Skype following the intervention period. The interview covered topics including likes, dislikes, effectiveness, and recommendations for future iterations. The interviews were recorded and transcribed verbatim. Data were analyzed using thematic analysis to determine key themes identified by participants [38].

Secondary Outcomes

Psychological Distress

The K10 self-report questionnaire was used to assess levels of psychological distress [39]. It consists of 10 items scored on a 5-point Likert scale, with total scores ranging from 10 to 50. Scores were grouped into 4 levels of psychological distress: low (scores of 10-15), moderate (scores of 16-21), high (scores of 22-29), and very high (scores of 30-50) [40]. The K10 has excellent psychometric properties [41], including high internal consistency (α=.93) [39] and discriminant validity [42].

Depression and Anxiety

The 21-item Depression Anxiety and Stress Scale (DASS-21) was used to assess the effects of the program on mental health symptoms [43]. Participants used the 4-point severity or frequency scale to rate the extent to which they had experienced each state *over the past week*. A total score and 3 separate subscales, each with 7 items, were calculated to identify severity ratings for depression, anxiety, and stress. Higher scores represented more severe symptoms. For the depression domain, scores of 0-4 were considered normal, 5-6 mild, 7-10 moderate, 11-13 severe, and >14 extremely severe. For anxiety, 0-3 was considered normal, 4-5 mild, 6-7 moderate, 8-9 severe, and >10 extremely severe. For stress, 0-7 was normal, 8-9 mild, 10-12 moderate, 13-16 severe, and >17 extremely severe. The psychometric properties of the DASS-21 have been comprehensively evaluated, and it has been found to be valid, consistent, and responsive to treatment [44,45].

Sleep Quality

The Pittsburgh Sleep Quality Index (PSQI) was used to assess participants' quality and patterns of sleep in the past month [46]. This self-report questionnaire was assessed at baseline, postintervention, and follow-up. A total of 7 subscores were calculated, ranging from 0 to 3, to yield a global score ranging from 0 to 21. A sum of 5 or greater indicates a poor sleeper. Acceptable measures of internal homogeneity, consistency (test-retest reliability), and validity were obtained. The components of the PSQI were shown to have a high degree of internal consistency (α=.83) [46].

Quality of Life

The Assessment of Quality of Life-6D (AQoL-6D) scale was used to assess quality of life [47]. A total simple psychometric score for health-related quality of life and profile scores for the different dimensions were calculated. The 6 dimensions include independent living, relationships, mental health, coping, pain, and senses. Scores can range from 20 to 99, with lower values representing a better quality of life. The AQoL-6D questionnaire has achieved construct validity and provides a sensitive description of health-related quality of life [47].

PTSD Symptoms

The Posttraumatic Stress Disorder Checklist (PCL-5) in the *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition) (*DSM-5*), is a 20-item self-report measure used to assess the *DSM-5* symptoms of PTSD [48]. Only the first responders were administered this questionnaire. Symptom severity scores range from 0 to 80, with a cutoff score of 33 indicating a provisional diagnosis of PTSD [49]. A decrease in scores of >10 points indicates a clinically significant change; >5 points indicates a reliable change. The PCL-5 is a psychometrically sound measure of *DSM-5* PTSD symptoms. It shows strong internal consistency (α=.94), test-retest reliability (r=0.82), and validity [48].

Social Support to Exercise

The social support and exercise survey was used to assess the level of support individuals making health behavior changes (exercise) felt they were receiving from family and friends [50]. Respondents rated the frequency with which family members and friends had done or said what was described in the item during the previous month on a 5-point scale, ranging from 1 (none) to 5 (very often). The survey was assessed at baseline, postintervention, and follow-up. The test-retest reliabilities of the factors were adequate, and the internal consistency reliabilities were high (α range .61-.91).

Minutes of Physical Activity

Physical activity levels were assessed subjectively using the Simple Physical Activity Questionnaire (SIMPAQ). The SIMPAQ is a 5-item clinical tool designed to assess physical activity among populations at high risk of sedentary behavior, with demonstrated validity and reliability among people with mental illness [51]. For the purpose of this study, the SIMPAQ was adapted to a web-based version using MetricWire. The SIMPAQ score was assessed at baseline, postintervention, and follow-up. The total time per week of walking, MVPA, and being sedentary was assessed.

Procedure

Consecutive observations of the K10 were assessed every 2 weeks as part of the interrupted time series design. During the 5-week baseline period, the K10 was asked at 3-time points before the intervention. At the end of the baseline period (before intervention), the DASS-21, PSQI, AQoL-6D, PCL-5, social support to exercise, and SIMPAQ were assessed, as shown in

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Figure 1. During the intervention, the K10 continued to be assessed every 2 weeks, with a total of 5 time points during this period. At the end of the 10-week intervention, all outcomes were reassessed, in addition to the feasibility and acceptability questionnaire and the optional qualitative interviews. At the 4-week follow-up, all baseline questionnaires were reassessed.

Statistical Analysis

In this study, we used two statistical approaches to test the changes during the intervention. First, we used a multiple baseline design to compare participants' psychological distress levels with their own baseline (which acted as a control) using Mplus version 8. Second, we tested for differences between preintervention and postintervention outcomes on a battery of tests (open trial, no control) using SPSS version 24 (IBM Corporation).

Comparing Multiple Baselines With Intervention

A multiple baseline design was used to test for significant differences in participant trajectories between the baseline and during the intervention. A piecewise latent growth curve model was fitted in the Mplus base package using complex analysis. The model included a slope model for each participant's K10 scores during the 3 baseline time points (baseline slope) and during the 5 intervention time points 4 to 8 (intervention slope). In latent growth curve models, each participant's repeated time points were modeled as a latent variable of slope for each participant and a mean slope across the group. That is, a multilevel model was designed in which each participant's time series is nested within each individual, which is nested within the overall group. Random effects were used to allow each participant to have their own intercept and slope. An assumption of linear modeling is that the observations between participants will be independent. However, partners in this study were likely to share characteristics and were thus nonindependent; clustering by partnerships was included to account for the nonindependence of results within pairs. A piecewise model can model 2 separate slopes for each participant within a time series (between baseline and intervention). Model constraints were used to test for significant differences between the slope estimates between baseline and intervention.

Pre-Post Intervention Tests

A multilevel modeling approach was used to test repeated measures for each individual, accounting for pairs (first responder and support partner). That is, while accounting for clustering within pairs, mixed models were run to test whether participants showed significant changes in outcome measures. Directional hypotheses were used (one-tailed tests), and Cohen *d* effect sizes were calculated. All analyses for the pre-post tests were conducted on SPSS version 24.

Results

Participant Demographics

In total, 24 participants (13/24, 54% female, 12/24, 50% first responders and 12/24, 50% support partners) were recruited for the study. Table 2 presents the demographic characteristics of the participants. The relationship between most participant-support partner pairs was life partners (10/12, 83%). Half of the first responders were former or current firefighters, 33% (4/12) were paramedics, and 17% (2/12) were police officers. Most of the total sample (17/24, 71%) used Facebook for >3 hours per week before the intervention. The flow of participants throughout the study is shown in Figure 1.

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Table 2. Baseline demographics.

Characteristic	First responder (n=12)	Partner (n=12)	Total (N=24)
Age (years), mean (SD)	48.1 (11.12)	44.8 (12.13)	46.5 (11.5)
Sex (male), n (%)	10 (83)	1 (8)	11 (46)
Smoker, n (%)	2 (17)	2 (17)	4 (17)
Marital status, n (%)			
Married	7 (58)	7 (58)	14 (58)
Single	2 (17)	1 (8)	3 (13)
Other or prefer not to say	3 (25)	4 (34)	7 (29)
Education, n (%)			
High school	2 (17)	3 (25)	5 (21)
Diploma or certificate	8 (66)	2 (17)	10 (42)
Bachelor or postgraduate degree	2 (17)	7 (58)	9 (37)
Occupation, n (%)			
Police	2 (17)	2 (17)	N/A[a]
Fire	6 (50)	N/A	N/A
Paramedic	4 (33)	1 (8)	N/A
Nonfirst responder	N/A	9 (75)	N/A
Work status, n (%)			
Current serving	7 (58)	N/A	N/A
Retired or medically discharged	5 (42)	N/A	N/A
Relationship with the first responder, n (%)			
Life partner	N/A	10 (84)	N/A
Friend	N/A	1 (8)	N/A
Family member	N/A	1 (8)	N/A
Facebook use per week, n (%)			
3+ hours	11 (92)	6 (50)	17 (71)
1-3 hours	N/A	4 (33)	4 (17)
<1 hour	1 (8)	2 (17)	3 (12)

[a] N/A: not applicable.

Feasibility and Acceptability

Retention

From a total of 24 participants, 21 (88%) completed the postintervention assessment questionnaires and 22 (92%) completed the program. One participant dropped out during the baseline period, before the intervention. Another participant dropped out during week 8 for unknown reasons. Participants completed 98% of the multiple time series design K10 assessments, which occurred at 8 time points across the baseline and intervention period. Only a minority (6/24, 25%) completed the 4-week postintervention follow-up assessment.

Engagement

Over the 10-week study period, there was a total of 544 likes and comments from 23 participants. There were a total of 76 individual posts, with 50 posts (66%) coming from participants and 26 posts (34%) from facilitators (Table 3). The total post views of the first responder, support partner, and facilitator-initiated responses were high, with a mean of 18.4 (SD 3.5) views per post across the 10 weeks, indicating an average view rate of 83% (Table 3). The highest response rate was a total of 26 comments and 5 likes from 12 participants and was in response to a post on goal setting. Poll responses were not included in the sum of likes and comments but received the highest interaction. Participants' posts included screenshots of their daily step counts, community exercise programs, personal barriers to getting active, and screenshots of sleep patterns as recorded by the Fitbit. Participant-initiated posts declined across the intervention, with the lowest being week 9, which focused on diet.

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Table 3. Engagement with Facebook posts initiated by first responders, partners, and facilitators.

Week, topic, and position	Number of posts	Post views, mean (SD)	Likes, mean (SD)	Comments, mean (SD)
1, Welcome				
First responders	13	16.5 (1.8)	3.3 (1.6)	3.5 (2.1)
Partners	4	18 (0.8)	4.8 (3.0)	3.8 (1.5)
Facilitators	4	11.5 (1.3)	3.8 (1.9)	9.6 (7.1)
2, Goal setting				
First responders	6	18.8 (1.7)	5.2 (1.5)	8 (3.7)
Partners	0	N/A[a]	N/A	N/A
Facilitators	4	19.5 (1)	6 (1.8)	6.8 (12.8)
3, Benefits of physical activity				
First responders	1	23 (0)	5 (0)	2 (0)
Partners	1	21 (0)	6 (0)	4 (0)
Facilitators	2	21 (1.4)	4.1 (2.1)	1.5 (2.1)
4, Barriers				
First responders	4	23.2 (0.9)	5.5 (1.3)	3.8 (1.3)
Partners	1	23 (0)	1 (0)	7 (0)
Facilitators	3	20.7 (1.5)	5 (5.3)	5.3 (3.8)
5, Support				
First responders	2	18 (1.4)	2 (0)	1 (1.4)
Partners	1	21 (0)	4 (0)	0 (0)
Facilitators	2	19 (1.4)	7.5 (4.9)	6 (5.7)
6, Sedentary behavior				
First responders	4	20.6 (1.7)	5.5 (1.7)	4 (2.1)
Partners	2	21 (4.2)	6 (1.4)	4 (4.2)
Facilitators	3	19 (1.4)	2.5 (3.5)	4 (4.2)
7, Aerobic exercise				
First responders	4	20.3 (1.0)	6.5 (3.7)	1.8 (1.0)
Partners	3	20.7 (3.2)	1.7 (0.6)	5 (3.0)
Facilitators	2	19 (1.4)	2 (0)	1.5 (0.7)
8, Resistance exercise				
First responders	3	22.7 (1.2)	5 (2.6)	1.7 (1.2)
Partners	0	N/A	N/A	N/A
Facilitators	2	20.5 (2.1)	4 (2.8)	3.5 (3.5)
9, Healthy eating				
First responders	0	N/A	N/A	N/A
Partners	0	N/A	N/A	N/A
Facilitators	2	20 (0)	3 (1.4)	4 (0)
10, Review				
First responders	1	17 (0)	0 (0)	5 (0)
Partners	0	N/A	N/A	N/A
Facilitators	2	20.5 (4.2)	9 (0.7)	6 (1.4)

[a] N/A: not applicable.

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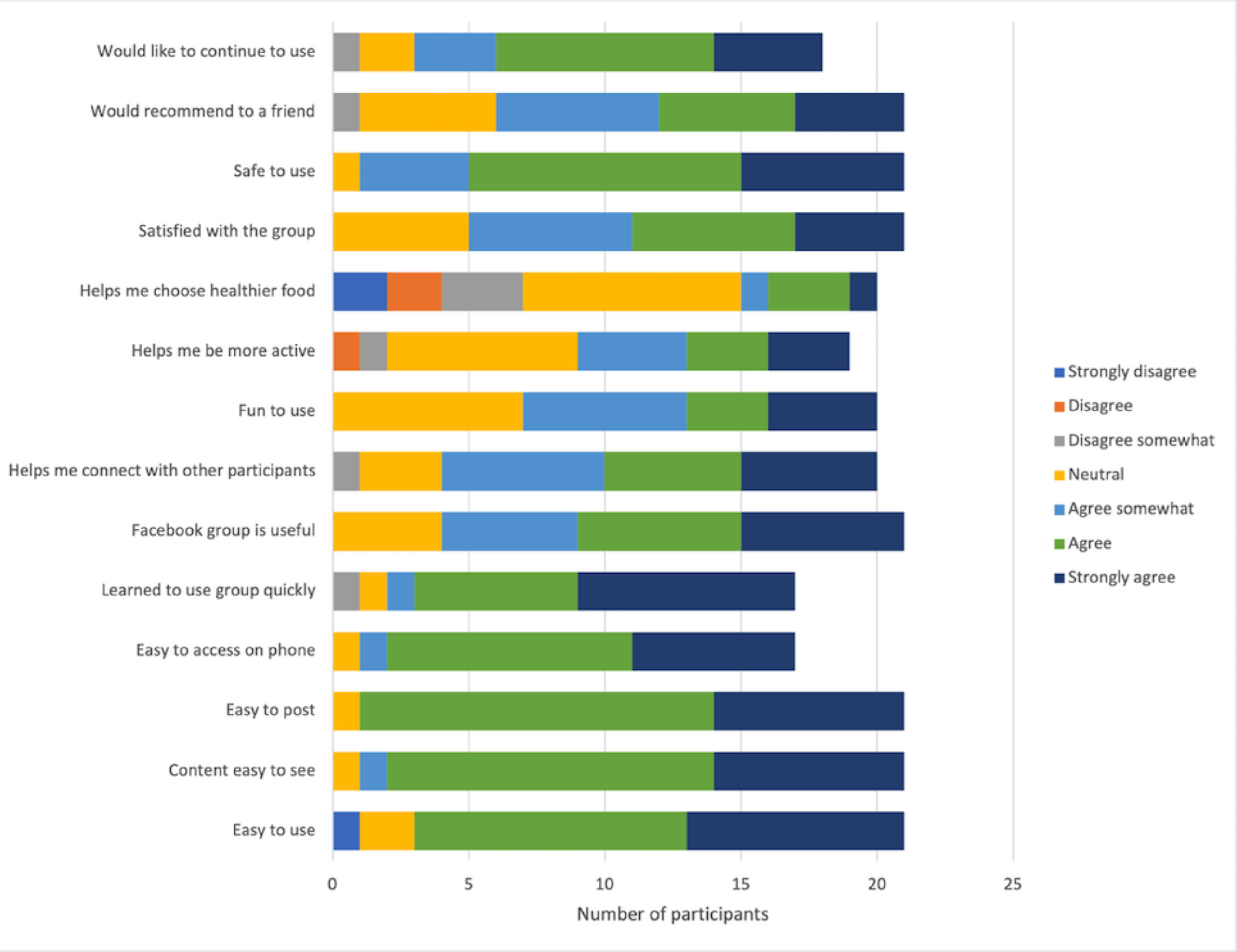
Fitbit Compliance

From a total of 24 participants, 22 participants (92%) downloaded the Fitbit app and activated their device. Once this setup had occurred, they were worn on 89% of the days during the 10-week intervention period and on 48% of the days during the 4-week follow-up period. From the 22 participants, 19 participants (86%) wore Fitbits >80% of the days during the 10-week program, and 21 (95%) wore them >50% of the days.

Acceptability

Figure 2 summarizes the participants' responses to a feasibility and acceptability questionnaire. On average, both participants and their support partners appraised the program positively. Mean scores across the 14 questions were 5.5 out of 7, meaning participants somewhat agreed or strongly agreed that the group was feasible and acceptable. Mean scores ranged from 3.79 to 7.0. Most of the participants agreed or strongly agreed that the Facebook group was easy to use (18/21, 86%) and useful (17/21, 81%); importantly, 95% (20/21) said it was safe to use. There was some discrepancy in whether the group helped participants be more active or eat healthier food; 7 participants disagreed to some degree that the program helped them eat healthier, and 2 participants disagreed that it helped them be more active. In addition, 5 first responders and 1 support partner participated in the optional qualitative interviews. All 6 participants experienced high or very high psychological distress levels at baseline, and engagement levels with the page varied between them. A total of 5 themes were identified from the data: (1) the role of physical activity and exercise for mental and physical health, (2) the contributing role of individual intervention components (eg, Fitbit and Facebook page), (3) the significance of social support, (4) identity and camaraderie associated with being a first responder, and (5) opportunities for future work and recommendations.

Figure 2. Participant responses to the feasibility and acceptability questionnaire.



Selected participant quotes relating to key themes are shown in Table 4. Participants identified that regular exercise improved their mental health by helping them better manage their symptoms. A subtheme emerged for physical activity acting as a catalyst for functional recovery, for example, facilitating participation in social activities. Participants reported that the use of Fitbit increased awareness of physical activity levels. Some participants reported that they would like to have seen more interaction on the Facebook page, whereas others appreciated the lack of pressure to contribute. Overall, the social support received from partners and other members of the group was well accepted and highly valued, and participants also reported forming friendships with other members of the group outside of the program. The camaraderie of being a first responder emerged as a theme, with participants appreciating that others in a similar position to themselves were participating and supporting each other.

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Table 4. Participant quotes from the qualitative interviews.

Themes and subthemes	Examples of supporting quotations
Benefits of physical activity	
Mental health	• "Definitely my consistency increased. And if I look at my data on my phone, or when I sync it, I can see that when I regularly exercise and don't miss a class and stuff, I certainly am a lot better mentally." • "...but I was talking to my psychiatrist yesterday and he was saying definitely increasing my exercise has helped me with my sleep because we've looked at my data on Fitbit and three months ago I wasn't sleeping as good as what I am now." • "Like, I know when I do my exercise,...I'm not thinking about my problems, I'm not thinking about any crappy job I've gone to, it's a form of mindfulness almost. It's a form of I'm being right present what I'm doing because I don't want to get injured, so I'm trying to do it right, so I am really concentrating on me and the task at hand which then takes the focus off your depression, or PTSD, or anxiety." • "And I just know hand in hand for me that when I don't exercise, my mental health deteriorates. When I exercise regularly and consistently, my mental health stays stable."
Catalyst for functional recovery	• "When my son says, 'Hey dad, you want to go tobogganing after school,' I'm like, 'Yes, let's go.'
Management tool	• "It's made me go out more. I find me going outside more, even if I don't feel like exercising. So, that for me, that's a big improvement, and I feel much more—it doesn't stop the posttraumatic stress. It doesn't stop me having a meltdown every time someone mentions something. But I don't stay stuck in the meltdowns now."
Role of intervention components and study design	
Fitbit	• "It was sitting there, I'm conscious that it's there because I can see it. And so it's like, oh yes, I need to be active. Does that make sense?...It was an actual talisman to trigger you to do things." • "And it did, I was more mindful of being more physical because I was wearing it. It was a reminder." • "But definitely having the Fitbit and I appreciate that so much because that's made a world of difference to my life insofar as I sync it every night. And, you know, some nights I haven't got to 10,000 steps, so I get up and I go and walk until I finished it." • "You've created this new—'conscience' is a good word, I think. You've created this new conscience within me because you've given me something that is a tangible and physical reminder of a need for change."
Facebook group	• "You guys did great. You could share as much as you wanted or you could just observe as much as you wanted. It was, and there was no pressure. I knew that if I was having a rough couple of days and I didn't say anything on there it wasn't taken negatively." • "Look, I think the threads and the general chats were good, absolutely. I just think it would be good if people just opened up a little bit more. Like, I was reserved and I didn't say much at all, to be honest. And in hindsight, I probably should have. But then you don't want to bombard." • "It's all positive. I think anything like this there are no negatives. I'd like to say thank you for involving us in it. It's been great. I've had probably the worst year of my life this year and it's been good to have this, the yoga, and I've been getting back into music and I'm just finding it's been good having those balanced pillars and this has been part of it." • "It encourages people. I've made contact with a few people out of it. I keep in contact with XXX from XXXX...So yes, the Facebook site's good." • "It's awareness. I know that, I can say oh yes, I know I've got to eat better, I know I've got to do more exercise. As soon as you've got 30 people that are looking at what you're doing like, I'm like oh shit, they can see what I'm doing on my Fitbit. So having a certain level of responsibility, almost. But it was very light, like, you guys didn't care at all what we did, I don't think. You were just, we'll see what happens. And that was really comforting, knowing that there was zero pressure." • "Guess I was probably looking for more because the problem I had was being motivated. I even had the same trouble speaking to my own psychologist, psychiatrist. I want to do it but I really struggle to motivate to do it, to exercise."
Questionnaires	• "So I gather they are the bread and butter of gathering information at any given point in time. But yes, they are a real pain in the arse to answer."
Significance of social support	
Support partners	• "So having the Fitbit was like, it was a reminder to her that she needs to take care of herself just as much as I do and that we are a team. So it was like, how many steps did you have today. She's like oh my gosh, I only got 2,000." • "XXX and I bouncing it off each other at the end of the day I'm like okay, how many steps did you do, that sort of—not in a competitive way but it was another avenue to be able to go okay, how was your day? How active were you? That sort of thing. So we would compare a little bit like that."

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Themes and subthemes	Examples of supporting quotations
Support group	- “It was a really good group where there was supportive people and I really connected with XXX, and he connected with XX as well because he’s all about yoga and peer support stuff. So we made a friendship. It’s pretty awesome that way. We’re lucky.” - “...you have created community, you have created a conversation.”
Identity	
Camaraderie of being a first responder	- “So that, knowing that there are other people out there doing a similar thing, involved in a similar study, and knowing, being aware that whatever data comes from this and future studies is going to help people. That gives me some encouragement and joy because that’s in my nature; I wouldn’t have spent so long as a paramedic.” - “But knowing that there’s a group of people out there doing the same sort of thing—I’m tribal and it’s kind of, I know ambulance and police and ADF, we are tribal by nature so there is a real comfort in being part of another tribe.”
Opportunities for future work and recommendations	
Peer support	- “So yes, you guys just—you’re doing amazing things. Keep up the good work and I’m hopping on-board. I’ll help in any way that I can.”
Recommendations	- “...and I guess the other thing is trying to get people outside...and a big thing for me walking was taking a photo - stopping to notice, and it became really mindful...For me, I realised with the posttraumatic stress, if I have an anxiety attack and I stop, and I just take a photo of something around me, of nature around me, it drops the anxiety attack out. So, it’s adding that little bit of mindfulness to the walking.” - “I would have liked to have seen a little bit more interaction on the Facebook page. I didn’t think there was a huge amount of interaction on the Facebook page either. Particularly towards the end, I felt like I was commenting, and I was commenting too much, because no one else was really doing that.” - “And even just these phone calls from you guys before you start because then that you actually feel it in your voice and even over a phone and get a feeling for a person, then just an email or just a comment on a Facebook page.”

Secondary Outcomes

Psychological Distress

Examination of the individual K10 means showed that participant trajectories of change did not form a straight line, meaning that in some weeks, participant levels of psychological distress would increase, whereas in others weeks, they would decrease, that is, there were nonlinear trends across time. A quadratic trend was therefore used to test for a change in the direction of the slope. The model showed an excellent fit (X^2_1=27.5; *P*=.38; root mean square error of approximation=0.05; comparative fit index=0.992; Tucker-Lewis index=0.991; standardized root mean square residual=0.086). The baseline slope was not significant (b=−0.09; *P*=.77). The intervention slope showed a significant decrease across the intervention period (b=−1.067; *P*=.003; ie, despite changes in direction, the overall K10 scores decreased during the intervention period). There was a significant quadratic trend over the intervention (b=0.148; *P*=.046), meaning that the change trajectories showed a change in direction during the intervention period. Model constraints showed a trend toward differences between the baseline and intervention slopes, but this was not significant (b=0.977; *P*=.09). Although there was no significant change at baseline and a significant change during the intervention, there was no significant difference between the 2 slopes.

Preintervention and Postintervention Outcomes

The results for all other secondary outcomes at baseline and postintervention are shown in Table 5. Significant improvements in the total DASS-21 scores (*P*=.047; Cohen *d*=0.35) and AQoL-6D (*P*=.001; Cohen *d*=0.60) were observed. Changes in sleep quality (*P*=.28; Cohen *d*=0.19) and social support from family (*P*=.07; Cohen *d*=0.37) and friends (*P*=.43; Cohen *d*=0.02) were not significant. Changes in mean PCL-5 were also not significant (*P*=.10; Cohen *d*=0.38); however, 36% (4/11) of the first responders’ PCL-5 scores decreased by >10 points, indicating a clinically significant change in that group, and 55% (6/11) of the first responders’ PCL-5 scores decreased by >5 points, indicating a reliable change. Self-reported average minutes of walking per day showed a significant effect on time from baseline to postassessment (*P*=.04; Cohen *d*=0.55). No statistically significant changes in self-reported levels of sedentary behavior (*P*=.18; Cohen *d*=0.22) or MVPA (*P*=.11; Cohen *d*=0.34) were found.

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Table 5. Preanalysis and postanalysis of secondary outcomes.

Variable and position	Baseline, mean (SD)	Postintervention, mean (SD)	Time		Position[a]		Time×position	
			F test[b]	*P* value	*F* test[b]	*P* value	*F* test[b]	*P* value
DASS[c]-21 total								
First responder	23.4 (11.2)	20.5 (13.3)	3.09	*.047* [d]	1.54	.23	0.35	.56
Partner	19.4 (14)	13.5 (11.4)	N/A[e]	N/A	N/A	N/A	N/A	N/A
DASS-21 depression								
First responder	8.5 (3.9)	7.4 (6.1)	2.22	.08	4.40	*.048*	0.13	.72
Partner	5.6 (4.1)	3.7 (3.3)	N/A	N/A	N/A	N/A	N/A	N/A
DASS-21 anxiety								
First responder	5.3 (2.9)	4.4 (3.7)	6.02	*.01*	0.54	.47	1.28	.27
Partner	4.9 (4.4)	2.6 (3.5)	N/A	N/A	N/A	N/A	N/A	N/A
DASS-21 stress								
First responder	9.3 (4.8)	8.2 (4.6)	1.94 (1)	.09	0.00	.99	0.11 (1)	.75
Partner	8.5 (6)	6.7 (5.6)	N/A	N/A	N/A	N/A	N/A	N/A
PSQI[f]								
First responder	12.7 (2.6)	12.1 (4.6)	0.34	.28	0.42	.53	3.18	.09
Partner	9.3(5.5)	8.1 (5.5)	N/A	N/A	N/A	N/A	N/A	N/A
AQoL-6D[g]								
First responder	48 (7.9)	43.6 (9.5)	13.64	*.001*	2.64	.12	0.02	.89
Partner	44.1 (7.9)	38.4 (8.1)	N/A	N/A	N/A	N/A	N/A	N/A
Mental health								
First responder	12.9 (2.6)	10.8 (2.6)	15.85	*.001*	1.33	.26	0.03	.86
Partner	11.4 (3.9)	9.4 (3.7)	N/A	N/A	N/A	N/A	N/A	N/A
Senses								
First responder	5.3 (1.2)	5.6 (1.6)	1.07	.16	0.74	.40	0.27	.61
Partner	4.9 (1.3)	5.0 (1.2)	N/A	N/A	N/A	N/A	N/A	N/A
Relationships								
First responder	6.7 (1.5)	5.6 (1.2)	8.46	*.004*	0.88	.36	0.75	.40
Partner	6.0 (1.6)	5.4 (1.2)	N/A	N/A	N/A	N/A	N/A	N/A
Independent living								
First responder	8.2 (2.4)	7.3 (2.2)	6.43	*.01*	4.586	*.04*	0.143	.709
Partner	6.9 (1.9)	5.6 (1.2)	N/A	N/A	N/A	N/A	N/A	N/A
Pain								
First responder	6.2 (2.5)	5.5 (2.1)	2.85	.05	0.04	.99	0.01	.89
Partner	6.4 (2.6)	5.8 (1.9)	N/A	N/A	N/A	N/A	N/A	N/A
Coping								
First responder	10.2 (2.5)	8.6 (1.8)	18.31	*<.001*	4.09	.06	0.17	.68
Partner	8.6 (1.8)	7.2 (1.8)	N/A	N/A	N/A	N/A	N/A	N/A
Family social support								
First responder	20.6 (7.6)	19.8 (5.3)	2.50	.07	0.56	.46	4.25	.05
Partner	18.3 (4.6)	24.9 (10.9)	N/A	N/A	N/A	N/A	N/A	N/A

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Variable and position	Baseline, mean (SD)	Postintervention, mean (SD)	Time		Position[a]		Time×position	
			F test[b]	*P* value	*F* test[b]	*P* value	*F* test[b]	*P* value
Friend social support								
First responder	19.5 (8.4)	18 (4.8)	0.03	.43	0.00	.99	1.63	.22
Partner	21.1 (9)	22.7 (8.7)	N/A	N/A	N/A	N/A	N/A	N/A
PCL-5[h]								
First responder	39.3 (18.8)	32.3 (21.1)	1.93	.10	N/A	N/A	N/A	N/A
Sedentary time, hours/day								
First responder	9.1 (3.5)	9.3 (3.5)	0.92	.18	0.08	.78	1.45	.25
Partner	10.4 (4.4)	8.7 (2.6)	N/A	N/A	N/A	N/A	N/A	N/A
MVPA[i], minutes/week								
First responder	72.27 (114.8)	130.91 (125.3)	1.67	.11	0.03	.86	0.42	.53
Partner	84.0 (127.3)	103.5 (129.7)	N/A	N/A	N/A	N/A	N/A	N/A
Walking, minutes/day								
First responder	56.82 (56.5)	87.73 (67.2)	3.616	*.04*	0.55	.47	0.10	.75
Partner	68.0 (72.7)	111.3 (82.1)	N/A	N/A	N/A	N/A	N/A	N/A

[a] Position indicates first responders or support partners.

[b] Degrees of freedom=1 for each interaction.

[c] DASS: Depression Anxiety and Stress Scale.

[d] Italics indicates statistical significance.

[e] N/A: not applicable.

[f] PSQI: Pittsburgh Sleep Quality Index.

[g] AQoL-6D: Assessment of Quality of Life. For AQoL-6D and its subscales, lower scores indicated better health.

[h] PCL-5: Posttraumatic Stress Disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition).

[i] MPVA: moderate-to-vigorous physical activity.

Discussion

Principal Findings

To the best of our knowledge, this is the first study to assess the feasibility, acceptability, and preliminary effectiveness of using a private Facebook group to deliver a physical activity intervention for first responders and their support partners. Current efforts to implement physical activity programs for populations at risk of poor mental health are often hindered in their scalability and sustainability by factors such as the high cost and lack of accessibility. Our study demonstrated that social media is a feasible and acceptable platform for delivering a mental health–informed physical activity intervention, and exploratory analysis of secondary outcomes appears promising.

Our study’s retention rates were high, with 92% (22/24) of participants remaining in the group and completing the 10-week program and 88% (21/24) completing the postassessment questionnaires. This is in line with the current literature, where compared with traditional web-based interventions, web-based social networks typically achieve high levels of user engagement and retention [52]. A systematic review of studies that used Facebook to deliver physical activity interventions found a comparable attrition rate of 9% [53]. The multiple time series design also proved to be feasible, with 98% of possible K10 assessment time points being completed by the participants. Satisfaction ratings were high, with participants agreeing that the Facebook page was safe and easy to use. On average, both first responders and their support partners stated that they would continue using the group and recommend the program to a friend. Having service end users involved from the initial development of the program is likely to have contributed to the high feasibility and acceptability observed in our pilot study.

There was strong compliance with wearing the Fitbits with regard to the percentage of days worn (89% of days) and high satisfaction reported in the interviews with using the wearable devices for activity tracking. This is consistent with previous studies on people with severe mental illness [54]. The use of existing low-cost and widely available wearable technologies that enable participants to see one another’s achievements and challenge each other may be particularly useful in partner support interventions targeting lifestyle change.

A decline in participant-initiated posts was observed over the 10-week intervention period; however, total views per post remained, with posts being viewed on average by 83% of participants. Research has shown that web-based interventions with a social media component help to sustain engagement [52]. Clinicians and researchers delivering web-based interventions should, however, be aware that it is difficult to determine

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engagement with web-based interventions [55]. Engagement does not necessarily predict effectiveness, and there is evidence showing that those lurking in online support groups may benefit to the same extent or even more than regular posters [56,57]. A potential strategy to address the decline in posts may be to have volunteers from previous iterations act as peer support members in future groups. Druss et al [58] have shown that peer support is a promising strategy for helping people change their lifestyle behaviors. In their study, 400 participants with serious mental illnesses were provided 12 sessions of a chronic disease self-management course led by mental health peers with chronic conditions, and they found statistically significant improvements in mental and physical components of quality of life and in recovery assessment scores. Peers could act as powerful role models for changing behaviors and may increase retention by relating to participants' challenges and offering personal advice [59].

Given that this was a pilot study, interpreting the secondary outcome data should be done with caution and treated as exploratory, not hypothesis testing. Although the sample size is small, it is consistent with the intent of pilot studies as an initial step in exploring the feasibility and potential benefits of a novel intervention [60]. A total of 61% (14/23) of participants experienced high or very high levels of psychological distress at baseline. As expected, there was no significant change in distress levels during the baseline period. A significant decrease in psychological distress was seen across the repeated time points during the intervention; however, the interaction between the baseline and intervention slopes did not reach significance. We would anticipate that a larger sample size would provide sufficient power to observe significant interactions.

Significant improvements were observed in the quality of life and total DASS-21 scores. Unexpectedly, no changes in perceived social support to exercise were observed. Similarly, an RCT using Facebook to assess changes in perceived social support among university students also found no significant difference in perceived social support following a web-based intervention [25]. It should also be noted that the social support to exercise questionnaire used in this study did not differentiate between perceived support received from the other participants in the group, their partner, or the facilitators. Therefore, it remains unclear whether a web-based group-based program is effective for increasing perceived social support.

Changes in sleep quality and PTSD symptoms were not statistically significant in this small sample. A significant change in self-reported minutes of walking per week was observed, but not in sedentary time or MVPA. A possible explanation could be the large group SD, which is typical of self-reported physical activity [61]. In addition, our inclusion criteria did not exclude support partners who were sufficiently active at baseline. In a larger-scale trial, these secondary outcomes could be pooled across iterations, clustered by cohorts, to test for statistical significance with a larger sample size.

Importantly, this pilot study focused on a major public health problem given the toll that providing care takes on people's physical and mental health [62]. The benefits in mental health outcomes experienced by the support partners warrant extending lifestyle interventions to include spouses and family members. Meta-analytic evidence from 21 RCTs (involving 1589 participants) has shown that both support groups and group-based face-to-face psycho-educational interventions are effective for caregivers of patients with severe mental illnesses [63]. However, few studies have addressed lifestyle behaviors among support partners [64,65]. In line with the literature [62], the support partners were experiencing high levels of psychological distress at baseline, with 55% (6/11) of the support partners experiencing at least moderate levels of psychological distress and 36% (4/11) of the support partners experiencing high or very high levels of distress. There was no significant difference in trajectories between the first responders and support partners in any of the outcomes.

Limitations and Future Research

Some limitations of this pilot study include the generalizability and inadequate statistical power. Our sample was small and involved only self-selected participants. In addition, the lack of age and gender diversity may limit the generalizability of these findings to other samples or broader characteristics of first responders, such as those with severe mental illness or those who are not active on social media. It is also difficult to dismantle the intervention components (eg, Fitbit and Facebook group) to determine which component has the greatest effect. Although there was a lack of a control group and a small sample size, the novel time series design proved to be feasible. A time series design should be considered when designing lifestyle interventions when RCTs may not be realistic or warranted; this design has been applied to a full-scale study of the program described here [66].

Another limitation was the insufficient follow-up data because of high attrition between postintervention and follow-up assessments. Therefore, it is inconclusive whether the short-term benefits obtained through this type of intervention would be maintained over the long term. Web-based programs are uniquely placed as content can be delivered more regularly than face-to-face interventions and accessed in the participants' own time. A short 10-week program may also be an important initial step in fostering autonomous motivation and self-efficacy to engage in further physical activity programs. Future research should examine whether web-based interventions have the ability to maintain positive behavior changes over the medium and long term. Future researchers should consider the views of posts as an important measure of passive engagement. Future studies should consider the cofacilitation of content delivery by peer support workers and the use of other Facebook group features, including video calls, to further enhance the participant experience.

Conclusions

Delivering web-based interventions to increase physical activity among first responders and their support partners presents a potentially useful implementation strategy because of its low cost and ability to reach a large number of people. The results of our pilot study show that using Facebook to deliver a physical activity program and using a multiple time series design are feasible. Exploratory analysis showed significant improvements in mental health symptoms and quality of life. Given these

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results, a larger-scale trial is warranted, and future iterations should build on the strengths and weaknesses of this pilot study.

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Conflicts of Interest

None declared.

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Abbreviations

AQoL-6D: Assessment of Quality of Life-6D
DASS-21: Depression Anxiety and Stress Scale
DSM-5: Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition)
K10: Kessler-10
MVPA: moderate-to-vigorous physical activity
PCL-5: Posttraumatic Stress Disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition)
PSQI: Pittsburgh Sleep Quality Index
PTSD: posttraumatic stress disorder
RCT: randomized controlled trial
SIMPAQ: Simple Physical Activity Questionnaire

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Original Paper

A Brief Training Program to Support the Use of a Digital Pill System for Medication Adherence: Pilot Descriptive Study

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Abstract

Background: Digital pill systems (DPSs), which comprise ingestible radiofrequency sensors integrated into a gelatin capsule that overencapsulates a medication, can directly measure ingestion events.

Objective: Teaching users to operate a DPS is vital to ensure the collection of actionable ingestion and adherence data. In this study, we aim to develop and pilot a training program, grounded in the Technology Acceptance Model, to instruct individuals on DPS operation.

Methods: A two-part training program, comprising in-person and text message–based components, was used with HIV-negative men who have sex with men with nonalcohol substance use, who had enrolled in a 90-day pilot demonstration study using the DPS to measure adherence to pre-exposure prophylaxis. We assessed the number of responses to text check-ins, the number and types of episodes where technical support was requested, the resolutions of such issues, and engagement with the program over the study period. Participant feedback on the program was evaluated through qualitative user experience interviews.

Results: A total of 15 participants were enrolled in and completed the program. Seven technical challenges related to DPS operations were reported across 5 participants. Most commonly, participants requested support connecting the wearable Reader device with their smartphone, charging the Reader, and operating the mobile app. A total of 6 issues were resolved asynchronously or in real time via phone; 1 required in-person evaluation and resolution. Preliminary qualitative findings indicate that both the in-person and remote follow-up components of the training program were perceived as acceptable. Suggested improvements included repeated DPS refresher sessions at in-person follow-up visits and enhanced written materials for the independent resolution of technological issues.

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Conclusions: A brief two-part DPS training program, drawing from individuals' experiences and from the Technology Acceptance Model, can provide valuable insights for users. The program also identifies and addresses several areas of actual or potential challenges related to operating a DPS and allows for the resolution of such issues within the first week of DPS use.

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KEYWORDS

digital pill system; technology training; HIV prevention; PrEP; ingestible sensors; mobile phone

Introduction

Digital pill systems (DPSs) use ingestible electronic sensors incorporated into gelatin capsules that overencapsulate medications. Ingestible sensors are activated upon entry into the stomach and exposure to gastrointestinal fluid, transmitting key data about medication ingestion patterns in real time. These data can be viewed by clinicians and patients via web-based platforms and smartphone apps. The provision of such feedback linked to medication ingestion patterns represents a novel, cybernetic closed-loop system that allows users to consider their medication adherence in light of digital pill–recorded data [1,2]. Behavioral interventions that are respondent to real-time adherence data can then be delivered both synchronously or asynchronously as contingent reinforcement or corrective feedback, and the effects of these interventions can be objectively measured.

For men who have sex with men (MSM) with concomitant substance use, the use of once-daily tenofovir disoproxil fumarate/emtricitabine as pre-exposure prophylaxis (PrEP) for HIV prevention has been demonstrated to be highly efficacious; however, PrEP efficacy remains closely linked to adherence [3]. Post hoc analyses from clinical trials and demonstration projects around PrEP rollout have consistently demonstrated that MSM with substance use disorder experience the highest rates of nonadherence [4,5]. Techniques involving mobile apps, social media, and technological devices have been deployed among MSM to discover episodes of nonadherence and deliver interventions to help boost adherence behavior [6,7]. The use of such innovative technologies may help overcome barriers to engagement in PrEP care experienced by MSM and individuals with substance use disorder [8]. Among substance users, smart pill bottles, biosensors, mobile apps, and interactive voice response systems have been successfully deployed and demonstrated to be acceptable in the context of medication adherence measurement [9]. The development of a DPS provides the additional benefit of obtaining PrEP adherence data in real time, thereby creating an opportunity to present adherence support and tools to PrEP users at the moment when nonadherence occurs.

Ensuring consistent use of the DPS is vital to obtain actionable medication ingestion data that would enable real-time adherence interventions. Although several clinical trials have demonstrated the feasibility and acceptability of deploying a DPS to measure medication adherence, barriers to the adoption of this technology may exist [10-14]. The Technology Acceptance Model (TAM) [15-17] can serve as a theoretical framework for understanding and evaluating potential facilitators and barriers to the adoption and use of novel technology systems such as the DPS. In the TAM, users of a technology are asked to consider how they might use the system (perceived use) in the real world. Next, the overarching goals of the system and its intersections with perceived use are considered (intended use). Finally, users are asked how they would adopt the system in real-world situations (actual use) [15].

Our team conducted qualitative exploration of these 3 TAM constructs with HIV-negative MSM who use substances, which found that such individuals are accepting the idea of using a DPS to measure adherence to once-daily PrEP and are willing to engage with the technology [18]. Participants perceived the DPS to be a useful, innovative tool for measuring adherence and providing increased accountability and reassurance around their PrEP-taking patterns and behaviors. In addition, participants described a number of potential barriers to the process of learning to operate a DPS and barriers to their understanding of how to address potential technical challenges associated with the use of the technology [18]. Importantly, participants in these qualitative interviews reported that the wearable Reader device would be the largest barrier to operating the DPS, as users may forget to wear or charge the Reader before their ingestion, which could influence the accuracy of their adherence data. A brief in-person training program, combined with a period of remote follow-up, was reported to be an acceptable method for learning the skills required to operate the DPS [18]. Participants emphasized the importance of supervised hands-on training with the DPS, including testing the functionality of all components of the system before initiation, and a monitored follow-up period to assess the ongoing DPS operation.

Accordingly, we developed a brief training program with features addressing the 3 pillars of the TAM to teach individuals how to operate and incorporate the DPS into their daily routine. Our goal is to design a program that could first be taught to individuals who were naïve to the DPS and subsequently be delivered to DPS users by these individuals once they obtained a basic understanding of the DPS, to maximize its scalability and use for individuals using a DPS. We piloted this training program as part of a clinical trial that deployed a DPS to measure PrEP adherence over a 90-day period in HIV-negative MSM with nonalcohol substance use. Finally, we aim to solicit qualitative feedback via user experience interviews to understand the experiences of individuals who participated in the DPS training program.

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Methods

Parent Study

The parent study consisted of a 90-day, open-label demonstration trial to evaluate the feasibility and acceptability of the DPS (ID Cap System, etectRx Inc) to measure PrEP adherence, in which digital pills for PrEP were deployed among HIV-negative MSM (N=15) older than 18 years who self-reported nonalcohol substance use (NCT03842436). Participants ingested digital pills once daily for 90 days and attended 5 study visits over a period of 3-4 months. In addition to DPS technology training, study visits consisted of laboratory work (to confirm eligibility for PrEP), a brief quantitative assessment, pill counts, reviews of DPS adherence data, blood draws to evaluate PrEP adherence, and provision of three 30-day supplies of digital pills. As part of this parent study, we developed a training program grounded in our initial qualitative work to ensure participants' successful operation of the DPS over the course of the study, which is the focus of this study, and all adherence metrics from participants' use of the DPS during the parent study will be reported elsewhere.

Participants

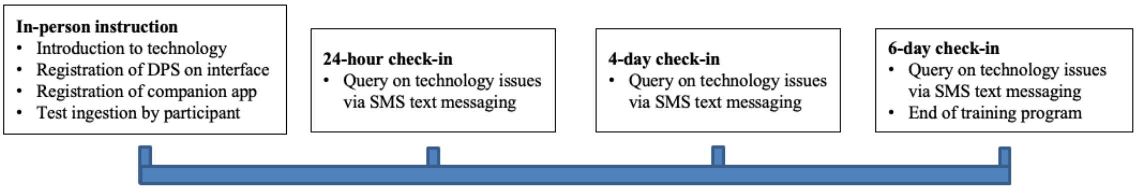
A total of 15 participants enrolled in the parent study, a sample size that corresponded to the preliminary pilot nature of the study and our aim to demonstrate the feasibility and acceptability of the technology. All 15 participants were enrolled in the DPS training program. Participants met the following inclusion criteria: 18 years or older, cisgender MSM, self-reported use of nonalcohol substances in the past 6 months, currently taking PrEP, and qualifying laboratory tests for the use of PrEP (negative rapid HIV test, creatinine clearance ≥60 mL/min, evidence of hepatitis B immunization, and screening for sexually transmitted infections). Individuals were excluded if they did not speak English; self-reported living with HIV; were identified as transgender; had an estimated creatinine clearance <60 mL/min; were receiving active hepatitis B treatment; were taking proton pump inhibitors; had a history of Crohn disease or ulcerative colitis; had a history of bowel surgery, gastric bypass, or bowel stricture; had a history of gastrointestinal malignancy or radiation to the abdomen; did not own a smartphone; or were unable or unwilling to ingest the digital pill. This study was approved by the Fenway Health Institutional Review Board. A parent study was conducted between March 2019 and March 2020.

Procedures

Training Program

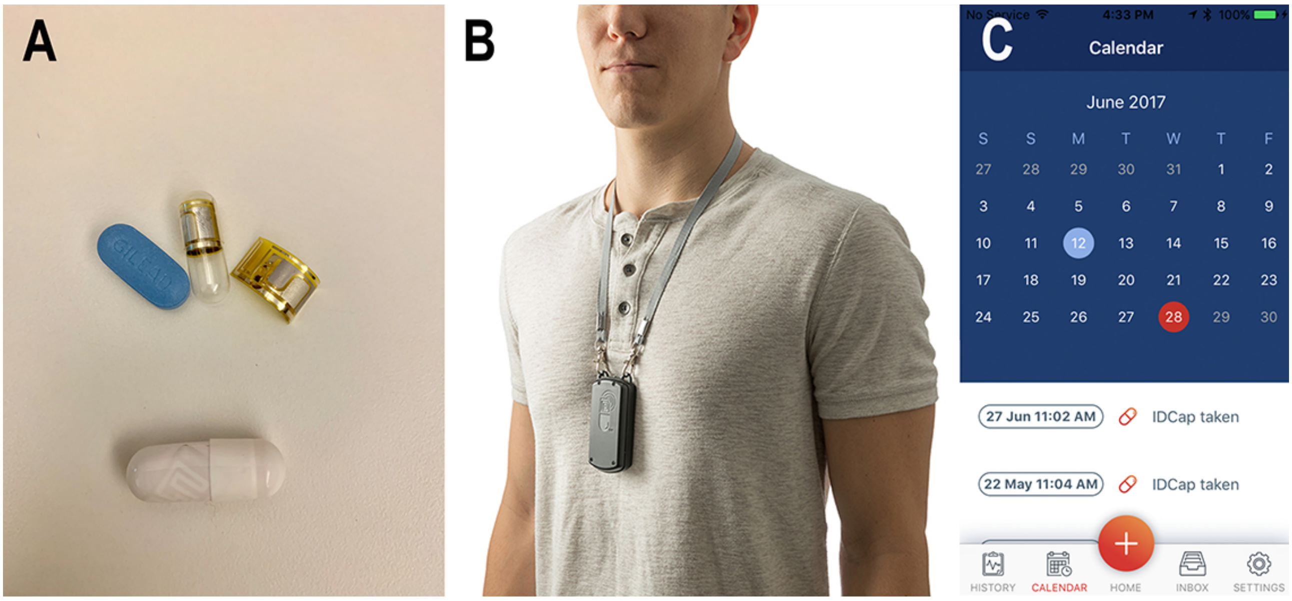
The DPS training program consisted of 2 components: an in-person training session during the study enrollment visit and a remote follow-up period of text message–based exchanges for 6 days after enrollment (Figure 1). The genesis of this training program was grounded in formative qualitative data collected from MSM who evaluated the DPS and provided insights into the perceived use and intended use of the device [18]. The study team members first received training and information on the DPS and operation of the DPS directly from the manufacturer (etectRx Inc). Next, the study team members demonstrated competence with activating and operating the DPS, completing the web-based DPS registration process with sample participants and troubleshooting common potential technological errors. After demonstrating competence in the DPS operation, the principal investigator approved the study team members for conducting DPS training directly with the study participants.

Figure 1. Overall structure of the digital pill system training program in-person session and remote follow-up. DPS: digital pill system.



Before the in-person session, the study team registered each participant on the web-based DPS interface, electronically assigned a Reader device to them, and prepared a prescription for their initial 30-day supply of digital pills. Each digital pill consisted of a capsule dosage form containing an ingestible sensor and an emtricitabine 200 mg/tenofovir disoproxil fumarate 300 mg tablet for PrEP, with instructions to take one capsule once daily (Figure 2). During the in-person session, participants were introduced to each part of the DPS, including a transparent version of the digital pill, which was used to illustrate its internal components, the wearable Reader device and the companion mobile app. Participants were instructed on proper charging procedures for the Reader, the importance of maintaining a full charge on the Reader's battery, and the process by which data would flow from the digital pill to the Reader and then to the cloud-based server.

Figure 2. Components of the digital pill system. The digital pill system comprises an ingestible electronic sensor integrated into a gelatin capsule overencapsulating tenofovir disoproxil fumarate/emtricitabine (Truvada) as a digital pill (A). Upon ingestion, the digital pill is activated and emits a radiofrequency signal that is transmitted to a wearable Reader device (B). Ingestion data then flow from the Reader device to a smartphone app (C).



27 Jun 11:02 AM IDCap taken

22 May 11:04 AM IDCap taken

Next, participants were instructed to download the smartphone app from either the Apple App Store or Google Play Store, depending on their device specifications. Following the installation of the mobile app, participants were instructed to activate the app by following in-app prompts and then pair the assigned Reader with the participant's smartphone using a standard Bluetooth Low-Energy protocol (similar to how a smart speaker or smart watch pairs with a smartphone). Once the pairing process was complete, participants were asked to confirm that all DPS components were ready for use; they were then instructed to wear the Reader around their neck on a lanyard, open the mobile app on their smartphone, and ingest their first digital pill. A successful DPS operation was defined as the ability to activate and operate the digital pill, Reader, and smartphone app and successfully record digital pill ingestion. Finally, we discussed the potential technological challenges and user errors that participants may encounter and solutions to those barriers. The in-person portion of the training program lasted approximately 45 minutes.

Once the in-person portion of the DPS training program was completed, participants automatically entered the remote follow-up period of the program. In this portion, the study team programmed a series of 3 automated technology check-in text messages to be sent to each participant: the first at 24 hours following their in-person enrollment visit and then again on days 4 and 6. These messages asked participants to report via text message any technological barriers they were experiencing with the DPS (ie, by texting back 0 for "I need help with something" or 1 for "everything's OK"). If technical assistance was requested in response to check-in messages, we attempted resolution via a standardized, hierarchical process, whereby resolution of all issues was first attempted via text message (through the web-based platform) and/or email with participants. If technical issues remained unresolved following attempts to rectify them via text message and/or email, a study team member escalated the issue to a phone call with participants for real-time evaluation and troubleshooting. Finally, participants were offered the opportunity to troubleshoot issues in person at the study site if they could not be resolved via any other means. Importantly, we did not offer advice through the training program regarding participants' medication ingestion behaviors, device use, or feedback on their specific adherence (or nonadherence) trends. The DPS training program was considered complete at the end of the 6-day remote follow-up period. Study staff were available during the entire 90-day study period for additional technology-related concerns.

Qualitative User Experience Interviews

At the end of the 90-day study period, participants returned their DPS equipment and completed an individual, audio-recorded, semistructured qualitative interview. The aim of these interviews was to understand participants' experiences operating the DPS and to obtain open-ended feedback on the DPS training program, including its perceived utility, adequacy for conveying the skills needed to operate the DPS, and suggested improvements to the training program. Interviewers were members of the study team who were trained in qualitative interviewing techniques (PRC, MJB, and YM).

Data Analyses

Training Program Metrics

We assessed the successful completion of the DPS training program among participants (attending the initial in-person training session and responding to text messages during the remote follow-up portion), reasons for failure to complete the DPS training program, and the portion (in-person or remote) that was not completed. In addition, we recorded reasons participants did not complete the training program. We also logged all instances where participants contacted the study team during the training program period and over the course of the 90-day parent study and calculated basic descriptive statistics regarding engagement with the DPS training program, defined as the number of times individuals responded to a text message check-in.

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Qualitative Analysis

All interviews were professionally transcribed and checked for errors. Three study team members trained in methods of qualitative analysis (GG, YM, and JN) read all transcripts individually to generate a qualitative codebook. The codebook was developed iteratively using the semistructured interview guide as a framework and consisted of both inductive and deductive themes. Team members reviewed the codebook throughout the development process, adding new codes and resolving discrepancies at each stage. Data related to participants' feedback on the DPS training program were extracted and discussed as a group to develop important themes around user experience.

Results

Training Program Metrics

We enrolled 15 individuals during the study period (Table 1). Most participants used a smartphone with Apple iOS (n=9, 60%). The median age was 32 years (IQR 6.5; range 24-49). A total of 93% (n=14) of individuals reported being on PrEP before the start of the study, and 21% (3/14) of these participants reported missing at least two doses of PrEP over the previous 2 weeks. All individuals completed both the in-person and remote portions of the DPS training program.

Table 1. Demographics of study population (N=15).

Variables	Value
Age (years)	
Median (IQR)	32 (6.5)
Range	24-49
Already prescribed PrEP[a], n (%)	
Yes	14 (93)
No	1 (7)
Nonadherent to PrEP (via self-report)[b], n (%)	
Yes	3 (21)
No	11 (79)
Own a smartphone, n (%)	
Android	6 (40)
Apple	9 (60)

[a] PrEP: pre-exposure prophylaxis.

[b] Defined as missing ≥2 doses over the past 2 weeks. The denominator for this variable is 14, as 14 participants had already been prescribed pre-exposure prophylaxis and 1 had not.

All participants enrolled in the training program were able to log an initial ingestion using the DPS during the in-person session and demonstrated the actual use of the DPS through recorded adherence events during the study period (Figure 3). During the remote text message follow-up portion of the training program, 67% (10/15) participants reported no issues with operating the DPS, whereas 33% (5/15) of participants requested technical assistance. Of those who requested technical assistance, 3 of the participants' queries were resolved asynchronously via email or text message, 3 required real-time support through a telephone call, and 1 required in-person resolution. The nature of the technical challenges included difficulty connecting the Reader to the participant's smartphone via Bluetooth, difficulty operating the mobile app, and technical questions related to charging and traveling with the Reader.

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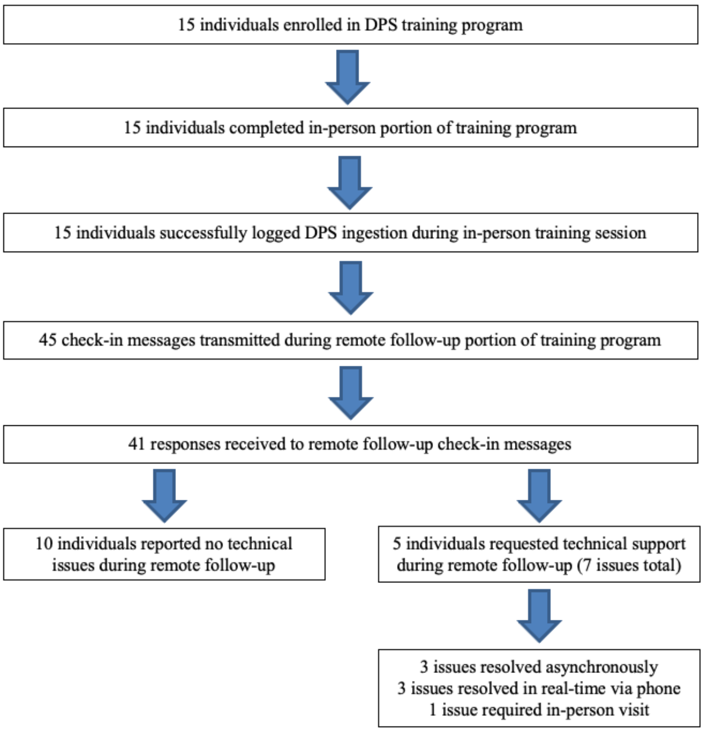
Figure 3. Participant enrollment and interaction with the digital pill system training program. DPS: digital pill system.



During the study period, we transmitted a total of 45 text messages to the 15 enrolled participants. Participants engaged with the DPS messages 91% (41/45 messages) of the time (ie, 41 messages were received from participants in response to DPS check-in messages). Of the 15 participants, 1 (7%) responded to just 1 of the 3 check-in messages, whereas 2 (13%) responded to 2 of the 3 messages, and 12 (80%) responded to all 3 messages. Of the 41 total responses received, 83% (n=34) of messages indicated that participants did not have difficulty operating the DPS, whereas 17% (n=7) of these messages included requests for technical assistance (a breakdown of message responses is given in Table 2).

Table 2. Characteristics of messaging and follow-up during the digital pill system training program.

Text message types	Value, n (%)
Total check-in messages transmitted during study period	45 (100)
Responses received to check-in messages	41 (91)
Participants respondent to 1 of 3 check-in messages	1 (7)
Participants respondent to 2 of 3 check-in messages	2 (13)
Participants respondent to 3 of 3 check-in messages	12 (80)
No difficulty operating the DPS[a]	34 (83)
Request for technical assistance	7 (17)
Asynchronous resolution	3 (43)
Real-time telephone support from study team	3 (43)
In-person assessment of technical issue	1 (14)

[a] DPS: digital pill system.

Of the messages requesting technical assistance, 43% (3/7) were successfully resolved asynchronously and 43% (3/7) were resolved in real time over the phone. One technical issue (1/7, 14%) required an in-person assessment, which was scheduled in addition to the existing study visits in the parent study. It was later determined that the participant had a malfunctioning mobile app and faulty Bluetooth permissions on their smartphone, which prevented successful pairing of the Reader with the phone. Once these issues were rectified, the participant was able to operate the DPS without any further problems. Although the study team remained available to troubleshoot further technological issues during the entire 90-day study period, no participants reported additional issues associated with the DPS after graduation from the training program.

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Qualitative User Experience Feedback

All participants completed a qualitative user experience interview at the end of the 90-day study period. Overall, the participants accepted the DPS training program. They reported that the information provided during the in-person portion of the program was clear, helpful, and adequate for understanding the purpose of the DPS and for troubleshooting minor technological issues. Participants perceived the remote text message follow-up portion of the training program to be highly valuable, as it reminded them to operate the DPS during their first week of use and enabled rapid communication with the study team in the event of technical issues. Participants also discussed a number of potential refinements that could be made to the DPS training program, including repeated refresher sessions on the DPS technology at each subsequent in-person visit (during the 90-day study period), as well as additional written materials to be used for self-guided troubleshooting of technological issues. Selected participant quotes from the qualitative user experience interviews are presented in Textbox 1.

Textbox 1. Qualitative user experience feedback (feedback content area and selected participant quotes).

Experiences with the in-person portion of the digital pill system (DPS) training program

- “I thought that the first class and everything that happened that first day went really well, and you did a great job. [Study team member] made sure I understood everything… how to pair the phone, and how the technology worked, and how to keep track of it. There were clear instructions. There were lots of people standing by to answer questions if I ever had any questions after that” (age 29 years)
- “I think it was fast, efficient. It’s very easy. I think the hardest part would be just to get it set up, but you do that in the meeting, so that was easy” (age 24 years)
- “I think that was sufficient for me. I had no problem understanding the goals and how to interact with the device” (age 32 years)

Experiences with the remote portion of the DPS training program

- “I think I had one issue with repairing my device when my device and my phone disconnected, so I had to ask for the pairing code, but someone was available to respond over text for that. [Study team member] was always available over email, but I didn’t really even need to ask many follow up questions, because that first session was very thorough… I thought it was very, very helpful” (age 29 years)
- “The only thing was… I had the connectivity issues. I didn’t really know exactly what was going on. I think I had texted you, and you got back to me quickly, so I was able to figure it out” (age 40 years)

Suggested improvements to the DPS training program

- “I think it's helpful, but I think every visit, maybe you should go over it, or review it, or actually have the person bring in the technology and show you. That way, it's drilled into their head… I learn by doing, so the more I do something, the easier it becomes to learn… I think that would've been helpful to have written instructions or be in the email… I just forgot some of the things you told me” (age 32 years)
- “I think that someone else who might not be as technologically savvy might want more time, might want somebody to go through it more than once… but for me that was perfectly fine” (age 29 years)
- “I think the only information [to add] is… tools to make sure that the Reader will pick up [the ingestion] and things to look for if it’s not picking up, so the user or the person has ways to troubleshoot it or figure it out when it’s not working” (age 28 years)

Discussion

Principal Findings

The adoption of a DPS to measure medication adherence has important implications for clinical trials, pharmaceutical drug evaluation, and real-world challenges to adherence in various disease states. Although DPSs are designed to be relatively unobtrusive, the requirements for using novel capsule-based dosage forms containing ingestible sensors and a wearable Reader device that is paired with a smartphone may present challenges to adherence to the DPS. Similar to other novel technologies, training participants to correctly operate the DPS is an important first step toward obtaining reliable and accurate adherence data. Although previous investigations have described the feasibility of deploying a DPS among individuals to measure medication adherence, few studies have described best practices around training study participants to use the DPS [19,20]. This investigation is the first to describe a simple, scalable training program, grounded in the TAM, which teaches individuals how to operate the DPS and adhere to DPS instructions for use. MSM who participated in the study were able to accept and engage with the DPS training program. We anticipate that research groups who wish to adopt the DPS to measure adherence behavior in their participants can adapt this training program to standardize training procedures across enrolled participants or in the setting of clinical care.

For MSM, a DPS is acceptable as a method to measure PrEP adherence, but a critical gap remains in understanding how best to impart tools to help MSM operationalize DPS. MSM account for most of the new HIV infections in the United States, and co-occurring psychosocial epidemics of mental illness and substance use in MSM are associated with further increased HIV incidence [21,22]. People who use drugs are at an elevated risk for HIV because of high rates of both drug-related and sexual HIV risk behaviors. Neurocognitive impairment is also prevalent in this population and may serve as a barrier to optimal PrEP adherence. Together, these factors suggest that MSM who use substances face unique barriers to PrEP adherence and may benefit from technology-assisted adherence interventions such as the DPS [23-25]. Although other investigations have described the use of DPS in other disease states, this is the first

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study to provide a description of optimal training methods that imparts key skills in DPS operation in a standardized fashion. By standardizing training, this ensures that all critical factors associated with a successful DPS operation can be delivered to individuals using this technology.

Operationalizing the deployment of the DPS will ultimately depend on users' experiences and acceptance of the tool, as well as robust methods for ensuring consistent use of the technology to receive actionable adherence data. By using the TAM to inform the development of our DPS training program, we were able to identify and understand participants' perceived uses of the DPS, integrate potential barriers related to the intended uses of the technology into the program, and provide ongoing support for actual real-world use. The preliminary findings from our qualitative user experience interviews demonstrate that the training program was acceptable for teaching participants important skills associated with operating the DPS. Participants reported that both the in-person and remote follow-up components of the program were valuable for providing and reinforcing operational skills, as well as for efficient communication with the study team for the purpose of troubleshooting technological issues. Continued DPS refresher sessions, as well as enhanced written materials for resolving technological issues related to DPS use, were among participants' proposed improvements to the training program. These data suggest that a variety of individuals can effectively and efficiently train future DPS users using this training program.

In the future, we anticipate that a training program such as that described here can be integrated into a starter package for DPS enrollment. Users may access the training program in a number of settings, including independently as part of a package sent directly to their homes or within a pharmacy while picking up their medications. Alternatively, in models where a DPS is used as a booster package when other adherence monitoring methods such as self-report or pharmacological measures have already detected nonadherence, this training program can capitalize on TAM pillars of perceived use and actual use to rapidly orient the user to the DPS and produce actionable data to improve adherence behavior. Finally, we intentionally designed the training program in such a way that it could be deployed by individuals with minimal training, to maximize its potential scalability. The study team members underwent a brief orientation to the DPS from the manufacturer (etectRx Inc) and received instructions on how to operate the system. After demonstrating competence in the DPS operation internally, they were cleared by the principal investigator to deliver the structured training program directly to the study participants.

The operational skills taught in this DPS training program can serve as a toolbox to help individuals who use these systems to measure adherence. Although we used this training program to teach operational skills to individuals using a DPS for the first time, periodic booster training programs may also be used to reinforce the use of the digital pill over the long term. The ideal structure of a DPS should include detailed plans for responding to nonadherence detected through the technology, whether in the form of in-person adherence assessments at clinical appointments, phone calls from care teams monitoring adherence behavior, or the automated messaging architecture to respond directly to DPS users following missed doses or changes in patterns of medication use. Ideally, any nonadherence-related assessments should also include an exploration of adherence to the DPS technology itself. Our data suggest that using a simple text message–based system can help detect potential technical difficulties associated with a DPS operation and can mitigate these barriers before participants' disengagement with the technology. Even when significant technical issues arise that impair the ability of the DPS to measure and report adherence, a training program can quickly diagnose these issues and allow a research or clinical team to determine the level of support needed to intervene.

Strengths and Limitations

This study had several limitations. First, we developed this DPS training program with a special focus on adherence to once-daily PrEP, and adherence to other medications may require specific and distinct instructions for integration with a DPS, to which PrEP-related guidelines may not be generalizable. However, we note that our training program can be easily modified to incorporate instructions specific to other xenobiotics. Second, we conducted the study at a single site with MSM who were young, well educated, and already engaged in health care services as well as research participation. The operation of a DPS may present specific barriers to other populations, especially those with less experience with novel technologies or who lack access to a smartphone. Third, the sample size of this preliminary pilot study was relatively small, and the findings may therefore not be representative of HIV-negative MSM who use substances. Finally, the parent study was conducted to understand the feasibility and acceptability of the DPS, and we therefore did not consider factors that would be required to integrate the training program of the DPS with clinical workflows.

Conclusions

Overall, this study demonstrates that a brief DPS training program consisting of in-person instruction and asynchronous text message–based follow-up can identify potential technical issues associated with the initial use of a DPS to measure medication adherence. The training program is simple to implement, requires only a single in-person visit, and can be adapted as a tool to integrate the DPS into adherence strategies in various disease states. Future studies to evaluate the efficacy of this educational intervention in the deployment of this novel technology for specific patient populations are required.

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Authors' Contributions

PRC was the principal investigator of the study and was involved in all methodological decisions and data collection efforts. PRC, KHM, RKR, EWB, and CO were responsible for the conception and design of the study. MJB, GG, and YM contributed to the study design, recruited participants, and collected all the data. MJB, GG, SLB, and PEA conducted data management and analyses, with oversight from PRC. SLB and PEA assisted with the retrieval of data from the web-based platform and provided valuable insights regarding the interpretation of the results. JCM and RPC contributed to field expertise throughout the process of data collection and manuscript preparation. PRC, MJB, and GG drafted the manuscript, with contributions from YM, JN, MCS, JCM, RPC, KHM, RKR, SLB, PEA, EWB, and CO. All authors reviewed and approved the final manuscript.

Conflicts of Interest

SLB and PEA are employees of etectRx.

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Abbreviations

DPS: digital pill system
MSM: men who have sex with men
NIH: National Institutes of Health
PrEP: pre-exposure prophylaxis
TAM: Technology Acceptance Model

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Original Paper

Mobile Sensing Apps and Self-management of Mental Health During the COVID-19 Pandemic: Web-Based Survey

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Abstract

Background: During the COVID-19 pandemic, people had to adapt their daily life routines to the currently implemented public health measures, which is likely to have resulted in a lack of in-person social interactions, physical activity, or sleep. Such changes can have a significant impact on mental health. Mobile sensing apps can passively record the daily life routines of people, thus making them aware of maladaptive behavioral adjustments to the pandemic.

Objective: This study aimed to explore the views of people on mobile sensing apps that passively record behaviors and their potential to increase awareness and helpfulness for self-managing mental health during the pandemic.

Methods: We conducted an anonymous web-based survey including people with and those without mental disorders, asking them to rate the helpfulness of mobile sensing apps for the self-management of mental health during the COVID-19 pandemic. The survey was conducted in May 2020.

Results: The majority of participants, particularly those with a mental disorder (n=106/148, 72%), perceived mobile sensing apps as very or extremely helpful for managing their mental health by becoming aware of maladaptive behaviors. The perceived helpfulness of mobile sensing apps was also higher among people who experienced a stronger health impact of the COVID-19 pandemic (β=.24; 95% CI 0.16-0.33; *P*<.001), had a better understanding of technology (β=.17; 95% CI 0.08-0.25; *P*<.001), and had a higher education (β=.1; 95% CI 0.02-0.19; *P*=.02).

Conclusions: Our findings highlight the potential of mobile sensing apps to assist in mental health care during the pandemic.

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KEYWORDS

app; awareness; behavior; COVID-19; helpfulness; mobile health; mobile sensing; self-management; sensing; web-based survey

Introduction

COVID-19 has currently affected over 213 countries [1]. In the absence of vaccines and antivirals, the remarkable speed and global spread of COVID-19 could so far only be reduced by rigorous implementation of traditional public health measures [2], such as quarantine and physical distancing. People have had to adapt their daily life routines to the currently implemented public health measures, which is likely to have resulted in a lack of in-person social interactions, physical activity, or sleep. These factors are known to have a significant impact on mental health, especially among vulnerable populations such as individuals living with a mental disorder. Preliminary health reports describe the adverse effects of the pandemic and its countermeasures on a range of aspects of mental health, including higher rates of anxiety, depression, abuse, and self-harm [3].

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The recent proliferation of mobile sensing apps offers novel opportunities to monitor people's behavior, thus potentially holding great promise for the self-management of mental health during the COVID-19 pandemic. Based on their passively recorded mobile sensing data, people could become aware of how their behaviors changed during the pandemic. For example, based on the global positioning system, accelerometer, and phone usage data, people could infer whether they are socially isolated, sleeping poorly, physically inactive, or not leaving their homes [4]. Importantly, such self-monitoring via mobile sensing has been previously shown to successfully increase people's self-awareness [5]. Self-awareness is theorized to reflect an automatic process by which people compare their current behaviors to their internalized standards and is the first step to self-regulation; that is, the adaption of people's actual behavior to their idealized behavior [6]. Thus, during the pandemic, mobile sensing apps might increase people's awareness of maladaptive behavioral changes, thereby potentially motivating them to engage in health-promoting behavior. Such self-management becomes especially important in a scenario in which a many of the health services and social infrastructures that normally bolster against mental health problems during emergencies have been withdrawn [7].

We hypothesize that mobile sensing apps can increase self-awareness and thereby have a potential for limiting the adverse consequences of the pandemic on mental health. To test this hypothesis, we conducted a web-based survey to explore whether mobile sensing apps are perceived as helpful tools by people with and those without mental disorders for self-managing their mental health during the COVID-19 pandemic by increasing awareness for potential maladaptive behaviors.

Methods

Recruitment

We chose Amazon Mechanical Turk (AMT) as our web-based platform as it would facilitate rapid, large-scale participant recruitment [8]. Importantly, AMT has become an increasingly accepted means of collecting responses from diverse participants [9]. We therefore ran an anonymous web-based survey from May 23 to June 7, 2020. Following AMT's standard procedure, we advertised the study and the qualification criteria on the platform worldwide. Interested participants clicked the link and responded to the survey. The survey was created using Dalhousie University's online survey platform Opinio. Participants received financial compensation for responding to the survey questions, which required 20 minutes of their time on average. All participants provided fully informed consent on the web-based platform. From among all participants aged ≥18 years, those who provided incorrect responses to 5 attention check questions and those who provided incomplete responses were excluded.

Survey

Participants rated their agreement with the statement, "a mobile phone–based tracking application for health and well-being will be helpful in a pandemic or crisis situation like COVID-19," on a 5-point Likert scale ranging from 1="not at all" to 5="extremely." Answers to this question defined our outcome of interest; that is, the perceived helpfulness of mobile sensing apps. The concept of mobile sensing apps was introduced through multiple examples of what type of sensors might be used in mobile sensing apps and what behavioral insights might be obtained from these sensor data. In particular, we asked participants to rate the likeability and comfort with different mobile sensing features (Multimedia Appendix 1). Such questions have been previously shown to successfully convey the concept of mobile sensing apps [10].

Participants provided further information on the predictors of perceived helpfulness such as basic demographics (age, gender, and education) and their mental health history (with responses of "yes," "no," or "prefer not to answer"). We also asked participants to rate their technology knowledge on a 5-point Likert scale ranging from 1="poor" to 5="excellent." Finally, we asked participants to rate the extent to which the COVID-19 pandemic has impacted their overall health and well-being, on a 5-point Likert scale ranging from 1="not at all" to 5="extremely." An overview of all questions is provided in Multimedia Appendix 1.

We set the type I error rate (Cronbach α) at .05. Power analysis indicated that a sample of at least 410 participants would be required to detect a moderate effect (Cohen d=0.5) of our predictors with a power of 0.95.

Statistical Analysis

After testing for homoscedasticity (determined using the Breusch–Pagan test [11]) and multicollinearity (determined from the variance inflation factor [12]), we used a linear model with the perceived helpfulness of mobile sensing apps as the outcome of interest and age, gender, education, mental health history, health impact of the COVID-19 pandemic, and technology knowledge as independent predictors. Additionally, we explored potential mediating effects based on the Sobel test [13]. SPSS (version 25, SPSS Inc) was used for all data analyses, and significance was set at P<.05.

Ethics

All study procedures comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the tenets of the 2008 revision of the 1975 Helsinki Declaration. All procedures were approved by the research ethics board at Dalhousie University. Furthermore, this study complies with the General Data Protection Regulation.

Results

Cleaning for incorrect and missing responses resulted in a survey sample of 474 participants, most of whom were from the United States (n=237, 50%) or India (n=175, 37%). Of them, 235 (50%) were aged 25-34 years, 170 (36%) were female, and 148 (31%) had a history of a mental disorders (Table 1).

The majority of our participants (n=312, 66%) perceived mobile sensing apps as "very" or "extremely" helpful for managing mental health during the COVID-19 pandemic. In total, 106 of the 148 (72%) participants with a history of a mental disorder found mobile sensing "very" or "extremely" helpful, whereas

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only 206 of 326 (63%) participants without a history of a mental disorder provided such responses (Figure 1). This difference was statistically significant, being controlled for age, sex, education, and technology knowledge (β=.12; 95% CI 0.03-0.21; *P*=.01), but fell short of significance after adjusting for the perceived health impact of the COVID-19 pandemic (β=.08; 95% CI –0.01 to 0.17; *P*=.06).

Specifically, participants with a history of a mental disorder reported experiencing a stronger health impact of the COVID-19 pandemic (β=.14; 95% CI 0.05-0.23; *P*=.002), which mediated the effect of a history of a mental disorder on the perceived helpfulness of mobile sensing (Sobel test, *P*=.01). Moreover, participants who experienced an even stronger health impact of the COVID-19 pandemic (β=.24; 95% CI 0.16-0.33; *P*<.001) had more technology knowledge (β=.17; 95% CI 0.08-0.25; *P*<.001), and those who had a higher education rated mobile sensing apps as more helpful (β=.10; 95% CI 0.02-0.19; *P*=.02); no differences were observed by age or gender (Table 2).

Table 1. Participant characteristics (N=474).

Characteristic	Participants
Age (years), n	
18-24	90
25-34	235
35-44	75
≥45	74
Gender, n	
Female	170
Male	304
Education, n	
High school	51
Bachelor's degree	336
Master's degree	87
Previously diagnosed with a mental disorder, n	
Yes	148
No	324
Health impacted by the COVID-19 pandemic, mean (SD)	4.10 (0.70)
Have technology knowledge, mean (SD)	3.29 (1.14)

Figure 1. Perceived helpfulness ratings of mobile sensing apps during the COVID-19 pandemic.

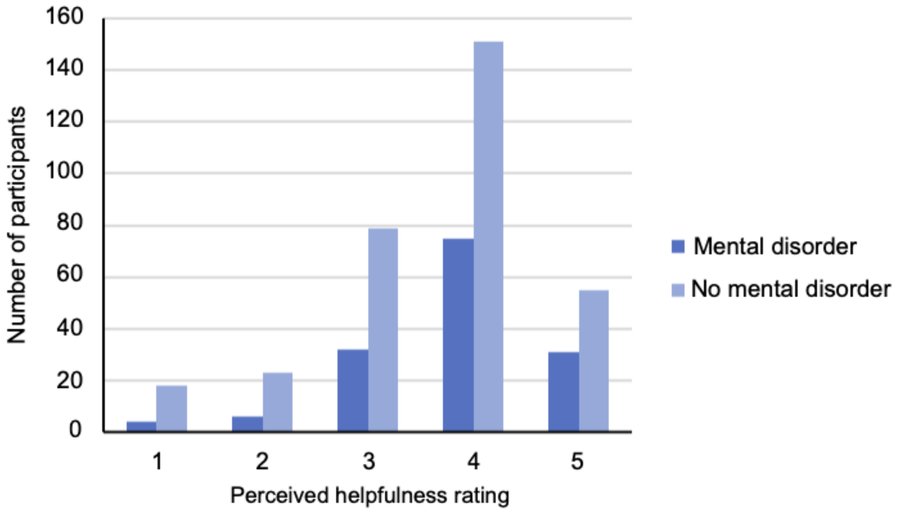

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Table 2. Linear regression model of the perceived helpfulness of mobile sensing apps.

Parameter	β	SE	*P* value
Age	–0.07	0.05	.13
Gender	0.06	0.09	.18
Education	0.10	0.08	.02
Technology knowledge	0.17	0.06	<.001
History of a mental disorder	0.08	0.09	.06
Health impact of the COVID-19 pandemic	0.24	0.04	<.001

Discussion

Principal Findings

Our findings indicate that mobile sensing apps that passively track the daily life behaviors of people are perceived as very helpful tools for the self-management of mental health during the COVID-19 pandemic. People with and those without mental disorders considered mobile sensing apps as helpful for the self-management of their mental health during the pandemic, although people with mental disorders found them slightly more helpful. Importantly, people with mental disorders are reportedly at a higher risk of severe clinical outcomes of COVID-19 [14], and their mental health has deteriorated more during the pandemic compared to their counterparts without a history of mental disorders [15,16]. Concurrent with these previous reports, people with mental disorders reported a higher health impact of the COVID-19 pandemic in our study. Our results further indicate that this experience of a higher health impact of the COVID-19 pandemic is mediating the observed effect of the history of mental disorders on the perceived helpfulness of mobile sensing apps. In other words, people with mental disorders likely consider mobile sensing apps as more helpful as they struggle more with the impact of the COVID-19 pandemic than their counterparts without mental disorders.

Fringe events such as the COVID-19 pandemic provide opportunities to examine how mental health and behaviors deviate from baseline. Initial mobile sensing studies during the COVID-19 pandemic indicated that mobile sensing apps can identify maladaptive behaviors such as decreased physical activity and increased screen time [17,18]. In this regard, studies have consistently shown that physical activity, particularly aerobic activity, reduces self-reported mental health symptoms [19]. Other studies have shown that increased sedentary time, along with increased phone usage, is implicated in depression and anxiety [20]. Thus, from a health belief model [21] perspective, mobile sensing apps can help people become aware that it is possible to adopt behaviors in order to improve their mental health even during the pandemic; for example, reducing their sedentary and screen times. In addition, while mobile sensing apps can be beneficial for self-management, they can also provide cues to clinicians on how to best assist their patients during the pandemic, if patients agree to share their mobile sensing data with them. Importantly, while this study specifically explored whether mobile sensing apps could be useful to identify maladaptive changes in behavior during the pandemic, we believe that mobile sensing apps will be of value for the self-management of mental health symptoms beyond the context of the pandemic as well. For example, people might be struggling to revert to their prepandemic routines; thus, by increasing self-awareness, mobile sensing apps could help people revert to healthy routines more easily.

An important of caveat of mobile sensing apps is that there are some limitations to the interpretation of the recorded data. When people stay at home, they may not have their mobile phones with them at all times, which could lead to the overestimation of their sedentary time. Additionally, people may be preferentially accessing larger screens such as tablets or laptops; therefore, mobile phone usage may underestimate the total amount of screen time. Such shortcomings will need to be considered in the design of mobile sensing apps for mental health care.

While our results indicate that gender and age do not seem to impact the perceived helpfulness of mobile sensing apps for self-management of mental health during the pandemic, participants with high technology knowledge were more likely to find mobile sensing apps helpful. Accordingly, increasing the technology knowledge of users would be a crucial step for the acceptance and usability of mobile sensing apps for mental health care. Future studies should aim to further the current understanding of additional characteristics that might determine perceived helpfulness in order to enable efficient integration of mobile sensing apps in current mental health care models.

Limitations

A considerable limitation of our survey is that our sample, though well-stratified and diverse, was not randomly recruited; people who have an interest in mobile sensing technologies might have been more likely to take part in this web-based survey. Our data might further be slightly biased by social desirability. However, we assume that such effects should only have been minimal, considering the anonymity of participants maintained throughout the survey. Nevertheless, our data suggest that a substantial number of people perceive mobile sensing apps as helpful tools for managing their mental health during the pandemic-related lockdown.

Conclusions

Our findings indicate that the use of mobile sensing apps might have the potential to directly reduce the burden on the mental health care system during the COVID-19 pandemic by promoting better self-management. People with and those without mental disorders found mobile sensing apps as helpful to self-manage their mental health during the pandemic, although

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those with a mental disorder found such apps especially useful. By making users aware of maladaptive changes in their behaviors, mobile sensing apps can assist and motivate people to take better care of their mental health, preventing novel onsets or a worsening of mental disorders. Remote empowerment of people in mental health care must be considered especially valuable as standard ways of delivering care have been severely compromised during the COVID-19 pandemic. Finally, the ability of mobile sensing apps to increase self-awareness might have the potential to advance current health care models beyond the context of the current pandemic.

Authors' Contributions

BS, RO, LW, and SM designed the study. BS and RO recruited the participants. BS, KB, and SM conducted the analyses. BS, KB, and SM drafted the manuscript. AB, LW and PM assisted in the clinical presentation. All authors critically revised the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey Questions.
[DOCX File , 228 KB - formative_v5i4e24180_app1.docx]

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Abbreviations

AMT: Amazon Mechanical Turk

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Original Paper

Evaluation of the Implementation and Effectiveness of Community-Based Brain-Computer Interface Cognitive Group Training in Healthy Community-Dwelling Older Adults: Randomized Controlled Implementation Trial

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Abstract

Background: Cognitive training can improve cognition in healthy older adults.

Objective: The objectives are to evaluate the implementation of community-based computerized cognitive training (CCT) and its effectiveness on cognition, gait, and balance in healthy older adults.

Methods: A single-blind randomized controlled trial with baseline and follow-up assessments was conducted at two community centers in Singapore. Healthy community-dwelling adults aged 55 years and older participated in a 10-week CCT program with 2-hour instructor-led group classes twice a week. Participants used a mobile app to play games targeting attention, memory, decision making, visuospatial abilities, and cognitive flexibility. Implementation was assessed at the participant, provider, and community level (eg, reach, implementation, and facilitators and barriers). Effectiveness measures were the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), Color Trails Test 2 (CTT-2), Berg Balance Scale, and GAITRite walkway measures (single and dual task gait speed, dual task cost, and single and dual task gait variability index [GVI]).

Results: A total of 94 healthy community-dwelling adults participated in the CCT program (mean age 68.8 [SD 6.3] years). Implementation measures revealed high reach (125/155, 80.6%) and moderate adherence but poor penetration of sedentary older adults (43/125, 34.4%). The effectiveness data were based on intention-to-treat (ITT) and per-protocol (PP) analysis. In the ITT analysis, single task GVI increased (b=2.32, P=.02, 95% CI [0.30 to 4.35]) and RBANS list recognition subtest deteriorated (b=–0.57, P=.01, 95% CI [–1.00 to –0.14]) in both groups. In the PP analysis, time taken to complete CTT-2 (b=–13.5, P=.01, 95% CI [–23.95 to –3.14]; Cohen d effect size = 0.285) was faster in the intervention group. Single task gait speed was not statistically significantly maintained in the intervention group (b=5.38, P=.06, 95% CI [–0.30 to 11.36]) and declined in the control group (Cohen d effect size = 0.414). PP analyses also showed interaction terms for RBANS list recall subtest (b=–0.36, P=.08, 95% CI [–0.75 to 0.04]) and visuospatial domain (b=0.46, P=.08, 95% CI [–0.05 to 0.96]) that were not statistically significant.

Conclusions: CCT can be implemented in community settings to improve attention and executive function among healthy older adults. Findings help to identify suitable healthy aging programs that can be implemented on a larger scale within communities.

Trial Registration: ClinicalTrials.gov NCT04439591; https://clinicaltrials.gov/ct2/show/NCT04439591

(JMIR Form Res 2021;5(4):e25462) doi:10.2196/25462

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KEYWORDS

group-based computerized cognitive training; cognition; gait; community program implementation; healthy older adults; cognitive; community program; cognitive training; elderly; aging

Introduction

Cognitive functions decline with age but can be maintained or improved through training [1,2]. Cognitive training involves structured, frequent, and repeated engagement in standardized cognitively demanding tasks targeting specific cognitive domains [3]. In old age, the brain still possesses neural plasticity, or the lifelong ability for physical and functional change in response to sensing, perceiving, and learning. Cognitive training can stimulate neuroplasticity and increase cognitive reserve in older adults [4]. Cognitive stimulation results in molecular, synaptic, and neural alterations in animal brains [5]. In humans, cognitive training increased serum brain-derived neurotropic factor, which plays an important role in memory processing [6]. Brain imaging post training revealed changes in brain activity during task performance, along with long-term global changes [7].

Technological advancements have encouraged the rise of computerized cognitive training (CCT). A meta-analysis concluded that CCT was modestly effective at improving cognitive performance in healthy older adults [8]. However, efficacy varied across cognitive domains and was largely determined by the study designs. Small to moderate effect sizes were found for verbal and nonverbal memory, working memory, processing speed, and visuospatial abilities but not for executive function and attention [8]. The same study also found that group-based training was more effective than home-based training with limited benefit when training more than 3 times per week, potentially due to the presence of direct supervision by a trainer in a group-based training to ensure adherence, treatment fidelity, compliance, and motivational support to master challenging tasks that are otherwise easy to avoid [8]. Another review uncovered improvements in everyday functioning and neuropsychological tests in untrained tasks [1]. Cognitive processing also plays an important role in balance and gait and reduced cognitive processing speed is a contributing factor to falls in older adults. This relationship may be explained by the fact that higher order cognitive functions (eg, executive functions) are called upon while walking. Attention and executive functions are associated with mobility, and several studies have shown that CCT improved gait speed and balance, with greater efficacy for sedentary older adults with low gait speed [9-12].

Other than an online study in healthy older adults [13], most studies have evaluated the efficacy of CCT on cognition and real-world function in healthy adults in research settings; there have been few implementation studies in real-world settings. Sufficient evidence exists for research to move beyond laboratory trials to evaluate CCT implementation and effectiveness in community-based settings [1].

In Singapore, two laboratory trials improved cognitive function in healthy older adults but showed inconsistent efficacy across cognitive domains [14,15]. These studies used the developmental version of a brain-computer interface cognitive training program, which has been commercialized (NeeuroFIT) and can be delivered as a community-based CCT program.

Therefore, in this study we aim to evaluate (1) the implementation of this community-based CCT at the participant, provider, and community level and (2) its effectiveness on cognition, gait, and balance in healthy older adults. We followed the approach to cognitive training targeting attention, memory, decision making, visuospatial abilities, and cognitive flexibility developed and implemented by the developer of the cognitive training program.

Methods

Setting

Community centers are neighborhood public spaces designed to provide sports, enrichment programs, and amenities. Community centers are equipped with the facilities and administrative processes that would support community-based CCT implementation and would be suitable sites for eventual wider community adoption of CCT. The CCT developer (Neeuro Pte Ltd) partnered with two community centers to offer the program at a subsidized rate with aid from a social enterprise grant.

Participants

Healthy community-dwelling adults aged 55 years and older participated in the CCT between September 2017 and November 2018. We targeted 55 years and above as that is the age for withdrawal of retirement funds from the national savings scheme in Singapore. As some may choose to retire at this age, there is demand for health-related activities. Recruitment was conducted at two community centers in western Singapore. The study initially sought to recruit sedentary older adults who exercised less than once per week. However, most participants at the first community center were not sedentary. As such, participants at both community centers were recruited regardless of their exercise frequency. The exclusion criteria were: (1) unable to understand English or Mandarin, (2) cognitive impairment (ie, modified Mini-Mental State Examination score ≤23), (3) diagnosis of neuropsychiatric disorder(s), (4) ongoing use of psychotropic medications, (5) depression (ie, Geriatric Depression Scale >9), (6) severe walking or balance impairments (eg, wheelchair-dependent), (7) self-reported vertigo, (8) visual acuity <20/80, (9) color-blind, (10) participation in a cognitive training program within the past year, or (11) plans for a balance training program during the study period. The study was conducted in accordance with the Declaration of Helsinki and received ethics approval from the National Healthcare Group’s Domain Specific Review Board. Written informed consent was obtained from all participants prior to study enrollment.

Intervention

The 10-week CCT program (NeuroFIT) consisted of 2-hour instructor-led group classes conducted twice a week in English

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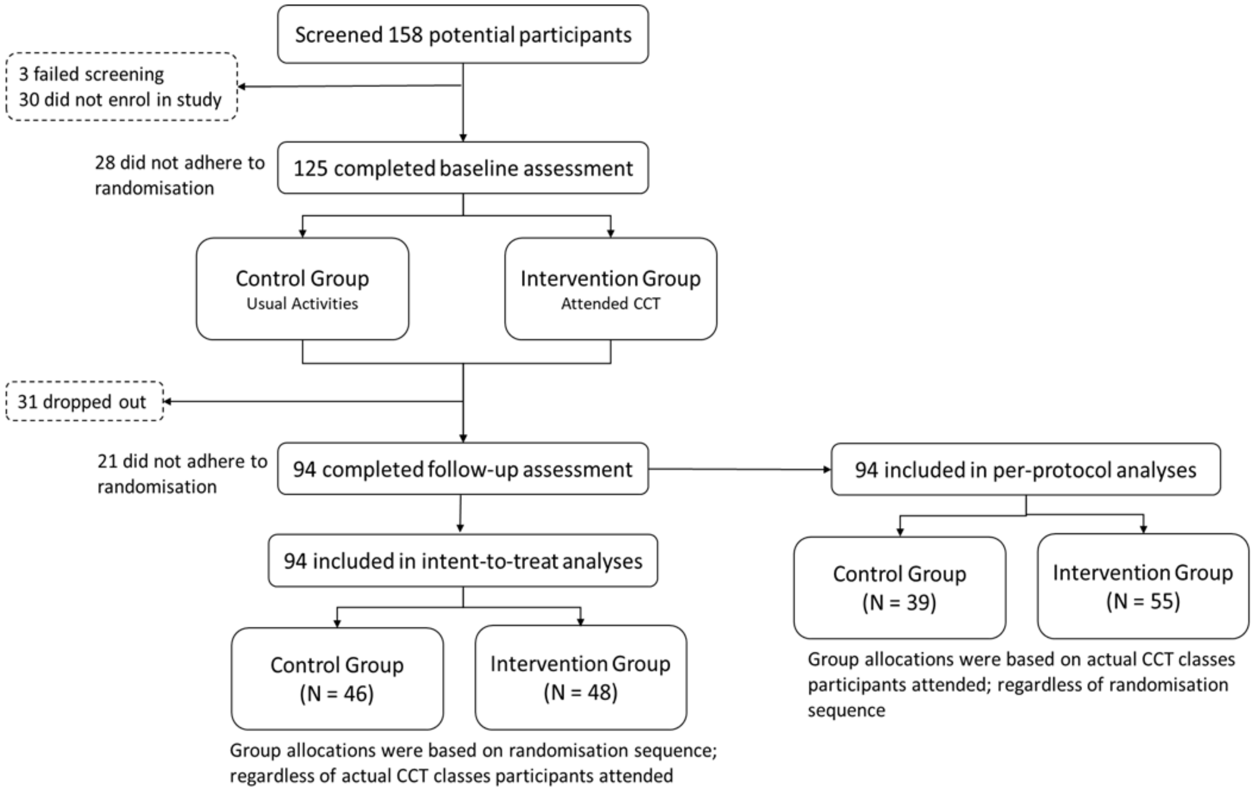
or bilingually (ie, English and Mandarin). Trained instructors guided participants through game-based training targeting attention, memory, decision making, visuospatial abilities, and cognitive flexibility using a mobile app (Memorie, Neeuro Pte Ltd). CCT was gamified to enable sustained interest and facilitate adaptive training where participants progressed to more cognitively demanding levels. Selected games were paired with an electroencephalography headset (Senzeband, Neeuro Pte Ltd) that quantified users' attention into scores that influenced their in-game avatar control or game performance. Participants paid a subsidized fee of SGD $20 (US $15) for the CCT.

Procedure

Within each community center, participants were randomized into the intervention or waitlist control group. Randomization sequence for the first community center was generated using Excel (Microsoft Corp) by a CCT provider staff member with no participant contact. Randomization sequence for the second community center was generated via a web-based randomization service by a biostatistician without participant contact [16]. A single-blind randomized controlled trial (RCT) design with baseline and follow-up assessment was used (Figure 1). Participants were blinded in this study. The control group continued with their usual activities while the intervention group attended CCT. Assessments were completed within 2 weeks of the CCT.

Figure 1. Participant flow diagram. CCT: computerized cognitive training.



Outcome Measures

Implementation Measures

Implementation was assessed at the participant, provider, and community level (Multimedia Appendix 1) [17]. The table describes measures taken at each of the levels and the type of data collected.

Effectiveness Measures

Assessments were conducted in English or Mandarin by trained study team members blinded to group allocation. Participants completed the Color Trails Test 2 (CTT-2) prior to the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) to prevent fatigue induced by RBANS from influencing CTT-2 performance. The order of other assessments was not fixed. Forms A and B of the CTT-2 and RBANS were used for baseline and follow-up assessments, respectively, to minimize learning effects. Standardized test instructions were translated from English to Mandarin for Mandarin-speaking participants.

The CTT-2 assessed sustained visual attention, executive function, and visuomotor skills [18]. This test possesses test-retest reliability and has convergent validity with the Trail Making Test, which indexes attention, visuospatial abilities, and cognitive flexibility [18]. As compared with the Trail Making Test, CTT-2's use of colors instead of letters renders it more cross-culturally appropriate, especially in the current sample that consists of both English and Mandarin speakers.

RBANS, the primary effectiveness outcome measure, is a neuropsychological battery comprising 12 subtests assessing 5 cognitive domains: immediate memory, visuospatial, language, attention, and delayed memory. It is reliable and has been validated against other tests assessing corresponding cognitive

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domains [18-20]. This study used RBANS Form A modified by the Singapore Longitudinal Aging Studies research team for Singaporean older adults [21]. To minimize differences in test difficulty across forms, subtest scores were standardized within each assessment (ie, across groups) before being summed to derive the domain scores and total score. Given inconsistencies in prior studies [14,15], analyses would assess changes in RBANS total score, domain scores, and subtest scores.

The Berg Balance Scale assesses balance via performance on 14 functional tasks [22]. Performance for each task was scored independently using a 0 to 4 scale, with higher scores reflecting better balance. Individual task scores were summed to derive a composite score for analyses.

Gait assessments were conducted using the 6 meter GAITRite walkway [22]. Participants started 1 meter behind the walkway and walked to a chair placed 1 meter past the end of the walkway. Under the single task condition, participants walked at their habitual walking speed. Under the dual task condition, participants walked while performing serial sevens subtraction. Participants were not instructed to prioritize either the cognitive or walking task. After attempting the dual task, participants completed serial sevens subtraction while seated. Participants completed 1 practice trial and 3 actual trials for each condition. Calculated using the mean of the actual trials, gait parameters examined in analyses included (1) single task gait speed (cm/s), (2) dual task gait speed (cm/s), (3) dual task cost, (4) single task gait variability index (GVI), and (5) dual task GVI. Dual task cost was derived using

GVI was calculated as in Gouelle et al [23].

Statistical Analyses

Some participants did not adhere to the randomization sequence (Figure 1). As such, 2 sets of parallel analyses were conducted. Intention-to-treat (ITT) analyses were based on the randomization sequence regardless of actual CCT class attendance. Per-protocol (PP) analyses grouped participants based on the CCT classes they attended regardless of the randomization sequence. Baseline group differences were examined using Pearson chi-square tests for categorical data, independent samples t tests for parametric data, and Mann-Whitney U tests for nonparametric data. Changes in outcome variables were explored using mixed models with missing data handling. Missing data were assumed to be missing at random. This assumption was made when dummy variables were created for missing variables (1 as missing; 0 as observed), and t tests and chi-square tests were performed between these dummy variables and other variables. The missingness on these variables was found to be related to the values of other variables. Parametric outcome variables were estimated using maximum likelihood with robust standard errors, while nonparametric data were assumed to be right censored and were estimated using maximum likelihood. A 2-sided P value of .05 was deemed statistically significant; no adjustments were made despite multiple comparisons for RBANS due to the explorative nature of these analyses. Statistical analyses were completed using R (version 3.4.4, R Foundation for Statistical Computing) and MPlus (version 7.11, UCLA Statistical Consulting Group).

Results

Implementation Measures: Participant Level

Of 155 individuals screened, 125 agreed to participate and completed a baseline assessment indicating reach as 80.6% (Figure 1). Moderate adherence was observed. First, 22.4% (28/125) of participants did not adhere to the randomization sequence (eg, due to conflicting schedules). Of these, 64% (18/28) attended CCT classes for the intervention group despite being randomized to the control group. The remaining 10 switched from intervention group to the control group. Second, the dropout rate was 24.8% (31/125) with no observed group differences in ITT (P=.38; Multimedia Appendix 2) or PP analyses (P=.20; Table 1). Third, participants attended 80% (16/20) of classes. Class attendance for the intervention group was higher than the control group in ITT (P=.02; Multimedia Appendix 2) and PP analyses (P=.03, Table 1).

Facilitators and barriers to CCT participation were obtained from participant feedback and observations by the study team. CCT classes, the mobile app, and electroencephalography headset were well received. Trainers’ in-class guidance and encouragement motivated participants to continue with classes and increasingly cognitively demanding games. A few expressed interests in more advanced level CCT. Barriers to program participation included busy schedules, loss of interest in CCT, and loss to follow-up. A few cited fatigue from prolonged screen use, noisy class environment, difficulty in selected games, and belief that CCT was ineffective. Two control group participants from the first community center dropped out from follow-up assessment and CCT as they did not receive reminders regarding CCT commencement. The program provider ensured that all participants from the second community center were reminded prior to CCT. Program participation was also influenced by proximity to implementation sites and strength of community ties. Most participants from the first community center lived near the community center and were well acquainted with each other and the community center staff. In contrast, the second community center was newer, and strong community ties had not been established. A substantial proportion of participants lived further away from the second community center. Such disparities likely explained the lower dropout rate at the first community center (n=12, 19%) as compared with the second community center (n=20, 32%, P=.11).

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Table 1. Baseline characteristics.

Characteristic	Intervention group (n=55)	Control group (n=39)	*P* value
Age (years), mean (SD)	68.05 (6.56)	69.83 (5.86)	.13
Female, n (%)	39 (71)	29 (74)	.71
Ethnicity, n (%)	—[a]	—	.81
Chinese	54 (98)	38 (97)	—
Indian	1 (2)	1 (3)	—
Highest education, n (%)	—	—	.06
Primary and below	15 (27)	6 (15)	—
Secondary	23 (42)	20 (51)	—
Postsecondary	14 (26)	10 (26)	—
Tertiary and above	3 (6)	3 (8)	—
Preferred language, n (%)	—	—	.92
English	26 (37)	18 (46)	—
Mandarin	29 (53)	21 (54)	—
Modified Mini-Mental State Examination, mean (SD)	28.11 (1.78)	28.46 (1.52)	.33
Geriatric Depression Scale, mean (SD)	0.84 (1.23)	1.08 (1.51)	.36
Sedentary[b], n (%)	21 (38)	11 (28)	.32
Class attendance, mean (SD)	17.24 (2.92)	14.28 (6.16)	.03
Adhered to randomization[c], n (%)	41 (75)	32 (82)	.39
Dropouts, n (%)	14 (20)	17 (30)	.20
RBANS[d]	—	—	—
Story memory subtest, mean (SD)	–0.17 (0.98)	0.36 (0.81)	.006
Story recall subtest, mean (SD)	–0.08 (1.02)	0.33 (0.84)	.05

[a] Not applicable.

[b] Exercised less than once per week.

[c] Attended computerized cognitive training according to randomization sequence.

[d] RBANS: Repeatable Battery for the Assessment of Neuropsychological Status. Subtest scores were standardized within each assessment (ie, across groups) before being summed to derive the domain scores and a total score; baseline differences between the intervention and control group were examined using Pearson chi-square tests for categorical data, independent samples *t* tests for parametric data, and Mann-Whitney *U* tests for nonparametric data. There were no significant group differences for other outcome measures not reported in this table.

Implementation Measures: Provider and Community Level

At the provider level, penetration into the target population was low while implementation fidelity was high. It was difficult to recruit the target population (ie, sedentary older adults) at community centers. Only 34% of participants exercised less than once per week. This eligibility criterion was relaxed, and research participation was extended to all regardless of exercise frequency. The maximum class size was 20. Each community center had sufficient demand to allow the formation of 3 to 4 CCT classes with 9 to 15 attendees each, ensuring efficient resource use. However, following dropouts, an English class was conducted for 3 participants who declined to join the bilingual class. CCT was implemented at both community centers with high fidelity. Class instructors adhered to class schedules and curriculum.

Facilitators and barriers to program delivery at the provider and community levels were resource availability, community partnerships, program demand, staff buy-in, and prior community implementation experience. At the provider level, the program provider secured a grant to cover some program costs (eg, instructor training and salary) while cofunding the remaining costs (eg, hardware, software). This allowed CCT to be offered at a subsidized rate of SGD $20, ensuring that it remained affordable to participants who were acquainted with subsidized fees for various community center programs. The program provider invested time and effort to establish community partnerships with the respective community centers. Participant recruitment was completed in 2 batches due to the resource-demanding nature of implementing multiple concurrent classes, recruitment issues, and interest in fine-tuning implementation for subsequent batches. Initially, the team sought to recruit 2 batches of participants from the same community center given the difficulty of securing implementation sites.

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However, subsequent recruitment efforts at the first community center revealed that demand for CCT has been exhausted. Engagement of the second community center delayed recruitment of the second batch by 4 months. The program provider pitched the CCT to 7 community centers and management committees before securing 2 implementation sites. The completion of this implementation at the community level could be attributed to extensive experience on the part of the community centers in delivering community-based programs. Both community centers leveraged existing administrative processes to promote the CCT and support class enrollment. They were also equipped with facilities needed for the CCT. Implementation was faster at the first community center due to better staff support and administrative processes.

Participant Baseline Characteristics

Participants' mean age was 68.8 (SD 6.3) years (Table 1). The majority were women, Chinese, and had at least secondary education. Dropouts were more likely to be sedentary compared with those who completed both assessments (*P*<.001). There were no baseline group differences in outcome variables in ITT analyses (Multimedia Appendix 2). In PP analyses, the intervention group had poorer baseline performance for RBANS story memory (*P*=.006) and story recall subtests (*P*=.05) compared with the control group (Table 1).

Effectiveness Measures

ITT Analyses

The interaction term was not statistically significant for RBANS coding (*b*=–0.15, *P*=.06, 95% CI [–0.30 to 0.00]) and list recall subtests (*b*=–0.39, *P*=.05, 95% CI [–0.78 to 0.00]. For both RBANS subtests, performance in the intervention group declined post-CCT while the control group improved (Multimedia Appendix 3). The assessment term was significant for single task GVI (*b*=2.32, *P*=.03, 95% CI [0.30 to 4.35]) and RBANS list recognition subtest (*b*=–0.57, *P*=.009, 95% CI [–1.00 to –0.14]) but not statistically significant for RBANS picture naming subtest (*b*=0.36, *P*=.07, 95% CI [–0.3 to 0.74]). From baseline to follow-up, single task GVI and RBANS picture naming scores increased while performance in RBANS list recognition subtest deteriorated in both groups (Multimedia Appendix 3).

PP Analyses

The interaction term was significant for time taken to complete CTT-2 (*b*=–13.5, *P*=.01, 95% CI [–23.95 to –3.14], Cohen *d* effect size = 0.285) and not statistically significant for single task gait speed (*b*=5.38, *P*=.06, 95% CI [–0.30 to 11.36]; Figure 2 and Table 2). The assessment term was significant for RBANS picture naming (*b*=0.43, *P*=.046, 95% CI [0.01 to 0.85]) and list recognition subtests (*b*=–0.54, *P*=.02, 95% CI [–1.00 to –0.08]). From baseline to follow-up, both groups' RBANS picture naming performance improved while their RBANS list recognition performance deteriorated (Figure 2 and Table 2). Effect sizes of the changes between baseline and follow-up in the intervention and control groups are presented in Multimedia Appendix 4 and Multimedia Appendix 5, respectively.

Figure 2. Results of per-protocol analyses.

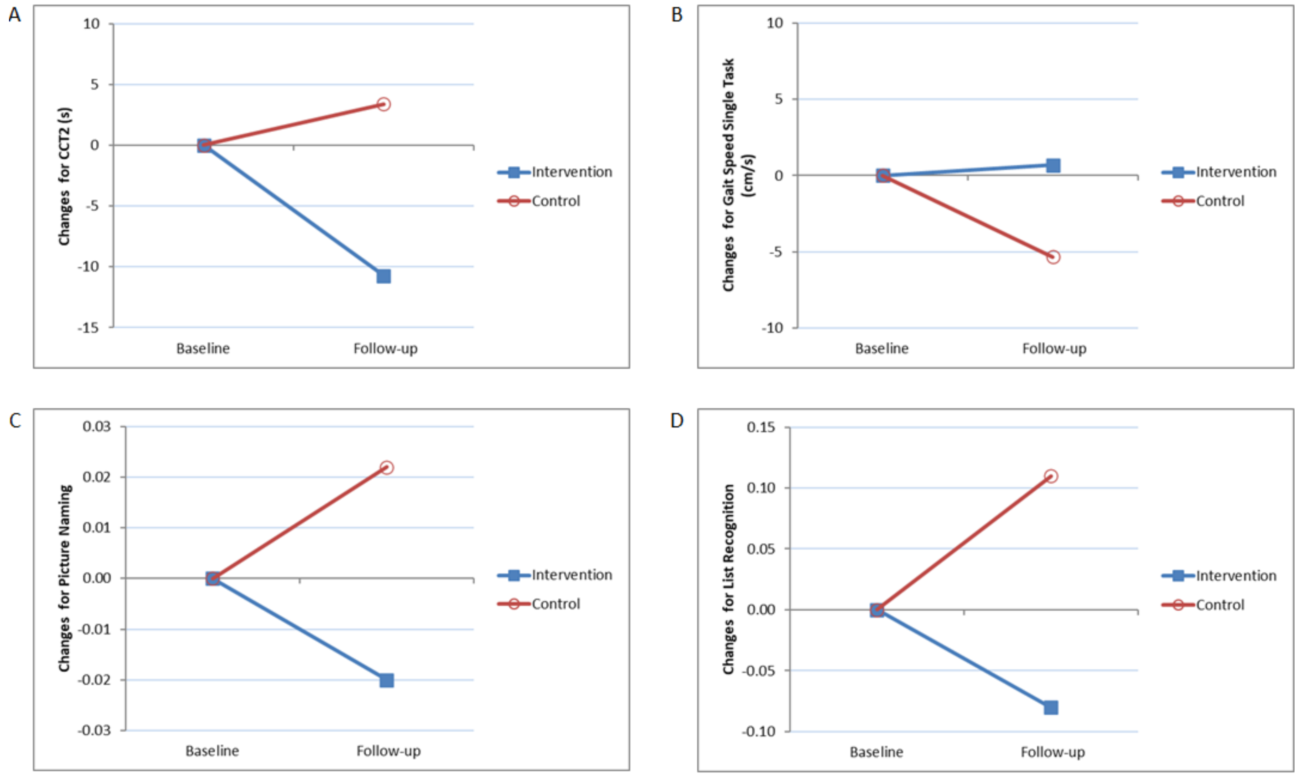

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Table 2. Means and standard deviations for effectiveness measures.

Effectiveness measures	Baseline assessment[a], mean (SD)		Follow-up assessment, mean (SD)	
	Intervention group (n=55)	Control group (n=39)	Intervention group (n=55)	Control group (n=39)
Time taken for Color Trails Test Part 2, seconds (n=91)[b]	124.43 (39.91)	111.99 (29.89)	113.69 (35.20)	115.38 (30.63)
RBANS[c] subtests[d]				
List learning	–0.04 (1.08)	0.06 (0.89)	–0.08 (1.03)	0.11 (0.96)
Story memory	–0.24 (1.04)	0.33 (0.85)	–0.17 (1.16)	0.24 (0.66)
Figure copy	–0.06 (1.08)	0.09 (0.89)	0.05 (1.09)	–0.07 (0.87)
Line orientation	–0.13 (1.05)	0.18 (0.91)	–0.02 (1.08)	0.03 (0.89)
Picture naming	–0.07 (1.04)	0.09 (0.95)	–0.09 (1.13)	0.11 (0.77)
Semantic fluency	–0.13 (0.96)	0.18 (1.03)	–0.02 (1.04)	0.03 (0.95)
Digit span	–0.13 (1.00)	0.18 (0.99)	–0.10 (0.92)	0.14 (1.10)
Coding	–0.09 (1.09)	0.13 (0.86)	–0.09 (1.11)	0.12 (0.82)
List recall	–0.05 (1.10)	–0.08 (0.85)	–0.07 (1.16)	0.10 (0.71)
List recognition	–0.09 (1.16)	0.13 (0.72)	–0.17 (1.20)	0.24 (0.54)
Story recall	–0.18 (1.05)	0.24 (0.87)	–0.18 (1.13)	0.25 (0.72)
Figure recall	–0.06 (1.04)	0.08 (0.94)	0.06 (1.10)	–0.08 (0.84)
RBANS domains[e]				
Immediate memory	–0.28 (1.80)	0.39 (1.44)	–0.25 (1.92)	0.35 (1.21)
Visuospatial	–0.02 (1.70)	0.27 (1.35)	0.03 (1.77)	–0.05 (1.43)
Language	–0.20 (1.54)	0.28 (1.63)	–0.10 (1.85)	0.15 (1.39)
Attention	–0.22 (1.55)	0.30 (1.44)	–0.18 (1.64)	0.26 (1.62)
Delayed memory	–0.28 (3.62)	0.39 (2.35)	–0.36 (3.81)	0.51 (1.74)
RBANS total score[e]	–1.15 (7.97)	1.62 (5.77)	–0.86 (9.08)	1.21 (5.00)
Berg Balance Scale (n=93)	52.75 (4.66)	54.61 (1.53)	53.27 (4.00)	54.08 (2.52)
Gait speed[f]				
Single task (cm/s; n=92)	101.60 (22.60)	105.26 (20.41)	102.29 (22.36)	99.92 (19.03)
Dual task (cm/s; n=91)	70.28 (23.50)	71.00 (25.75)	70.77 (22.29)	66.12 (20.44)
Dual task cost (n=90)	–32.88 (14.16)	–32.53 (19.66)	–30.33 (19.85)	–34.12 (14.52)
GVI[g] (n=90)				
Single task	88.49 (6.43)	88.60 (6.29)	89.31 (5.62)	91.27 (6.59)
Dual task	84.71 (13.14)	86.48 (15.64)	85.12 (13.02)	85.47 (12.59)

[a] Baseline differences between the intervention and control group were examined using Pearson chi-square tests for categorical data, independent samples *t* tests for parametric data, and Mann-Whitney *U* tests for nonparametric data.

[b] Time taken for Color Trails Test Part 2 was missing for 7 participants who exceeded the maximum time provided during 1 or more assessments.

[c] RBANS: Repeatable Battery for the Assessment of Neuropsychological Status.

[d] RBANS subtest scores were standardized within each assessment (ie, across groups) prior to analyses.

[e] RBANS domain scores and total score were derived by summing standardized subtest scores.

[f] Physical outcome measures were missing for selected participants for the following reasons: did not complete physical assessment at baseline (n=2), lack of eligible trials (eg, not performing serial subtraction during dual task condition, taking too few steps per trial, <3 trials for GVI derivation; n=3).

[g] GVI: Gait Variability Index.

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Discussion

Principal Findings

In this single-blind RCT in 94 healthy community-dwelling adults, there were improvements in attention and executive function. We showed that it was feasible to implement community-based CCT in community centers to promote cognitive improvements in healthy older adults. Implementation measures revealed high reach and moderate adherence but poor penetration of sedentary older adults. Most community center users were physically and socially active. Participants paid for and attended 80% of classes. Attendance was higher in the intervention group than the control group. However, 25% dropped out and 22% did not adhere to randomization. Implementation was facilitated by CCT trainers' in-class guidance and encouragement, participant proximity to and strong community ties at implementation sites, resource availability, strong community partnerships, staff buy-in, and prior program implementation experience.

Implementation of Community-Based CCT Program

It is feasible to implement CCT at community centers for healthy older adults. At the participant level, there was good program reception and adherence. Participants were interested in CCT despite relative unfamiliarity with the technology. Reach was high (81%), and participants were willing to pay SGD $20 for the CCT, increasing the economic viability of CCT implementation in community centers provided it is subsidized as with other community center programs. Program interest and adherence could be attributed to in-class guidance, timely technical support from the program provider, and participants' higher educational attainment [24]. Modest adherence was observed despite participants' busy schedules. Dropout rate was 25%, largely due to busy schedules, loss of interest in research participation or CCT, and loss to follow-up. Class attendance was 80%, with higher attendance in the intervention group. In other local studies with community-based interventions, dropout and attendance rates were 2% to 11% and 79% to 95%, respectively [25-27]. The relatively higher dropout rate in this study was likely due to participant characteristics. The current sample consisted of healthy physically and socially active older adults already occupied with various community center programs or commitments. Future studies can include additional measures to boost adherence (eg, follow-up with participants who miss 2 consecutive CCT classes, maintain regular contact with the control group through monthly health talks). Another area for further study pertains to trade-offs regarding CCT frequency and duration, adherence, and effectiveness.

At the provider level, there was high fidelity to program implementation but low penetration into the target population. The program provider successfully delivered the program without deviating from planned schedules and curriculum. Instructors were well trained and well received. Participants cited trainers' in-class guidance and encouragement as motivation to continue with CCT despite increasing gaming complexity. Penetration into the sedentary older population was low; only 34% exercised less than once per week. Different sites and recruitment strategies (eg, targeted outreach at senior activity centers) will be needed to reach out to sedentary older adults. When this eligibility criterion was relaxed, there was sufficient demand at each community center to allow formation of classes with 9 to 15 participants each. This ensured efficient resource use given a maximum class size of 20. Thereafter, demand at each community center is likely to be geared toward more advanced CCT to promote continuity and maintenance among experienced attendees. The feasibility and efficacy of advanced CCT requires further research.

Facilitators and barriers to CCT implementation at the participant, provider, and community level were identified. Participant adherence was boosted by CCT trainers' in-class guidance, proximity to implementation sites, and strong community ties. Participants in the first community center lived nearer to the community center and were close-knit. Provider and community implementation success depended on resource availability, community partnerships, staff buy-in, and prior program implementation expertise. CCT could be offered at a subsidized rate with grant support and cofunding by the CCT provider. In community centers, CCT may not be feasible without subsidized class fees as community center-goers are acquainted with subsidized fees for community center programs. Lower demand and smaller class sizes would negate the minimal economy of scale CCT providers need. Successful implementation was also contingent on community partnerships between the program provider and implementation sites. Identifying suitable community centers required substantial time and effort from the program provider. The difficulty of establishing new partnerships delayed recruitment of the second batch of participants by 4 months. Within community centers, implementation success was associated with prior experience in delivering community-based programs and staff buy-in. Implementation was better executed at the first community center due to better staff support and administrative processes. Future implementers should consider population characteristics, program demand, prior program implementation experience, staff buy-in, and existing administrative processes and facilities when shortlisting implementation sites.

Effectiveness of CCT for Healthy Older Adults

CCT improved executive function and attention in agreement with previous reports [8,14,15]. CCT's impact on memory should be a subject of future implementation studies given previous reports of memory improvements [8,14,15].

In this study, CCT's modest efficacy may be attributed to participants' relatively high educational and physical activity levels. Participants were more educated than the average Singaporean older adult [25], and a substantial proportion were enrolled in various community center programs, including fitness classes and enrichment lessons. This might explain why high scores and even ceiling effects were observed for various RBANS subtests and the Berg Balance Scale at baseline. Participants had less room for cognitive improvements, with benefits observed only for attention and executive function.

We found that there was no significant improvement in gait speed from baseline to follow-up in the intervention group, while gait speed deteriorated in the control group. In prior studies [9-12], gait and balance improvements were more pronounced in sedentary older adults with low gait speed (ie, <1 m/s). In our study, 66.0% of the sample exercised at least once a week, a level higher than the average Singaporean older adult [28]. Low gait speed was also not observed in 61.3% of the sample at baseline. This suggests future investigation given gait improvements uncovered in prior studies [9-12]. More sensitive effectiveness measures and a larger sample size might be needed to detect the small effect size of CCT in healthy high-functioning older adults.

Given that 22% did not adhere to randomization, it was unsurprising that results for ITT and PP analyses differed. Of the 22%, 64% crossed over from their assigned control group to the intervention group. This predominant direction of switch likely explained unexpected findings in ITT analyses. From baseline to follow-up, the control group improved in RBANS coding and list recall subtests while performance in the intervention group declined. ITT analyses uncovered no baseline group differences across outcome measures while PP analyses found that the control group performed better in RBANS story memory and story recall subtests at baseline. The lack of adherence to randomization likely led to a situation where the control group had more individuals with better memory for narratives. More weight was given to PP analyses as it was difficult to interpret ITT analyses given the substantial number of individuals who did not adhere to randomization.

Strengths and Limitations

CCT was implemented with high fidelity to planned class schedule and curriculum. In-class guidance and timely technical support mitigated technological barriers faced by older adults and likely boosted receptiveness to CCT. Attendance was comparable to other local studies with community-based interventions [25-27]. However, dropout rate was higher (25%) even though participants paid a subsidized fee to attend. The target population (ie, sedentary healthy older adults) could not be recruited at community centers. Instead, the inclusion criterion was relaxed to include older adults regardless of their exercise frequency. This, together with participants’ high educational attainment and participation in various community center programs, likely limited CCT’s effectiveness. We encountered difficulty recruiting enough sedentary older adults. In addition, the dropout rates were highest in the older adult group. This may suggest that the implementation in its current form is not suitable for the population at the community centers. Online implementation option of group training should be considered in the future, especially in the context of the COVID-19 pandemic. The convenience of online training may address adherence, group training, and maintaining motivation while achieving necessary social distancing. Nevertheless, the study remains informative given that the sample might be more representative of CCT attendees, especially in community-based or commercial settings. It also provides useful information on suitable healthy aging programs that can be implemented on a larger scale within communities.

Outcomes measures could be improved upon. The adapted RBANS and CTT-2 were not well validated for Singaporean older adults. Norms were available for Form A of both tests for Chinese Singaporean older adults [21]. Except for the digit span subtest, the English and Mandarin versions of RBANS Form A were equivalent in this population [29]. However, RBANS and CTT-2 Form B were modified for this study and have not been validated previously. RBANS was selected as the primary effectiveness measure as it was one of the few validated tools with parallel forms that assessed various cognitive domains. Implementation could have been evaluated more rigorously via standardized feedback questionnaires and semistructured interviews.

Conclusion

In conclusion, this study showed that it was feasible to implement community-based CCT in community centers, and the CCT program resulted in modest cognitive improvements among healthy Singaporean older adults. With the study being conducted in a real-world setting, the challenges and necessary adjustments and adaptations made is common with such implementations, but it allows for lessons to be learned and documented for improvement. CCT can be implemented with relatively good uptake and adherence in community centers but at a subsidized fee as with other community center programs. Implementers should consider participants’ proximity to implementation sites, strength of community ties, resource availability, staff buy-in, and prior program implementation expertise when shortlisting implementation sites. Future studies can explore the effectiveness of community based CCT for older adults who are sedentary or at risk of cognitive impairment.

Acknowledgments

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Authors' Contributions

NTN, PLKY, TPN, and SLW were involved in study concept and design. Acquisition of data was carried out by PSY and PEMN. Analysis and interpretation of data was performed by PSY, RWMC, TPN, and SLW. Drafting of the manuscript was performed

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by PSY, NTN, PEMN, and SLW. Critical revision of the manuscript for important intellectual content was done by PLKY, TPN, and SLW. All authors reviewed the results and drafts and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Implementation measures.
[DOCX File , 15 KB - formative_v5i4e25462_app1.docx]

Multimedia Appendix 2
Baseline characteristics based on intention-to-treat analysis.
[DOCX File , 17 KB - formative_v5i4e25462_app2.docx]

Multimedia Appendix 3
Effectiveness measures (intention-to-treat analysis)—means and standard deviations.
[DOCX File , 18 KB - formative_v5i4e25462_app3.docx]

Multimedia Appendix 4
Effect sizes at baseline and follow-up in the intervention group.
[DOCX File , 25 KB - formative_v5i4e25462_app4.docx]

Multimedia Appendix 5
Effect sizes at baseline and follow-up in the control group.
[DOCX File , 24 KB - formative_v5i4e25462_app5.docx]

Multimedia Appendix 6
CONSORT-EHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 1090 KB - formative_v5i4e25462_app6.pdf]

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Abbreviations

CCT: computerized cognitive training
CTT-2: Color Trails Test 2
GVI: Gait Variability Index
ITT: intention-to-treat
PP: per protocol
RBANS: Repeatable Battery for the Assessment of Neuropsychological Status

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RCT: randomized controlled trial

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Original Paper

Conducting Internet-Based Visits for Onboarding Populations With Limited Digital Literacy to an mHealth Intervention: Development of a Patient-Centered Approach

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Abstract

Background: The COVID-19 pandemic has propelled patient-facing research to shift to digital and telehealth strategies. If these strategies are not adapted for minority patients of lower socioeconomic status, health inequality will further increase. Patient-centered models of care can successfully improve access and experience for minority patients.

Objective: This study aims to present the development process and preliminary acceptability of altering in-person onboarding procedures into internet-based, remote procedures for a mobile health (mHealth) intervention in a population with limited digital literacy.

Methods: We actively recruited safety-net patients (English- and Spanish-speaking adults with diabetes and depression who were receiving care at a public health care delivery system in San Francisco, United States) into a randomized controlled trial of text messaging support for physical activity. Because of the COVID-19 pandemic, we modified the in-person recruitment and onboarding procedures to internet-based, remote processes with human support. We conducted a preliminary evaluation of how the composition of the recruited cohort might have changed from the pre–COVID-19 period to the COVID-19 enrollment period. First, we analyzed the digital profiles of patients (n=32) who had participated in previous in-person onboarding sessions prior to the COVID-19 pandemic. Next, we documented all changes made to our onboarding processes to account for remote recruitment, especially those needed to support patients who were not very familiar with downloading apps onto their mobile phones on their own. Finally, we used the new study procedures to recruit patients (n=11) during the COVID-19 social distancing period. These patients were also asked about their experience enrolling into a fully digitized mHealth intervention.

Results: Recruitment across both pre–COVID-19 and COVID-19 periods (N=43) demonstrated relatively high rates of smartphone ownership but lower self-reported digital literacy, with 32.6% (14/43) of all patients reporting they needed help with using their smartphone and installing apps. Significant changes were made to the onboarding procedures, including facilitating app download via Zoom video call and/or a standard phone call and implementing brief, one-on-one staff-patient interactions to provide technical assistance personalized to each patient's digital literacy skills. Comparing recruitment during pre–COVID-19 and COVID-19 periods, the proportion of patients with digital literacy barriers reduced from 34.4% (11/32) in the pre–COVID-19 cohort to 27.3% (3/11) in the COVID-19 cohort. Differences in digital literacy scores between both cohorts were not significant (*P*=.49).

Conclusions: Patients of lower socioeconomic status have high interest in using digital platforms to manage their health, but they may require additional upfront human support to gain access. One-on-one staff-patient partnerships allowed us to provide unique technical assistance personalized to each patient's digital literacy skills, with simple strategies to troubleshoot patient

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barriers upfront. These additional remote onboarding strategies can mitigate but not eliminate digital barriers for patients without extensive technology experience.

Trial Registration: Clinicaltrials.gov NCT0349025, https://clinicaltrials.gov/ct2/show/NCT03490253

(JMIR Form Res 2021;5(4):e25299) doi:10.2196/25299

KEYWORDS

digital literacy; digital divide; underserved; patient-centered; digital health; mhealth; intervention; telehealth; COVID-19

Introduction

Background

The COVID-19 pandemic has drastically changed how health care is delivered, resulting in an increasing shift to digital and telehealth approaches. The pandemic has also substantially altered patient-facing research, relying on similar digital outreach and implementation strategies [1,2]. Many of these changes to practice and research will likely be sustained into the future even after the pandemic ends.

Despite the ubiquitous integration of technological innovations into health care, it is important to recognize the inequitable access to digital health tools among marginalized populations. Notably, previous studies show that reduced access to sufficient internet or data plans and low computer use remain barriers to participation in digital strategies among racial or ethnic minorities with low socioeconomic status (SES) [3-5]. Additionally, research has shown that even when access to internet devices and data exists, disparities in usage persists. Specifically, although previous studies have reported high rates of smartphone ownership among minoritized racial or ethnic populations [6], populations of lower SES are more likely to have lower digital literacy [7]. Limited digital literacy has been defined as not having the digital skills necessary to use and navigate internet-driven technology and/or being less comfortable or willing to use digital tools [8-10]. Lower access to digital devices and home internet, combined with limited digital literacy, has alarming implications, given that vulnerable populations are at greater risk for contracting COVID-19 and, therefore, have had to rely on digital and telehealth strategies throughout this pandemic [11].

As patient-facing research transforms into digitized clinical trials, it is important to adopt patient-centered models to ensure recruitment of diverse populations and equitable access to digital health tools for all. Patient-centeredness is defined as “care that is respectful of and responsive to individual patient preferences, needs, and values” and provides patients with the “tools and support they need” [12] to engage in the delivery of their health care [13]. Adopting a patient-centered model of care that focuses on providing patients with the tools necessary to be able to access health care via telehealth strategies would allow research teams, as well as clinicians, to adequately develop generalizable guidelines for conducting internet-based remote visits among vulnerable populations. As health care systems increasingly rely on digital interventions (from telemedicine and beyond), their need to understand the digital profiles of individual patients also increases, especially to improve diverse patient experience.

Objectives

Through our experience of recruiting English and Spanish speakers of lower SES into clinical research in a public health care delivery system, we developed practical guidelines for internet-based remote recruitment of populations who have access to technology but face digital literacy barriers to self-enroll into mobile health (mHealth) interventions. This paper explains the development process and preliminary acceptability of altering our study procedures from previous in-person sessions to internet-based remote visits for the recruitment of patients with diabetes and depression into an mHealth intervention. We also conducted a preliminary examination of how the composition of recruited patients might have changed from pre–COVID-19 to COVID-19 enrollment periods.

Methods

Overview of the mHealth Intervention

The data herein are part of a larger randomized controlled trial (RCT). The Diabetes and Depression Text Messaging Intervention (DIAMANTE) study (NCT03490253) is testing a smartphone-based mHealth intervention (ie, a text messaging system that uses machine learning to personalize content) [14], aiming to increase physical activity among patients with type 2 diabetes and depression and lower SES backgrounds. Patients enrolled in the RCT are sent text messages for a 6-month period. We aim to recruit 276 English- and Spanish-speaking patients aged 18-75 years from a public health care system in San Francisco, USA. This public health care system typically serves patients who are publicly insured and are of low-income status. Interested patients are excluded if they do not own a smartphone or present suicidal ideation and/or active or severe psychosis. Patients are recruited through phone calls following a provider referral and are scheduled for a baseline interview session where they provide consent, answer demographic and relevant questionnaires, and downloaded the DIAMANTE application with support from research assistants. Participants are paid US $40 at baseline and US $70 at the 6-month follow-up. The study was approved by the Institutional Review Board Committee at the University of California, San Francisco (IRB: 17-22608). Prior to the COVID-19 pandemic, we conducted in-person sessions during the usability testing phase and the earlier phase of the RCT (n=32), from January 2019 to March 2020. During this period of in-person interaction with the study participants, our team leveraged existing digital research tools to streamline recruitment and improve retention. We collected measures using Qualtrics surveys [15] rather than paper-based questionnaires; documented patient health information on Research Electronic

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Data Capture (REDCap)—a secure, web-based software platform [16,17]; and then implemented remote patient monitoring with HealthySMS, a text-messaging platform developed by Dr Adrian Aguilera and approved by the Health Insurance Portability and Accountability Act (HIPAA). HealthySMS has shown high acceptability and engagement among populations of lower SES [18-20]. Each of the above steps were completed in-person during the pre–COVID-19 period, allowing the research assistant to administer face-to-face online Qualtrics assessments or download the intervention app for participants if they were not able to use these platforms on their own.

However, social distancing due to the COVID-19 pandemic necessitated the transition to remote recruitment strategies, without the ability to troubleshoot onboarding issues in-person (eg, assistance with app downloads). To be as efficient as possible in addressing any challenges our target population might encounter in providing consent to participate via DocuSign (rather than via pen-and-paper), completing the online Qualtrics baseline enrollment assessments, and downloading the smartphone application remotely, we significantly altered our study procedures for the screening and recruitment of eligible patients.

Conceptual Framework

Patient-centeredness has traditionally been used to improve health equity within research and operational programs. In the context of mHealth, patient-centeredness is rooted in active collaboration between patients and research staff [12]. Patients provide insights on unique challenges they face in adopting study procedures, how comfortable they are with trying new modalities, and the level of social support available to them to circumvent challenges. Research staff can leverage their training and expertise to successfully integrate university-mandated measures, processes to increase access to the intervention, and create the infrastructure to offer technical assistance. As such, researchers have the duty to account the demographics of the target population and barriers or facilitators among participants when designing study procedures.

Approach and Development of Remote Study Procedures

The adaptation of previous in-person study procedures to remote practices took place from March to April 2020. As an initial step, we analyzed the digital profiles—including digital literacy and device or broadband access—of patients who participated in our previous pre–COVID-19 in-person sessions (hereafter referred to as the pre–COVID-19 cohort). Following the analysis, research staff met to discuss personal experiences encountered during previous in-person onboarding sessions. Analysis and feedback allowed us to address the most relevant barriers to and facilitators of an internet-based remote visit. The results led us to alter our study procedures to orient patients to download the digital health application being studied via an internet-based remote visit (ie, by using the Zoom video conferencing software or during a phone call). The project coordinator conducted several educational meetings to introduce and share the rough outlines of the new study procedures with the entire research team. Several amendments were made to these outlines based on onboarding research staff's feedback and internal piloting efforts.

The final versions were then used to enroll eligible patients (n=11) into a complete, digitized version of the clinical trial during the period of social distancing in the context of the COVID-19 pandemic (hereafter referred to as the COVID-19 cohort), from April 2020 to September 2020. Finally, the enrolled patients who were able to attend a remote onboarding visit were asked about our new remote recruitment processes, and their feedback was both audio-recorded and documented with detailed field notes.

Measures

Using the online Qualtrics surveys conducted during the usability testing phase and the RCT phase of the DIAMANTE study, we collected several measures to conduct a preliminary examination of how the composition of the recruited sample might have changed from the pre–COVID-19 to the COVID-19 enrollment period.

First, we measured the participants' SES using the MacArthur Scale. This scale captures the cumulative influences of social hierarchy (including income, education, and occupation) and has been shown to better predict health and wellbeing [21-23]. The description of the MacArthur scale explicitly references objective indicators of SES such as income, education, and occupation. Participants were asked to rate where they perceive their relative position in society on a scale of 1 to 10, wherein 10 signifies the highest SES.

We also measured the patients' digital literacy. Digital literacy, defined as "the ability to use emerging information and communication technologies to find, access, create, download and communicate information" [24]. Notably, there is no gold-standard measure of digital literacy [25]. Previous studies have measured digital literacy in different ways, including self-reported assessment of perceived skills, with response items ranging from "very poor" to "excellent"; these assessments heavily rely on exploring an individual's self-efficacy [26-28]. In the context of mHealth interventions, digital literacy involves technical skills (eg, knowing how to use the device) and navigational skills (eg, knowing how to navigate to the App Store) [24]. For our analysis, we considered the conceptual domains of technical and navigational skills and operationalized them. We created our own variable using two multiple choice questions developed by the research team. Participants were asked to rate their answers to the question "How difficult is it to use your smartphone [AND] install mobile applications/apps on your smartphone without someone else helping you?" on a Likert scale of "very difficult," "somewhat difficult," or "not difficult." For our analysis, a patient answering *very* or *somewhat difficult* on both questions was considered to have limited digital literacy.

Finally, semi-structured interviews were conducted to explore the acceptability of remote onboarding procedures. Questions were based around downloading the app and the experience during and after completion of an internet-based remote session for clinical research.

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Data Analysis

Given the small sample size, nonparametric, paired-sample, one-sided Fisher exact test was performed using SPSS (version 27.0; IBM Corp) software to capture differences in digital literacy scores between the pre–COVID-19 and COVID-19 cohorts. We considered a difference to be statistically significant at *P*<.05.

To explore acceptability of the new onboarding procedures, we categorized enrolled participant feedback about the remote onboarding procedures from our field notes and audio-recorded interviews. RH read the interviews in their entirety, using the semistructured format of the interview guides to code for the categories represented in the interview guide as follows: (1) overall experience with an internet-based remote session and (2) difference and benefits or drawbacks of an internet-based remote visit in comparison to a patient-facing visit.

Results

Study Characteristics

Table 1 summarizes overall characteristics of the study participants. Their mean age was 52.8 (SD 10.5) years. Of the 43 participants, 24 (55.8%) were female; 38 (88.4%) were non-White participants; 20 (46.5%) were Spanish-speaking participants; 30 (69.7%) had a high-school education or lower; and 29 (67.4%) were unemployed, retired, or on disability.

Table 1. Baseline demographic characteristics.

Self-reported characteristic	Overall (N=43)	Pre–COVID-19 cohort (n=32)	COVID-19 cohort (n=11)
Age (years), mean (SD)	52.8 (10.5)	53.6 (9.45)	50.5 (0.6)
Socioeconomic status (score), mean (SD)	4.66 (2.30)	4.79 (2.11)[a]	4.36 (2.77)
Interview language, n (%)			
Spanish	20 (46.5)	18 (56.3)	5 (45.5)
English	23 (53.5)	14 (43.8)	6 (54.5)
Sex, n (%)			
Female	24 (55.8)	20 (62.5)	4 (36.4)
Male	19 (44.2)	12 (37.5)	7 (63.6)
Ethnicity, n (%)			
White	4 (9.3)	3 (9.4)	1 (9.1)
Black	4 (9.3)	3 (9.4)	1 (9.1)
Hispanic or Latino(a)	26 (60.5)	20 (62.5)	6 (54.5)
Asian or Pacific Islander, or other	9 (20.9)	6 (18.8)	3 (27.3)
Marital status, n (%)			
Single	18 (41.9)	12 (37.5)	6 (54.5)
Married or partnered	9 (20.9)	6 (18.8)	3 (27.3)
Divorced or legally separated	13 (30.2)	12 (37.5)	1 (9.1)
Widow	3 (7.0)	2 (6.3)	1 (9.1)
Education, n (%)			
High school or lower	30 (69.7)	23 (71.9)	7 (63.6)
More than high school	13 (30.2)	9 (28.1)	4 (36.4)
Employment status, n (%)			
Disabled or on disability	17 (39.5)	14 (43.8)	3 (27.3)
Part-time or more	14 (32.6)	10 (31.3)	4 (36.4)
Unemployed	10 (23.3)	8 (25)	2 (18.2)
Retired	2 (4.7)	0 (0)	2 (18.2)

[a] Results for this question are missing data from 8 patients who participated in the usability testing phase of the project and were not provided with this measure.

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Socioeconomic Status

In all, 35 of the 43 (81.4%) participants filled out the MacArthur Scale, including all RCT participants. Overall, our sample self-identified as having low SES (mean 4.66, SD 2.30). Specifically, the self-reported mean score for patients in the pre–COVID-19 cohort was 4.79 (SD 2.11), whereas the mean score for those in the COVID-19 cohort was 4.36 (SD 2.77).

Changes to Study Procedures

Multimedia Appendix 1 details the pre–COVID-19 (in-person) versus the current COVID-19 (remote) recruitment and onboarding procedures. Broadly, these steps outline our implementation of brief, one-on-one staff-patient interactions to provide technical assistance personalized to each patient's digital literacy. More specifically, we rolled out multiple new procedures. First, we prepared for the remote onboarding visits: our team developed educational materials, such as YouTube videos on how to download the Zoom app onto a smartphone device, written brochures on how to access an email or sign with DocuSign using a smartphone device, and a manual on how to download the DIAMANTE mobile app. Then, during the recruitment visits, we sent real-time SMS links for app downloads and used a video conferencing software (eg, Zoom) for initiating communication on the onboarding session. If we were successful with the Zoom call for the onboarding session, we were then better able to establish a rapport with the participant despite the remote environment. This allowed us to be able to see the participant's digital devices better, which facilitated troubleshooting of any technical issues. In the event that a video call via Zoom was not possible, the staff learned more details about Android and iOS operating systems to assist with common technical problems and be able to verbally explain the various steps involved (in both English and Spanish versions of the operating systems). Finally, patients who seemed hesitant (either in their ability to set-up for a Zoom session and/or in downloading the smartphone app based on remote instructions) requested that their tech-savvy loved ones be present during the onboarding session. Staff then worked with these patients and their loved ones and ensured that both of them understood every step of the process.

Digital Profiles

After implementing these procedures, we then compared the digital access and literacy among participants in the pre–COVID-19 cohort with those in the COVID-19 cohort (Table 2). Although we enrolled participants who were racially or ethnically diverse and had lower SES in both time periods, we had a higher recruitment rate of individuals with access to Wi-Fi within the COVID-19 cohort. A total of 18 of the 32 (56.3%) participants in the pre–COVID-19 cohort had access to Wi-Fi at their home, compared to all 11 (100%) participants in the COVID-19 cohort. Primary outcome results indicated a nonsignificant reduction in the self-reported digital literacy between the cohorts, with 34.4% (11/32) of the participants in the pre–COVID-19 cohort reporting limited digital literacy as compared to 27.3% (3/11) of the participants in the COVID-19 cohort (*P*=.49).

Table 2. Patients' digital profiles.

Self-reported characteristic	Overall (N=43)	Pre–COVID-19 cohort (n=32)	COVID-19 cohort (n=11)
Digital access, n (%)			
Wi-Fi at home	29 (67.4)	18 (56.3)	11 (100)
Smartphone type, n (%)			
Android	27 (62.8)	18 (56.3)	9 (81.8)
iPhone	16 (37.2)	14 (43.8)	2 (18.2)
Digital literacy, n (%)			
Difficulty using smartphone	18 (41.8)	14 (43.8)	4 (36.3)
Difficulty installing apps	22 (51.2)	18 (56.3)	4 (36.3)
Interviewer downloaded the app for the participant	32 (74.4)	32 (100)	0 (0)

Patient Experience

Finally, we summarized patient experiences with the new remote onboarding procedures. In all, 8 of 11 (73%) patients in the COVID-19 cohort had never participated in a remote visit for research in the past, but all 11 (100%) patients stated that they enjoyed participating in remote visits for research. One patient, for example, expressed that staff taking the time to offer technological assistance allowed them "*to see the hospital's commitment to the community.*" In addition, 7 of 11 (64%) patients classified time efficiency and the convenience of not having to travel outside their home as a major benefit to participating in research via remote visits.

When discussing how this research study fit into their overall needs for digital health care at our safety-net health care setting, the patients remained supportive of these remote approaches during the COVID-19 pandemic and beyond:

> *It's still important to have someone guide patients for things that are confusing in this remote session. I felt safe doing this.*
>
> *The technology for video conferencing is overdue, and we should have been doing it for a longer time, but now we have been forced to adapt…[it] feels wonderful to be included in all… Video conferencing*

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> *can be used to reach out to populations or cultures that have a harder time going to their appointments.*

Despite these positive comments, 3 of 11 (27%) patients stated that they would still prefer an in-person patient-facing session in the future, given the simplicity of steps involved.

Discussion

Principal Findings

With the speedy uptake of digital and telehealth strategies propelled by the COVID-19 pandemic, it is a high priority to proactively reform current practices to ensure equitable access among vulnerable populations, including those who might have access to technology and broadband but face additional digital literacy barriers. Prior to the COVID-19 pandemic, the majority of health care systems did not provide training for populations with limited digital literacy to ensure adoption of the available digital health tools, including mHealth interventions and telehealth or telemedicine [29-31]. To address this challenge, our research team altered the screening procedures and developed a new onboarding protocol that centrally considered a patient's digital literacy skills. This resulted in the development of one-on-one staff-patient partnerships and a multitude of resources for users and staff to circumvent challenges in accessing a new modality of engagement instead of the previous face-to-face research participation approach. In developing and piloting new onboarding procedures, we leveraged several implementations strategies, including conducting educational meetings with onboarding research assistants, development of educational materials for users and staff, identification of early adopters, and building expertise with participant facilitation via phone and Zoom calls. A patient-centered approach allowed us to anticipate possible challenges our target population might face and proactively prepare strategies or materials to circumvent such challenges. For example, early on, we knew that there was a need to develop steps that accounted for smartphone software given the many technical differences that exist between Android and iOS interfaces. In addition, we also personalized the level of human support provided in our study by using our digital access and literacy questions to offer the right type of assistance.

Furthermore, we started data collection to evaluate whether patients of lower SES and limited digital literacy were still able to participate in mHealth research in the midst of direct economic and health consequences of the COVID-19 pandemic. Our findings indicate that one-on-one staff-patient partnerships can be effective in providing technical assistance to populations who have limited digital literacy skills and are interested in gaining access to digital health tools. We were able to enroll a sample similar to our pre–COVID-19 cohort during the COVID-19 social distancing period by using a new onboarding procedure. Specifically, although, there was a nonsignificant reduction in patients with limited digital literacy enrolling into our study during the COVID-19 pandemic, both cohorts had challenges with digital literacy. The COVID-19 cohort had unique challenges in trying to use both our DIAMANTE app as well as Zoom (many participants were using these apps for the first time) without the assistance of in-person support (eg, research assistants assisting participants to download the app if they were not able to use these platforms on their own). Our findings demonstrate that with adequate attention and support, it is possible to reach patients with limited digital literacy by using remote strategies. This finding is consistent with the previous literature that shows that patients of lower SES have high interest in using digital platforms to manage their health, but they may require additional upfront human support to gain access and have an overall better user-experience [32,33]. At the same time, it is important to recognize that this is not a one-size-fits-all approach. Importantly, 3 of 11 (27%) patients that enrolled in our study using the new screening and onboarding procedures indicated they preferred in-person sessions as opposed to an internet-based remote session for research enrollment.

Although our rate of recruitment has slowed down overall given the pandemic, we know that patients are able to enroll into the study and successfully download a smartphone app through visual and verbal coaching from research assistants. Patients showed willingness to participate in the development of procedures, provided feedback on how to improve user-experience, and ultimately, showed acceptability of internet-based remote sessions for research.

Limitations and Comparison With Prior Work

Previous research reveals gaps in accessibility to telehealth, telemedicine, and remote strategies within vulnerable populations, particularly those with lower technical abilities, older age, and limited English proficiency—these issues are particularly acute in the context of the COVID-19 pandemic [34,35]. Other work has specifically called for researchers working with vulnerable populations to consider different participant profiles and target individuals' needs [36,37]. As this preliminary study was conducted with a small sample size and only in San Francisco, our results might not be generalizable to other settings. We did not perform statistical comparisons of our remote onboarding approaches, but we expect to gain and report more data as the DIAMANTE RCT continues. Moreover, we believe the enumeration of protocol adaptations made in this study increases the concrete tactics for others working with individuals with limited digital literacy on telehealth and digital health interventions in general.

Conclusions

The COVID-19 pandemic has emphasized that we must identify clear strategies for engaging patients with limited digital literacy to extend health care services (and access to research studies) outside of in-person care. Engagement strategies in clinical settings are necessary in order to prevent further growth of health disparities. In addition, ensuring engagement in digital and remote research will ensure an inclusive knowledge base.

Responses to expanding the use of technology in care have included policy changes to expand reimbursement for telemedicine, and efforts to expand access to the internet. In addition to these priorities, our findings indicate the need for additional research and practice to address digital literacy barriers and ensure equitable access to digital health care interventions in the near and long term. Researchers who focus

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on digital health interventions should prioritize better reporting of digital literacy capabilities of their enrolled participants, incorporate service design frameworks within their trial protocols, and thoroughly explain the steps needed to enroll in digital health interventions. Implementation techniques across digital health trials should be leveraged to facilitate the translation of research findings into clinical practice. For example, health care systems could implement brief screenings prior to remote visits to know whether a patient is ready to try a video visit or needs additional support or training. The guidelines we have developed can benefit clinicians and clinical researchers working with vulnerable patients with limited digital literacy to ensure that digital advancements in health care do not lead to increased health disparities. Moving forward, we must dedicate attention and practical resources to those with lower levels of digital literacy as we continue to rapidly expand access to digital health tools; otherwise, we risk increasing existing health disparities for both telemedicine uptake as well as broader health care and research interventions.

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Authors' Contributions

AA and CL designed the study. RH wrote the first draft of the manuscript. All authors revised the manuscript for relevant scientific content and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Comparison of recruiting and onboarding practices for enrolling patients with limited digital literacy onto a digital health intervention during the pre–COVID-19 and COVID-19 periods.
[DOCX File , 22 KB - formative_v5i4e25299_app1.docx]

Multimedia Appendix 2
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 2804 KB - formative_v5i4e25299_app2.pdf]

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Abbreviations

DIAMANTE: Diabetes and Depression Text Messaging Intervention
HIPAA: Health Insurance Portability and Accountability Act
mHealth: mobile health
RCT: randomized controlled trial
REDCap: Research Electronic Data Capture
SES: socioeconomic status

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Original Paper

Innovative Virtual Role Play Simulations for Managing Substance Use Conversations: Pilot Study Results and Relevance During and After COVID-19

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Abstract

Background: Substance use places a substantial burden on our communities, both economically and socially. In light of COVID-19, it is predicted that as many as 75,000 more people will die from alcohol and other substance use and suicide as a result of isolation, new mental health concerns, and various other stressors related to the pandemic. Public awareness campaigns that aim to destigmatize substance use and help individuals have meaningful conversations with friends, coworkers, or family members to address substance use concerns are a timely and cost-effective means of augmenting existing behavioral health efforts related to substance use. These types of interventions can supplement the work being done by existing public health initiatives.

Objective: This pilot study examines the impact of the *One Degree: Shift the Influence* role play simulation, designed to teach family, friends, and coworkers to effectively manage problem-solving conversations with individuals that they are concerned about regarding substance use.

Methods: Participants recruited for this mixed methods study completed a presurvey, the simulation, and a postsurvey, and were sent a 6-week follow-up survey. The simulation involves practicing a role play conversation with a virtual human coded with emotions, a memory, and a personality. A virtual coach provides feedback in using evidence-based communication strategies such as motivational interviewing.

Results: A matched sample analysis of variance revealed significant increases at follow-up in composite attitudinal constructs of preparedness ($P<.001$) and self-efficacy ($P=.01$), including starting a conversation with someone regarding substance use, avoiding upsetting someone while bringing up concerns, focusing on observable facts, and problem solving. Qualitative data provided further evidence of the simulation’s positive impact on the ability to have meaningful conversations about substance use.

Conclusions: This study provides preliminary evidence that conversation-based simulations like *One Degree: Shift the Influence* that use role play practice can teach individuals to use evidence-based communication strategies and can cost-effectively reach geographically dispersed populations to support public health initiatives for primary prevention.

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KEYWORDS

simulations; behavior change; motivational interviewing; virtual humans; role play; substance use; prevention; alcohol; public awareness; innovation; interview; COVID-19; pilot study; simulation; communication; problem solving

Introduction

Introduction to Substance Use

Prevalence and Outcomes of Substance Use in the United States

According to the Substance Abuse and Mental Health Services Administration National Survey on Drug Use and Health (NSDUH), 20.3 million Americans 12 years and older had been diagnosed with a substance use disorder in 2018 [1]. Alcohol is the most commonly used substance in the United States with 139.8 million people 12 years and older reporting having drank alcohol in the past month at the time of the NSDUH [1]. Although most people who use alcohol do not have a substance use disorder, many still drink at levels that can be hazardous to their health. For example, 67.1 million Americans reported binge drinking in the past month, and another 16.6 million reported heavy drinking in the past month [1]. Aside from short-term risks such as accidents, injuries, and alcohol poisoning, long-term excessive alcohol use can contribute to cancers, high blood pressure, and heart disease among other illnesses, and can exacerbate existing health conditions [2]. Further, alcohol is the third leading cause of preventable death in the United States. From 2011 to 2015, alcohol contributed to an average of 93,000 deaths annually, accounting for a total of 2.7 million years of potential life lost [2].

The impact of substance use on communities can be devastating. In addition to injury, illness, and social consequences, there are also exponential economic costs. In 2010, the impact of excessive alcohol use alone was US $249.0 billion nationally with a median cost of US $3.5 billion per state [3]. These costs include losses in workplace productivity (72%); health care expenses (11%); and additional costs for motor vehicle accidents, property damage, and criminal justice expenses [2,4]. Despite this, the US $35.6 billion National Drug Control Strategy budget allocates 45.1% to treatment yet only 17% (US $2.1 billion) goes toward prevention, a number that has steadily decreased every year since 2018 [5]. Prevention programs are essential for lessening the public health burden of alcohol and other substance use in our communities, and there is a need for implementation of effective initiatives that mitigate the physical, social, mental, and economic consequences of substance use.

Prevalence and Outcomes of Substance Use in Colorado

The state of Colorado, where this pilot study was conducted, has recognized and is responding to the prevalence of substance use and substance use disorders within its communities as evidenced by funding new and innovative approaches like the one outlined in this study. In Colorado alone, 16.3% of the population 12 years and older have been diagnosed with an alcohol or substance use disorder, which is approximately 927,000 people [6]. Approximately 1 million Colorado adults, 27% of the state's adult population, indicate that they themselves, or someone that they know, has been addicted to alcohol or another substance in their lifetime [7]. Further, one in five Colorado adults report binge drinking, and excessive drinking costs the state roughly US $5 billion each year [3,8]. In addition, as of 2019, Colorado had the fifth highest number of alcohol-related deaths compared to other US states, averaging 5 deaths per day due to excessive drinking [9,10].

Colorado also has progressive legislation surrounding cannabis use, which adds an additional layer to the social and legal impact of substance use among residents. As the culture of cannabis use shifts, it is increasingly subjective and difficult to recognize when substance use progresses into a substance use disorder. According to a 2018 study, 17.5% of Colorado adults were current cannabis users and of those who reported using cannabis in the past 30 days, 51.5% reported that they used it either daily or near daily [9].

Substance Use and COVID-19

The collective impact of COVID-19 has resulted in substantial stress associated with unemployment, mandated social isolation, grief and loss, and the many other collateral consequences that increase the susceptibility to substance use, addiction, and relapse [11,12]. June 2020 research found that 13.3% of US adults reported having started or increased substance use as a direct result of coping with stress, new or worsened depression and anxiety, or other emotions related to COVID-19 [13]. This research noted that younger adults, racial and ethnic minorities, essential workers, and unpaid adult caregivers reported experiencing negative mental health outcomes, increases in substance use and increased suicidal ideation at a disproportionally high rate compared to other groups of people [13]. Studies also show that, post disaster, people can exhibit psychological distress or trauma, thus are more likely to initiate or increase alcohol or prescription and illicit drug use [14]. It is predicted that there will be as many as 75,000 more preventable deaths from alcohol and other substance use, and suicide in the coming years due to isolation, mental health concerns, and various other stressors related to the pandemic [15,16].

Substance Use and Stigma

Stigmatization of substance use and mental health is perpetuated by a number of different factors, including blame, stereotypes, a lack of knowledge around mental health and substance use disorders, a lack of personal contact with people who have experienced substance use, and negative media portrayals [17]. According to 2018 NSDUH data, nearly 15% of individuals who indicated that they needed substance use treatment in the past year, but did not receive it, reported that they avoided seeking treatment because they "felt that getting treatment would cause their neighbors or community to have a negative opinion of them" [1]. Similarly, the Colorado Health Institute reported that over 70% of respondents who needed but did not receive substance use treatment in 2019 indicated that the main reasons for not seeking help for substance use were that they were afraid

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someone would find out that they had a problem or that they did not feel comfortable talking about personal issues [7].

An additional challenge in Colorado and other states with legalized cannabis is understanding the cultural aspect of recreational drug use in the United States, as it can impact stigma regarding help seeking for those with a more serious disorder. It can also lead to misunderstandings regarding the health-related risks of recreational drug use. Similarly, normalization and general acceptability of alcohol use across the United States combined with its place in social and celebratory environments may lead to risky and excessive alcohol use that is not properly addressed in many health care settings. Stigmatization and normalization of certain substances can negatively impact opportunities for conversations around substance use and may stop people from seeking treatment.

The One Degree Simulation

Background

The *One Degree: Shift the Influence* is a Colorado public awareness campaign consisting of virtual human role play simulations in which individuals can practice having conversations with loved ones about substance use. The main goals of the public awareness campaign are to decrease stigma around substance use and to inspire others to seek help as needed through meaningful and effective conversation. The simulation was developed by Kognito in collaboration with Peer Assistance Services, Inc and with input from nationally recognized subject matter experts in the fields of mental health, nursing, public health, social work, and health education. Peer Assistance Services is a Colorado-based nonprofit agency, leading with prevention and intervention for substance use and mental health concerns.

The *One Degree: Shift the Influence* simulation is built around a series of mini conversations where users interact with intelligent, fully animated, and emotionally responsive virtual humans experiencing the negative effects of alcohol or cannabis use. Possessing their own personalities and memories, these virtual humans adapt their verbal and nonverbal responses to the conversation tactics or dialogue options that participants select throughout the role play. The dialogue options represent a variety of effective, neutral, and ineffective tactics in managing a conversation and are controlled by a set of mathematical behavioral models and algorithms specifically designed to simulate real interactions. These algorithms permit the learner to continually experience the consequences of their dialogue selections within the role play to develop skills and knowledge. In some cases, a tactic that is ineffective at one point in the conversation may be effective elsewhere. Once learners choose a dialogue option, they see their virtual human *perform* the dialogue and then observe the response of the virtual human. A new set of dialogue options then appears based on which tactic was selected (an example of which can been seen in Figure 1). If the participant selects choices that include being critical, judgmental, or labeling, the virtual human will react negatively to the tactic, thus providing immediate feedback to the learner. Throughout the simulation, participants are able to occasionally view the virtual human's private thoughts, which are designed to provide the learner with greater insight and understanding, thus fostering empathic communication skills. In addition, a virtual coach occasionally provides positive feedback for selecting effective dialogue tactics and corrective feedback for selecting ineffective ones. The role play is complete once the participant successfully uses evidence-based conversation tactics such as motivational interviewing (MI) that build the virtual human's trust, resulting in opportunities to discuss substance use concerns in a helpful way.

Figure 1. Example of dialogue options to build rapport between characters Phil and Donna.

What happened with the car accident?

Where do things stand with the divorce right now?

How are the kids handling the divorce?

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Simulation Platform and Efficacy Research

The simulation is based on a digital conversation platform that includes an innovative group of development, delivery, an application programming interface, data collection, and analytic technologies that integrate evidence-based communication strategies that include elements of mindfulness, emotional regulation, empathy, adult learning theory, and the four core MI skills. These MI skills include (1) asking open-ended questions, (2) providing affirmation, (3) reflective or active listening (listening closely and periodically confirming comprehension), and (4) summarizing what was said. MI, originally developed by Miller [18,19] to address problem drinking, has been shown in numerous meta-analytic studies to be an effective modality for bringing about behavioral change in various clinical contexts [20-28]. Traditionally, MI is most effective when preceded by a "teachable moment " [21]. In a clinical setting, this may be a visit to an emergency department following an incident directly related to substance use or in a primary care setting when a patient presents with concerns such as worsened depression or anxiety, which can be directly attributed to substance use. In the *One Degree: Shift the Influence* simulations, conversations also follow teachable moments, which provides an opportunity for the subject of substance use to be approached naturally. With Donna, one of the two character options, the teachable moment comes when a friend of hers expresses concern to her cousin, Phil, about the amount of alcohol that she has been drinking at recent happy hours. For the conversation with Jordan, the other character option, the teachable moment involves repeated occurrences of Jordan coming in late to work or missing shifts entirely due to excessive partying the night before.

Numerous studies have examined the efficacy of using virtual human role play simulations, similar to that of *One Degree: Shift the Influence*, to teach MI skills. These studies have found that virtual role play practices can provide an efficacious means of delivering screening and brief intervention training for health care providers [29-34], and have proven to successfully change attitudinal constructs and behaviors in K12 and higher education settings related to identifying; talking to; and, if necessary, referring students in psychological distress. [29,35-39]. Virtual role play simulations that integrated MI techniques were equally effective across multiple races and ethnicities including people who were Black, Hispanic, Latinx, White, Asian, and American Indian or Alaska Native [40,41].

Advantages of Role Play Simulations

The success of virtual role plays in having a positive impact on attitudinal constructs that predict behavior such as increasing learner preparedness and self-efficacy is partly due to the ability to create realistic and contextually appropriate role plays in an environment that is risk-free and confidential. The virtual learning promotes skill building at one's own pace without concern for making mistakes in a public forum, such as live instructor driven role plays with other learners present. Learners are not at the center of attention, which helps to avoid social evaluative threat and anxiety; thus, they are less likely to feel judged or embarrassed and more likely to be themselves and reveal information [42,43]. Finally, due to the algorithms specifically designed to simulate real interactions, trainer bias and possible fatigue is eliminated, and content can be presented with high fidelity, optimizing the learning experience [29]. This means that the virtual humans will consistently respond verbally and nonverbally in the most efficacious way to promote skill development and drive behavior change.

Simulation Story Lines Overview

The story lines developed for the simulation were the result of an iterative process between subject matter experts, instructional designers, and Peer Assistance Services of Colorado. The criteria established was that they would have to appeal to the broadest group of people; be a family member, friend, or coworker; and vary in ages.

The first role play conversation is with Donna, a single mom who is going through a difficult divorce. She has always been outgoing, extroverted, and successful at work, but lately, she has been drinking more to cope with the stress. Now, Donna is having two or three drinks each night, even on nights when she is not with her friends. She has also started relying on alcohol to help her get to sleep. Donna's friends and family have noticed that she has been acting differently than her usual self. In the simulation, the learner plays the role of Phil, a relative who is concerned about Donna's increased drinking as a coping mechanism for her stressful life. The learner will practice how to bring up their concerns without upsetting Donna and help her brainstorm alternative ways to cope with stress. The goal when creating Donna was to characterize unhealthy alcohol use that was not at the level of alcohol use disorder and to demonstrate how a person may turn to alcohol to cope with everyday stressors. Donna represents a middle-aged woman facing a significant common life stressor, divorce, while also balancing the challenges of parenting and supporting her children. Donna's story presents an opportunity to highlight parenting and role-modeling appropriate adult use of alcohol use as a possible motivating factor for a person to change alcohol use. Coping with stress and symptoms of depression are common reasons that lead people to drink too much and often the person is unaware that, over time, alcohol can actually make stress and depression worse. Insomnia is also a common complaint, and alcohol plays an important role in the quality of sleep a person is getting. Lack of sleep or poor quality sleep can make stress and depression worse because healthy sleep is so critical for overall emotional well-being. Both of these common health concerns are demonstrated in Donna's story. Her story allows individuals who do not have a background in health care to understand some of the most common reasons that people may begin using substances and speaks to some common health outcomes of excessive use.

The second conversation is with Jordan, a young adult who has been thinking about going to college. He's been saving money by working in restaurants while living with his parents. Jordan used to enjoy being outdoors and camping on the weekends, but recently, he has been spending most of his time and savings on partying with his friends, smoking cannabis, and drinking. He is routinely intoxicated, and it has been affecting his work performance and relationships, including with his boss. In this

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simulation, the learner will play the role of Phil, a coworker who is concerned about Jordan. The learner will practice how to bring up their concerns without upsetting Jordan and brainstorm ways to balance his partying with his goal of saving money and going to college. The primary goal with this character was to characterize how cannabis use can affect aspects of life other than health, especially because sometimes health issues take longer to develop. Young adult males are more likely to use cannabis frequently. In addition, especially since the legalization of cannabis in Colorado, its use has continued to increase among adults at the same time that the public's perception of harm is decreasing. Because of this, recreational cannabis use may be a common concern seen among friends and family members of individuals using this simulation. Jordan is a young adult using cannabis in ways that may seem ordinary and unlikely to cause major problems but that can actually begin to interfere with his motivation and capacity to reach his goals of saving money and returning to school. Cannabis and alcohol use can become financially costly, and some people choose to change cannabis, alcohol, or tobacco use to use the money for other things that matter to them. The effects of cannabis on motivation and ability to reach personal goals can be fairly subtle and unrecognized by the individual, and a compassionate friend can sometimes help a person identify that this is happening, and the person will make a change before the pattern of use becomes far more difficult to change.

In both scenarios, the role play begins with a didactic introduction from Phil. Given that these role play scenarios are directed at the public rather than at behavioral health professionals, he provides some tips to be mindful of while completing the simulations. He explains the character's background and then provides an overview of the order that the conversation should be approached: bring up concerns without upsetting the other person, discuss the other person's stressors or goals, and help the other person problem solve if they are open to it. Phil also cautions that how well this conversation goes will depend on how the other person is feeling but explains that there are strategies that can be used to improve the odds that this will go well, which will be learned and practiced through this simulation. This gives the individual that is interacting with the simulation realistic expectations and an understanding that not all conversations will go as planned. Although not explicitly described as motivational interviewing, the final tips that Phil gives are clearly rooted in the principals of MI: stick to the facts, show you understand, and ask questions.

Throughout the simulations, if the learner selects conversation tactics that cause the virtual human to feel judged, offended, or otherwise have a negative emotional reaction, the learner will be prompted to undo their last action. The learner is then required to pick a different tactic based on the coach's recommendation. The purpose of the coach is to provide a baseline understanding of how to use MI techniques to elicit behavior change; therefore, coaching suggestions are rooted in best practices for MI. The coach does not introduce any additional information related to risk factors or facts about substance use. However, if the learner seeks information or guidance on additional topics related to substance use, they can easily locate that information at the end of the simulation. Upon completion, participants view a dashboard that provides an overview of their performance, including feedback on how well they met different goals throughout the conversation. This dashboard also links back to the Shift the Influence website, which houses a number of resources such as fact sheets, crisis lines, treatment locators, and other statewide public awareness campaigns.

Objective of This Study

The aim of this study is to examine the impact of the *One Degree: Shift the Influence* simulation on participant ability to engage in and effectively manage conversations with individuals they have concerns about due to their substance use. We hypothesize that the simulation will increase participant preparedness, likelihood or behavioral intent, and self-efficacy to initiate a conversation, avoid upsetting someone when bringing up concerns, focus on observable facts, and problem solve. An additional aim is to observe changes in both personal and public stigma regarding substance use as a result of using this app. By addressing these key areas, we aim to provide preliminary evidence that community members can play an active role in ameliorating a major public health problem by learning from this new and innovative teaching tool, and normalizing having conversations about substance use in their daily life.

Methods

Recruitment

A total of 80 participants were recruited for this mixed methods pilot study by responding to an ad in regional press publications covering four counties in the state where Colorado's *One Degree: Shift the Influence* campaign focused their marketing efforts. The ad stipulated that we were seeking people to participate in a study to evaluate the effectiveness of a game-based virtual human (avatar) role play simulation that teaches individuals how to manage a conversation with someone that they are concerned about regarding their alcohol or other substance use. Participants were informed by email that they would need to take a short presurvey (baseline), then complete a 30-minute online role play simulation, followed by an immediate postsurvey and a 6-week follow-up survey. Participants received a US $30 gift card upon completing the simulation with the associated pre- and postsurveys, and a US $20 gift card after completing the follow-up survey. The entire study required approximately 45-60 nonconsecutive minutes.

To qualify, participants must have been 18 years or older and had access to a computer with audio and internet capabilities. Upon agreeing to participate, participants received a link to the study that led them to the informed consent page and the Survey Monkey hosted presurvey. After completing the presurvey, they selected and completed one of two role play simulations followed by a postsimulation survey. They were emailed a follow-up survey 6 weeks later. The Baruch College Human Research Protection Program/Institutional Review Board and Peer Assistance Services, Inc, a Colorado-based nonprofit agency, determined that no ethics approval was required for this study.

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Statistical Analysis

Quantitative Measures

Kirkpatrick's [44,45] training evaluation model was used in assessing the impact of the *One Degree: Shift the Influence* simulation. This model evaluates four levels: reaction, learning, behavior, and results. Level one, reaction, is the level of user satisfaction with the training. Level two, learning, is the impact on attitudes, knowledge, or skills. Level three, behavior, represents the change in behavior. Level four, results, are final outcomes such as overall long-term benefits that could include a shift in culture or return on investment. The fourth level was not assessed for it was not within the scope of this study.

Level one assessment questions were asked in the postsurvey immediately after participants completed the simulation. They included:

- Overall, how would you rate the course (five-point Likert scale from "very poor," 1, to "excellent," 5)?
- Would you recommend this simulation to a friend or colleague ("yes" or "no")?
- Is the simulation based on scenarios that are relevant to you ("yes" or "no")?

Level two survey questions were asked in the pre-, post- and follow-up surveys and included ten items that assessed three attitudinal constructs including participant (1) preparedness, (2) likelihood (or behavioral intent), and (3) self-efficacy. Specifically, these items were drawn from the validated Gatekeeper Behavior Scale [46] and modified for the purpose of this study. This was accomplished by drawing from social cognitive theory [47], Bandura's [48] integrative framework of personal efficacy to assess preparedness and self-efficacy, and the theory of reasoned action [49,50] to assess behavioral intention or likelihood. All three theories act as a direct precedent of behavior; thus, the three attitudinal construct measures include:

1. Preparedness to engage in helping behaviors related to substance use was measured with four items, which were averaged to create a composite score (Cronbach alpha .82). Responses were set on a five-point Likert scale that ranged from (1) "very low" to (5) "very high." The common stem for all items was "Please rate your preparedness to" start a conversation about substance use with someone you are concerned about, avoid upsetting someone while bringing up concerns about their substance use, focus on observable facts while bringing up concerns about their substance use, and problem solve with someone to help them address their substance use.
2. Likelihood was measured with two items, which were averaged to create a composite score (Cronbach alpha .72). Responses were set on a five-point Likert scale from (1) "very unlikely" to (5) "very likely." The common stem for all items was "How likely are you to" start a conversation about substance use with someone you are concerned about and problem solve with someone to help them address their substance use.
3. Self-efficacy was measured with four items, which were averaged to create a composite score (Cronbach alpha .83). Responses were set on a five-point Likert scale from (1) "strongly disagree" to (5) "strongly agree." The common stem for all items was "Please indicate how much you agree or disagree with the following statements": "I feel confident in my ability to" start a conversation about substance use with someone you are concerned about, avoid upsetting someone while bringing up concerns about their substance use, focus on observable facts while bringing up concerns about their substance use, and problem solve with someone to help them address their substance use.

Level two survey questions also included measures of social and subjective norms, which are components of the theory of planned behavior and are correlated with helping and help-seeking behaviors [50]. For example, one's public stigma regarding whether most people approve or disapprove of a behavior influences their decisions to engage in behaviors because it reflects on how aligned those behaviors are with their sense of self and with the community. Personal and public stigma were comprised of two items, for which Cronbach alpha was not calculated as each stigma item was assessed separately (eg, public vs private or personal stigma). Responses were set on a five-point Likert scale from (1) "strongly disagree" to (5) "strongly agree." The common stem for all items was "Please indicate how much you agree/disagree with the following statements":

- Most people think less of a person who has been in treatment for substance use (public stigma).
- I think less of a person who has been in treatment for substance use (personal stigma).

Level three survey questions were asked in the pre- and follow-up surveys. Self-reported behavioral measures included "in the past 6 weeks, approximately how many times have you: started a conversation about substance use with someone you are concerned about? Problem solved with someone to help them address their substance use? Consulted with a health professional about substance use?"

The quantitative statistical analysis includes descriptive data for level one, a repeated measures analysis of variance (ANOVA) for level two as there were three measurement points to compare (pre, post, and follow-up), and a paired sample *t* test for level three as there were only two comparison points (pre to follow up). All analyses were conducted using SPSS version 26 (IBM Corp). For the repeated measures ANOVA, separate analyses were run for each of the outcome variables (ie, each preparedness item, composite preparedness, each likelihood item, composite likelihood, each self-efficacy item, composite self-efficacy, and both stigma items). In cases where the overall F value was significant, post hoc tests were conducted with a Bonferroni adjustment to correct for type I error. The paired samples *t* tests were also conducted separately for each of the three behavioral variables.

Qualitative Measures

Qualitative measures were asked in the post and follow-up survey and included:

- Now that you have completed the simulation, please describe a situation that you would have managed

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differently. What happened and what would you have done differently? Please do not include any names of people (asked immediately after training in postsurvey).

- Now that you have completed the simulation, can you recall a situation where you used the skills learned in the simulation? Please describe what happened and be sure not to include any names of people (asked at follow-up survey).

The qualitative analysis involved coding for reoccurring themes using a joint inductive–deductive coding process (see Shockley et al [51] for a similar example). This involved two independent coders where the first coder read through the various questions and identified common themes; the second coder did the same, adding and refining categories where applicable; once a final coding template was established, both coders independently coded the responses into the full set of thematic categories; the head coder reviewed the coding for agreement and resolved any discrepancies through discussion with the other coder; the head coder organized the thematic categories into higher order themes as reported in a later section; and the head coder chose quotes that best represented each theme for further illustration. For all content categories, only those with at least 2 statements fitting into that category were reported. Percentages do not add to 100% because a single statement could fit into multiple categories. Statements have been copied verbatim (typos were not corrected).

Results

Descriptive Statistics

There were 80 participants recruited for this study whose average age was 31.01 (SD 10.66) years, with 50% (n=40) female, 45% (n=36) male, 1.3% (n=1) gender nonconforming, and 3.8% (n=3) preferring not to answer. Race/ethnicity and employment status can be seen in Table 1.

After completing the first part of the study (presurvey, the simulation, and the postsurvey), 28 participants dropped out. A chi-square compared the differences between those participants who completed the entire study (N=80) to those who did not complete the follow-up survey (n=28). Participants who completed all three survey time points had a significantly higher presurvey score for preparedness (*P*=.01) and self-efficacy (*P*=.02) compared to those who did not complete the follow-up survey. There were no other significant differences in dependent variables including attitudinal measures, age, gender, ethnicity, simulation rating, and satisfaction measures.

Table 1. Participant demographics (N=80).

Demographics	Participants
Age (years), mean (SD)	31.01 (10.66)
Gender, n (%)	
Female	40 (50)
Male	36 (45)
Gender nonconforming or other gender identity	1 (1.3)
Prefer not to answer	3 (3.8)
Race or ethnicity, n (%)	
White	55 (68.8)
Black or African American	5 (6.3)
Hispanic or Latinx	11 (13.8)
American Indian/Alaska Native	1 (1.3)
Asian	5 (6.3)
Native Hawaiian/Other Pacific Islander	2 (2.5)
Prefer not to answer	7 (8.8)
Employment status, n (%)	
Full time	41 (51.3)
Part time	16 (20)
Not working	17 (21.3)
Prefer not to answer	6 (7.5)

Quantitative Measures

Level one satisfaction findings showed that 100% of all 80 participants rated the simulation either excellent (n=24, 30%), very good (n=41, 51%), or good (n=15, 19%). Additionally, 95% (n=76) stated they would recommend the simulation to a friend, and 84% (n=67) reported that the simulation was based on scenarios that were relevant to them.

Table 2 shows descriptive statistics for individual and composite scores across all three survey time points and shows the results of the repeated measures ANOVA analysis, post hoc tests, and

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effect size information (partial eta^2). Similar tables are shown for the likelihood (Table 3) and self-efficacy (Table 4) attitudinal constructs. The results show that preparedness and self-efficacy composite attitudinal measures significantly increased from the presurvey to the follow-up survey after post hoc adjustment. The likelihood construct did not maintain its significance after the post hoc correction.

The stigma findings show a slight nonsignificant decrease in both private and public stigma (see Table 5).

Table 2. Preparedness descriptive statistics and repeated measures ANOVA results.

Preparedness[a]	Response, mean (SD)[b]	Repeated measures ANOVA[c], *F* value	*P* value	Post hoc tests, mean difference			*P* value			Partial eta^2 for F
				Pre to post	Pre to follow-up	Post to follow-up	Pre to post	Pre to follow-up	Post to follow-up	
Start a conversation about substance use with someone you are concerned about		16.09	<.001	0.37	0.64	0.27	.005	<.001	.04	0.24
Pre	3.40 (1.05)									
Post	3.77 (0.81)									
Follow-up	4.04 (0.74)									
Avoid upsetting someone while bringing up concerns about their substance use		13.46	<.001	0.43	0.69	0.27	.02	.001	.09	0.21
Pre	3.17 (094)									
Post	3.60 (0.89)									
Follow-up	3.87 (0.74)									
Focus on observable facts while bringing up concerns about their substance use		5.62	.005	0.27	0.44	0.17	.23	.006	.39	0.10
Pre	3.62 (0.95)									
Post	3.88 (0.83)									
Follow-up	4.06 (0.70)									
Problem solve with someone to help them address their substance use		9.33	<.001	0.46	0.58	0.12	.008	.004	.78	0.16
Pre	3.52 (1.04)									
Post	3.98 (0.70)									
Follow-up	4.10 (0.82)									
Composite preparedness		17.71	<.001	0.38	0.59	0.21	.004	<.001	.03	0.26
Pre	3.42 (0.85)									
Post	3.81 (0.69)									
Follow-up	4.01 (0.58)									

[a] Each item begins with “How would you rate your preparedness to...”

[b] n=52 for all time points. All preparedness items are the same across all survey time points.

[c] ANOVA: analysis of variance.

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Table 3. Likelihood descriptive statistics and repeated measures ANOVA results.

Likelihood[a]	Response, mean (SD)[b]	Repeated measures ANOVA[c], F value	*P* value	Post hoc tests, mean difference			*P* value			Partial eta^2 for F
				Pre to post	Pre to follow-up	Post to follow-up	Pre to post	Pre to follow-up	Post to follow-up	
Start a conversation about substance use with someone you are concerned about?		4.55	.01	0.27	0.33	0.06	.05	.06	>.99	0.10
Pre	3.73 (0.97)									
Post	4.00 (0.71)									
Follow-up	4.06 (0.64)									
Problem solve with someone to help them address their substance use?		1.03	.36	N/A[d]	N/A	N/A	N/A	N/A	N/A	0.02
Pre	4.12 (0.65)									
Post	4.15 (0.57)									
Follow-up	4.25 (0.59)									
Composite likelihood		3.15	.047	0.15	0.23	0.08	.25	.14	.97	0.06
Pre	3.92 (0.73)									
Post	4.07 (0.55)									
Follow-up	4.15 (0.54)									

[a] Each item begins with “How likely are you to...”

[b] n=52 for all time points. All likelihood items are the same across all survey time points.

[c] ANOVA: analysis of variance.

[d] N/A: not applicable.

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Table 4. Self-efficacy descriptive statistics and repeated measures ANOVA results.

Self-efficacy[a]	Response, means (SD)[b]	Repeated measures ANOVA[c], F value	*P* value	Post hoc tests, mean difference			*P* value			Partial eta^2 for F
				Pre to post	Pre to follow-up	Post to follow-up	Pre to post	Pre to follow-up	Post to follow-up	
Start a conversation about substance use with someone you are concerned about		11.23	<.001	0.54	0.50	0.04	<.001	.007	>.99	0.18
Pre	3.52 (1.09)									
Post	4.06 (0.57)									
Follow-up	4.02 (0.75)									
Avoid upsetting someone while bringing up concerns about their substance use		8.46	<.001	0.46	0.54	0.08	.01	.005	>.99	0.14
Pre	3.29 (0.98)									
Post	3.75 (0.76)									
Follow-up	3.83 (0.76)									
Focus on observable facts while bringing up concerns about their substance use		1.87	.16	N/A[d]	N/A	N/A	N/A	N/A	N/A	0.035
Pre	3.92 (0.79)									
Post	4.15 (0.61)									
Follow-up	4.08 (0.74)									
Problem solve with someone to help them address their substance use		3.97	.02	0.23	0.33	0.10	.23	.07	.77	0.072
Pre	3.92 (0.86)									
Post	4.15 (0.64)									
Follow-up	4.25 (0.65)									
Composite self-efficacy		9.28	<.001	0.37	0.38	0.01	.002	.01	>.99	0.15
Pre	3.66 (0.78)									
Post	4.03 (0.78)									
Follow-up	4.04 (0.61)									

[a] Each item begins with “I feel confident in my ability to...”

[b] n=52 for all time points. All self-efficacy items are the same across all survey time points.

[c] ANOVA: analysis of variance.

[d] N/A: not applicable.

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Table 5. Stigma descriptive statistics and repeated measures ANOVA results.

Stigma	Responses, mean (SD)[a]	Repeated measures ANOVA[b], F value	*P* value	Post hoc tests, mean difference	Partial eta^2 for F
Most people think less of a person who has been in treatment for substance use		0.22	.80	N/A[c]	0.004
Pre	3.58 (1.00)				
Post	3.56 (0.90)				
Follow-up	3.84 (1.08)				
I think less of a person who has been in treatment for substance use		0.03	.96	N/A	0.001
Pre	1.98 (0.98)				
Post	1.94 (0.98)				
Follow-up	1.96 (1.12)				

[a] n=52 for all time points.

[b] ANOVA: analysis of variance.

[c] N/A: not applicable.

Level 3 self-reported behavior results (see Table 6) show no significant change from the presurvey to the follow-up survey in the number of participants that started a conversation with someone they were concerned about regarding their substance use, problem solved with someone to help them address their substance use, and consulted with a health professional about substance use. The lack of significant change led us to examining the responses of the two open-ended questions originally designed to help participants accommodate skill acquisition into the learning experience.

Table 6. Self-reported behavior descriptive statistics and repeated measures t test results.

Behavior	Pre, mean (SD)	Follow-up, mean (SD)	Paired sample *t* test (*df*)	*P* value
Started a conversation about substance use with someone you are concerned about	1.46 (2.49)	0.88 (1.94)	1.47 (51)	.15
Problem solved with someone to help them address their substance use	1.37 (2.47)	0.98 (1.92)	1.02 (51)	.31
Consulted with a health professional about substance use	0.92 (2.57)	0.50 (1.38)	1.18 (51)	.24

Qualitative Measures

The open-ended question included in the postsurvey was, “Now that you have completed the simulation, please describe a situation that you would have managed differently. What happened and what would you have done differently?” Answers were divided into two parts that included (1) describe a situation and what happened, and (2) how would you have managed it differently?

The open-ended question included in the 6-week follow-up survey was, “Now that you have completed the simulation, can you recall a situation where you used the skills learned in the simulation?” Thematic categories and exemplary statements for the postsurvey and 6-week follow-up survey responses can be found in Tables 7-9. The themes and their relative frequencies that emerged from the coding process previously described are listed in Multimedia Appendix 1.

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Table 7. Postsurvey responses for describing a situation and what happened (N=80).

Thematic categories	Exemplary statements	Sample size[a], n (%)
Presimulation conversation tactics		
Approached person in a condescending or attacking manner	“I have tried to approach one of my friend's about their mental health before and I came off too strong and she got offended. Now I feel like I know how to sound more like I'm listening and not make her angry.”	13 (16.3)
Choose not to address the person’s substance use	“My roommate in college was beginning to use alcohol as a crutch. Rather than address it, I just let it happen. That person is fine today, but I feel I could have improved their lived experience if I had started a conversation. As the simulation shows, it doesn't take much to start someone thinking about their behavior.”	5 (6.3)
Too scared/unsure how to initiate conversation	“The hardest thing is to initiate the conversation. I'm not sure I, someone who is conflict averse, will be able to...”	3 (3.8)
No example		
Do not have an example	“I have never been in a situation like that, but it definitely gave me some tools I can use if I need to have a similar conversation in the future.”	9 (11.3)
Other		
Other	N/A[b]	10 (12.5)

[a] Not all respondents (N=80) clearly answered both parts, hence the smaller number of responses.

[b] N/A: not applicable.

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Table 8. Postsurvey responses for describing a situation that you would have managed differently (N=80).

Thematic categories and subcategories	Exemplary statements	Sample size[a], n (%)
General mention of skills		
General mention of using the strategies learned to initiate and guide the conversation in a productive direction	"When confronting a niece about her substance abuse the conversation took a wrong turn and became adversarial so this simulations showed how to approach that differently."	15 (18.8)
Provided general support		
Initiated a conversation about substance use	"I would have told my friend to stop drinking so much when he was underage. He could've been saved from a underage drinking ticket."	12 (15)
Offering empathy	"I had a conversation about drug abuse with a family member recently, but instead of empathizing with him, i just attacked him for how his choices were affecting the rest of the family. If I could go back, I'd definitely try to empathize a lot more"	9 (11.3)
Provided support	"I would have approached addicts with more of an understanding and hopeful attitude, rather than with pity and reprimand"	3 (3.8)
Offered sympathy	"I would have approached addicts with more of an understanding and hopeful attitude, rather than with pity and reprimand"	3 (3.8)
Conversational tactics		
Focus more on problem solving	"I would have focused more on the problem solving part. I think I tend to go into therapist mode and want to talk alllllllll about whats causing it and totally skip over the "now what to we do" until there isn't a lot off time, or its late or whatever. So then the problem solving is a second thought. i would also have eased into it a little more. I confronted someone about it rather bruskly and i think it just started the whole ordeal off wrong..."	9 (11.3)
Offer less advice/opinion	"I will definitely be more empathetic with active listening and avoid reaching conclusions and solutions and advice for the situation. It's better to be the guider of conversation to the solution."	8 (10)
Asked more questions	"i would empathize more with my friend instead of giving her advice that pushed her away, and I would ask her questions to help her figure it out by herself."	4 (5)
Approached the person without accusing them	"I myself am a recovering alcoholic. I talk to people all the time about my addiction and frequently have conversations with other people about theirs. I thought it was awesome that even though I've been sober for 9 years, I still learned something from this simulation - if you jump in with accusations (even if they are based on fact or observation) the other party may get defensive and close up."	4 (5)
Discussed consequences of substance use	"approaching the individual without drinking the issues at hand. maybe have the environment different, more in a his comfort zone. Making more of a point of the issues at hand and making it very clear that there is a problem and the consequences at hand. Knowing what words to say and how to approach the individual."	3 (3.8)
Discussed cause of the substance use	"I would have brought up my health concerns for my roommate who recently had picked up smoking as well as figuring out what could possibly be the trigger (stress). Then problem-solving some other ways to deal with it if she agreed it was a problem."	2 (2.5)
Self-reflection		
Would have managed my own substance use differently	"I've struggled with addiction problems myself, so looking back, realizing how young I started using would've changed, being aware of my family history, and realizing there was a deeper reason for why I felt the need to alter my state of mind."	3 (3.8)
Other		
Other	N/A[b]	6 (7.5)

[a] Not all respondents (N=80) clearly answered both parts, hence the smaller number of responses.

[b] N/A: not applicable.

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Table 9. Six-week follow-up survey responses for recalling a situation where you used the skills learned in the simulation and what happened (n=57).

Thematic categories and subcategories	Exemplary statements	Sample size[a], n (%)
Did not use skills yet		
Have not used skills from the simulation yet	"I have not used the skills in the simulation yet, but I do believe they would be useful if I needed to talk to someone about substance abuse."	23 (40.4)
Mentioned using the simulation but did not give specifics of how or the situation	"I work in HR and while I don't address substance use specifically, I often mediate and this skills have been useful in helping people find solutions that work for them."	7 (12.3)
General support		
Initiated a conversation about substance use	"I felt a little more confident in my skills to do this with a friend I know who has been struggling. After doing the simulation, I had some ideas about how to subtly bring it up without sounding like I was accusing them of anything. I'm not sure if it will result in anything positive but I think our talk helped at least a little"	10 (17.5)
Provided a listening ear and support	"An old friend from high school struggled with drug addiction throughout his early college years. It was always swept under the rug until he broke and finally entered rehab and began exercising addiction programs. We talk regularly and always talk about our substance use, we confront each other when we know were on a slippery slope, and have an open dialogue about substance use without judgement."	5 (8.8)
Acted in nonjudgmental way		
Adopted a nonjudgmental lens when having a conversation	"I was talking about cannabis use with a friend, and I used what I learned in the simulation. I tried to stay factual with my approach and help problem solve and get into a healthier state. I was non judge-mental and was encouraging and shared my own success with them."	3 (5.3)
Approached the person without accusing them	"I felt a little more confident in my skills to do this with a friend I know who has been struggling. After doing the simulation, I had some ideas about how to subtly bring it up without sounding like I was accusing them of anything. I'm not sure if it will result in anything positive but I think our talk helped at least a little"	2 (3.5)
General conversational tactics		
Mentioned facts related to substance use	"I talked to a ex friend who's son killed someone because his was drunk driving. The kid is 17 years old. I explained that there were plenty of signs that he had a problem. Plus his living situation did not help..dad has a drinking problem and was addicted to pills. Dad's girlfriend is an addict and dealer. I tried to explain how his home life had an effect on his actions."	3 (5.3)
Discussed consequences of substance use	"I spoke to a friend about their drinking habits. Brought it up as a question, talking about how expensive alcohol is and how I could save a lot of money if I stopped, and about the health benefits of drinking less. I then went on to ask my friend what he thought"	2 (3.5)
Told person to slowdown	"My old roommate drank too much and didn't spend time with us, so we told him he should think of slowing down."	2 (3.5)
Instrumental or specific conversational tactics		
Talked to person about getting professional help	"My sister was high on drugs and I talked her into going to rehab"	4 (7.0)
Offered options or ways to help solve the substance use problem	"Recently I went to a concert and my friends were doing inappropriate drugs. I calmly turned down the offers to partake and used problem solving skills learned in the situation to get my friends to chill out"	3 (5.3)

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Thematic categories and subcategories	Exemplary statements	Sample size[a], n (%)
Helped person get out of the bad situation that was fueling substance use	"I talked with a friend about his drinking and helped him to decide to end his relationship with the person enabling him and to move on."	2 (3.5)
Behavioral tactics		
Convinced someone to stop/plan to stop substance use	"I approached my girlfriend about cocaine usage and we agreed upon tapering, quitting, and general therapy. I as careful not to be irritating and I feel the varying convos were successful."	4 (7.0)

[a]Not all respondents (n=57) clearly answered both parts, hence the smaller number of responses.

Discussion

Principal Results

Findings show that participants highly rated the simulation, would recommend it to others, and felt that it was based on relevant scenarios. Participants also reported significant increases in their preparedness and self-efficacy from baseline to follow-up to start a conversation with someone they were concerned about regarding their substance use, avoid upsetting someone while bringing up concerns, focus on observable facts, and problem solve. The results showed a significant overall effect for composite preparedness, likelihood, and self-efficacy. For preparedness, post hoc tests revealed that there was a significant increase in preparedness across all time points (ie, follow up was significantly higher than post and pre, and the post was significantly higher than the pre). For likelihood, although the overall F statistic was significant, there were no individual significant differences between time points due to the adjustment in type I error with the Bonferroni correction. However, the trend was such that the scores increased over time. With self-efficacy, there was also an increase in means over time, but the post and follow-up means were not significantly different than each other, although both were significantly higher than the pretest means.

There were no significant changes in self-reported behaviors regarding starting conversations about substance use with others, problem solving with someone to address their substance use, or consulting with a health professional about substance use. However, the qualitative data provided a more nuanced perspective of the positive impact the simulation had on how people would have applied the skills they learned if they could redo past experiences and how they actually used what they learned as a direct result of the simulation. Perhaps self-reported behaviors were influenced by a number of participants revealing that they themselves were personally dealing with, or had dealt with, substance use issues, which might have incentivized them to enroll in the study as opposed to being specifically concerned about others. Another factor could be that the short 6 week follow-up was not an adequate amount of time to capture changes in behavior. Both of these factors, past exposure to substance use and the short 6-week follow-up period, could have also influenced the small change in personal and perceived public stigma. Despite seeing a slight decrease in negative personal and perceived public stigma toward those experiencing substance use struggles, there was no systematic difference in these measures before and after participating in the simulation.

To extrapolate on the qualitative data, we hypothesize that we would have observed higher use of strategies had we implemented the pilot in a more targeted manner by identifying and recruiting individuals that were specifically interested in this content due to some personal or professional relevancy. In theory, a study sample that expresses a particular need for this type of intervention would lead to a higher number of participants indicating that they used the skills learned in the simulation. This more targeted recruitment would also influence the behavioral results, likely increasing reports of identification, approach, and referral. However, this pilot was conducted without specifically targeting an at-risk group, and we did not screen the participants for content relevancy to their current personal or professional lives prior to recruitment, as this initiative was a part of a general Colorado public health campaign.

These types of virtual role play training simulations have shown to be efficacious in training targeted populations such as health care providers including social workers, educators, school counseling professionals, and students in the health care field [29-34]. Data from these studies show significant improvements in attitudinal constructs related to interpersonal skills acquisition and behavioral changes. Thus, the results in this study, where users were not identified as part of a population of people that were concerned about or affected by family members, friends, or colleagues take on added meaning for they still reported significant changes in attitudes and positive qualitative responses.

Limitations

There are several limitations of this pilot study; the first being that it is not a randomized controlled trial (RCT). In addition, participants self-selected into the study, which is a common selection bias often found in similar studies. Another limitation is that changes in behaviors were self-reported; therefore, they may not be an accurate indication of the number of conversations participants engaged in about substance use, the number of people they problem solved with, or the number of times they consulted with a health professional. Future studies should use an RCT design and be more rigorous in controlling for possible confounders in participant selection. To confirm this study's findings and perhaps better observe changes in stigma and help-seeking behavior, future studies should recruit

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larger sample sizes and should follow up with participants beyond the 6-week timeframe used in this pilot study.

Although this study provides a baseline understanding of the ways in which the simulation may affect changes in preparedness and confidence around initiating conversations about substance use, the results are also limited by the fact that many participants were not presented with opportunities to practice their newly learned skills within the 6-week study timeframe. A similar study with a more targeted audience may have provided better insights in to different aspects of behavior change as a result of the simulation. Future studies should use alternative methods of recruitment targeted at individuals who are more likely to have conversations about substance use arise in their daily life. For example, targeted outreach to support groups for friends and family of individuals who use substances may result in a sample that is more likely to initiate conversations within a 6-week period. In addition, since this study was carried out, Peer Assistance Services, Inc and Kognito Solutions, LLC have developed a third simulation that centers around discussions between adults and adolescents. This simulation could be piloted with parents, coaches, teachers, or other trusted adults who may be in a position to initiate conversations about substance use with young people before it even begins.

There is also one limitation to the One Degree: Shift the Influence application itself that is worth noting. In real life scenarios, not all individuals will be ready or willing to participate in conversations about substance use if approached by a peer, family member, or colleague. Although the virtual humans do provide negative feedback throughout the role play to express when they are unhappy with a chosen conversational technique, these simulations do not address alternative techniques to use if the person approached about their substance use is unwilling to participate in a conversation in the first place. However, simply raising the topic of substance use with someone who is struggling with addiction, regardless of whether or not they are ready to have the conversation, does increase the likelihood of future behavior change [52].

Conclusions

The preliminary results of this study indicate that, in general, public awareness initiatives may benefit from integrating easy to access, experiential, online virtual human role play simulations. These simulations allow individuals to gain skills and confidence around initiating and managing conversations about substance use by using evidence-based communication strategies such as motivational interviewing. Walker et al [53] points out that, in these critical times of COVID-19, MI is an ideal framework to address substance use. Even before this crisis occurred, alcohol use was the third leading cause of preventable death, and data has shown that the isolation and anxiety around the COVID-19 pandemic have increased the use of alcohol and other substances. Normalizing discussions about substance use is an important first step toward identifying and mitigating risky use. Simulations like *One Degree: Shift the Influence* provide a unique and engaging mode of education aimed at improving individuals' preparedness and confidence to manage difficult conversations with people that they care about, supplementing existing public awareness initiatives.

Peer Assistance Services, Inc and Kognito Solutions, LLC have also developed online training geared toward health care providers. These training simulations help providers build the skills necessary to integrate an early intervention practice called Screening, Brief Intervention and Referral to Treatment (SBIRT) into their workflow. The brief intervention component of SBIRT requires health care providers to initiate conversations about substance use. Brief interventions are tailored to the patient's unique needs and concerns, and are rooted in MI techniques. Concurrent efforts to increase and improve the quality of conversations about substance use both in the home and within primary care will lead to overall improvements in health outcomes, reductions in stigma, and earlier referrals to specialized treatment as needed across Colorado.

The results of this study hold promise that this type of new and innovative learning experience can support public health initiatives to cost-effectively reach large numbers of geographically dispersed communities. Online role play simulations can supplement existing substance use prevention and early intervention work, enabling people to manage conversations with others about substance use and motivating them to decrease substance use and seek treatment as necessary. The need for this type of outreach has been delineated in the public health program literature [54,55] and by the Office of the Surgeon General's Report on Alcohol, Drugs, and Health [56], which emphasized that the substance use care continuum begins with enhancing health, primary prevention, and early intervention.

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The data are not available due to ethical and legal restrictions. Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

Conflicts of Interest

Peer Assistance Services, Inc is a Colorado nonprofit organization that implements substance use prevention and early intervention programs. Those staff involved in this pilot study have no financial interest relating to this pilot study. Kognito, the developer of

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the simulation used in this pilot study, is a subcontractor with Peer Assistance Services, Inc. Compensation to Kognito was not tied to study results.

In accordance with JMIR Publications’ policy and our ethical obligation as researchers, we are reporting that GA and NK have employment agreements with Kognito, the company that developed the simulation used in this pilot study. KS was an independent statistical consultant from the University of Georgia who received payment from Kognito for the data analysis. Compensation from Kognito was not tied to study results. There are no other conflicts of interest to declare, thus we have disclosed those interests fully to JMIR Publications and have in place an approved plan for managing any potential conflicts arising from this pilot study.

Multimedia Appendix 1
Correlation matrix of all study variables.
[DOCX File , 15 KB - formative_v5i4e27164_app1.docx]

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Abbreviations

ANOVA: analysis of variance
MI: motivational interviewing
NSDUH: National Survey on Drug Use and Health
RCT: randomized controlled trial
SBIRT: Screening, Brief Intervention and Referral to Treatment

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Original Paper

Written Advice Given by African American Smokers to Their Peers: Qualitative Study of Motivational Messages

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Abstract

Background: Although African Americans have the lowest rates of smoking onset and progression to daily smoking, they are less likely to achieve long-term cessation. Interventions tailored to promote use of cessation resources in African American individuals who smoke are needed. In our past work, we demonstrated the effectiveness of a technology-assisted peer-written message intervention for increasing smoking cessation in non-Hispanic White smokers. In this formative study, we have adapted this intervention to be specific for African American smokers.

Objective: We aimed to report on the qualitative analysis of messages written by African American current and former smokers for their peers in response to hypothetical scenarios of smokers facing cessation challenges.

Methods: We recruited African American adult current and former smokers (n=41) via ResearchMatch between April 2017 and November 2017. We asked participants to write motivational messages for their peers in response to smoking-related hypothetical scenarios. We also collected data on sociodemographic factors and smoking characteristics. Thematic analysis was conducted to identify cessation strategies suggested by the study participants.

Results: Among the study participants, 60% (25/41) were female. Additionally, more than half (23/41, 56%) were thinking about quitting, 29% (12/41) had set a quit date, and 27% (11/41) had used electronic cigarettes in the past 30 days. Themes derived from the qualitative analysis of peer-written messages were (1) behavioral strategies, (2) seeking help, (3) improvements in quality of life, (4) attitudes and expectations, and (5) mindfulness/religious or spiritual practices. Under the behavioral strategies theme, distraction strategies were the most frequently suggested strategies (referenced 84 times in the 318 messages), followed by use of evidence-based treatments/cessation strategies. Within the seeking help theme, subthemes included seeking help or support from family/friends or close social networks (referenced 56 times) and health care professionals (referenced 22 times). The most frequent subthemes that emerged from improvements in the quality of life theme included improving one’s health (referenced 22 times) and quality of life (referenced 21 times). Subthemes that emerged from the attitude and expectations theme included practicing positive self-talk (referenced 27 times), autonomy/independence from the smoking habit (referenced six times), and financial cost of smoking (referenced five times). The two subthemes that emerged from the mindfulness/religious or spiritual

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practices theme were use of self-awareness techniques (referenced 36 times) and religious or spiritual practices to cope (referenced 13 times).

Conclusions: Our approach to adapt a prior peer-message intervention to African American smokers yielded a set of evidence-based messages that may be suitable for smokers at all phases of motivation to quit (ready to quit or not ready to quit). In future research, we plan to assess the impact of texting these messages to African American smokers in a smoking cessation trial.

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KEYWORDS

tobacco disparities; peer-to-peer; communication; smoking; cessation; thematic analysis; intervention; African American

Introduction

Smoking is the leading cause of preventable death in the United States [1]. Smoking cessation programs have reduced overall smoking rates, but their impacts have not been uniformly beneficial [2,3]. Smoking-related disparities have noticeably expanded, resulting in calls for targeted cessation programs to meet the needs of minority and disadvantaged populations [3]. African Americans are disproportionately affected by tobacco-related diseases in terms of mortality and morbidity. African Americans are 20% more likely to die from heart disease than non-Hispanic Whites and have a higher incidence of lung cancer compared with the general population [4-7].

Although African Americans have the lowest rates of smoking onset, have slower progression to daily smoking [8], and report attempting to quit (63%) more often than non-Hispanic White smokers (53%) [9], they are less likely to achieve long-term cessation [10]. Tailored cessation interventions are needed to support African American smokers [11].

We conducted formative research to adapt a technology-assisted peer message intervention for African American smokers. The effectiveness of a peer-written message intervention has been demonstrated in a large randomized trial conducted among mostly non-Hispanic White smokers, who were recruited from medical practices across the United States [12,13]. In this study, participants were enrolled into a web-assisted tobacco intervention. The intervention group was emailed one peer and one expert (written by a team of behavioral scientists and clinicians) message weekly for 6 months. Compared with the control group, receiving a combination of peer- and expert-written messages significantly increased the odds of 7-day point prevalence cessation at 6 months (odds ratio [OR] 1.69, 95% CI 1.03-2.8) [12,13]. We further compared the effect of peer versus expert-written messages on intervention engagement, which was defined by return visits to the intervention website. Peer-written messages were more likely to generate a return visit to the intervention website (OR 2.03, 95% CI 1.74-2.35) than expert-written messages [14]. There were significant interactions of the effect of the peer-written message with time from registration ($P<.001$). As the time interval from registration increased, the benefits of peer-written messages were accentuated over time [14]. Preserving engagement in digital interventions is challenging yet critical to intervention fidelity and subsequent cessation. These results highlighted the benefit of peer message interventions [15]. Further details of our prior evaluation demonstrating the feasibility and effectiveness of a peer message intervention in a general population of smokers has been published [12-14].

Research shows that African American communities may be influenced by unique sociocultural dimensions, such as interconnectedness, level of health socialization, and ecological and health care system factors [16]. Messages written by health experts may not incorporate these dimensions. Thus, we hypothesize that African American smokers may particularly benefit from peer messages (messages written by African American smokers) as these messages could reflect shared experiences and exemplify difficulties of quitting, skills, and strategies needed for smoking cessation [17]. African American participants have reported greater engagement and improved outcomes when they felt a strong sense of community or support from social networks [18,19]. Prior studies that have tested a peer-driven digital intervention among African American participants have reported improved satisfaction and outcomes [17,18,20]. The peer messages developed in our prior work were written by a population of smokers (mainly non-Hispanic White smokers) [12,13]. To adapt the prior intervention, we asked African American adults, who were current or former smokers, to write messages to their peers guided by various hypothetical scenarios. In this paper, we focused on the qualitative assessment of the peer-written messages and report on the cessation strategies that emerged from the messages written by African American current and former smokers. In the future, these peer messages will be tested in an adapted and tailored technology-assisted behavioral intervention to promote cessation in African American smokers.

Methods

Study Design

We conducted a formative qualitative study of motivational messages written by African American current or former smokers. Writers (n=41) responded to various hypothetical scenarios (Multimedia Appendix 1) via an online semistructured questionnaire. Details on participant recruitment, data collection procedures, and analysis of peer-written messages are provided below. This protocol was approved by the University of Massachusetts Medical School Institutional Review Board.

Participant Recruitment

Participants were recruited online via ResearchMatch between April 2017 and November 2017. ResearchMatch is an online web-based recruitment database freely available to individuals

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interested in volunteering for research studies [19]. Researchers can search the database and filter the list of volunteers by demographic information, such as age, race, ethnicity, and tobacco use. Participants were eligible if they self-identified as African American, were current or former smokers, were 18 years or older, and were willing to write messages for peers (n=41). Participants received a US $50 Amazon gift card for their contribution in the study.

Data Collection

We collected data on sociodemographic factors and smoking characteristics. Sociodemographic factors included age, gender, education, and ability to pay for medical care. The ability to pay for medical care measure was used as a proxy for socioeconomic status, providing insights into household resources and demands placed on participants by medical expenditures [21,22]. Smoking characteristics included readiness to quit, number of cigarettes smoked per day, past year quit attempts, past 30-day use of menthol cigarettes, level of nicotine dependence, and electronic cigarette (or e-cigarette) use. The readiness to quit measure was based on stages of change as described in the transtheoretical model of behavior change [23], and was captured by asking current and former smokers to indicate whether they (1) were not thinking about quitting, (2) were thinking about quitting, (3) had already quit, (4) had set a quit date, or (5) had quit today.

Current and former smokers were matched to hypothetical scenarios by age group (45 years or younger and older than 45 years) and gender (male and female). We requested that participants write motivational messages about quitting based on each scenario. We suggested they describe experiences that might be useful to other smokers before, on, and after a set quit date. We also asked them to include suggestions for maintaining motivation and addressing barriers to quitting (eg, how to handle urges and cravings). Each participant responded to the following two hypothetical scenarios: for a smoker ready to quit and one not ready to quit. All responses to the scenarios were captured through a semistructured questionnaire that was distributed through Research Electronic Data Capture (REDCap) (Multimedia Appendix 1).

Data Analysis

The percentages and mean distributions of smoker characteristics were calculated. Informed by our previously published methods [14], we reviewed all messages to identify those with specific characteristics. First, the messages had to be directly quotable, include sufficient details, and be self-explanatory. Directly quotable messages with sufficient details were those that were written in sentence form and contained clear and detailed information targeted to the scenario. Second, the messages had to have behavioral content that reflected personal quitting experiences. The underlying assumption for this criterion is that personal experiences are considered credible and trustworthy and therefore can potentially motivate behavior change [24]. Messages were selected by research team members with relevant expertise in smoking cessation (CSN and RSS), health behavior change (CSN, AJM, JMF, RSS, and JHW), and qualitative analysis (JHW and AJM). Out of the 1200 messages written, 318 messages (27% of the original messages) met the criteria.

Examples of the messages selected are as follows:

> *She can speak with doctor and discuss methods of quitting, and what's available to help her. Try to reach out and see if there's a quit smoking program that either she can go to in person or she can call when she has urges.*
>
> *Figure out what triggers her to smoke throughout the day have a plan. If you typically smoke after meals, you might want to have something planned after you eat to keep mind off it. Sometimes certain rooms of the house cause cravings if that's where you smoked. You might want to change the decor, try to reduce the smell of smoke, etc., to make the environment less triggering.*

Examples of the messages excluded are as follows:

> *Secondhand smoking kills.*
>
> *The cause and the effect.*

Two coders (CSN and DM) reviewed selected messages in an open coding process until concepts became apparent, at which point a code was assigned. Labels and definitions of themes were based on words in the message text. This approach to developing sets of codes is a grounded theory approach to qualitative data analysis that limits researchers from erroneously “forcing” a preconceived result [25]. Data analysis was conducted using MAXQDA qualitative data analysis software developed and distributed by VERBI Software based in Berlin, Germany.

Results

Demographic and Smoking Characteristics

Among the participants, 60% (25/41) were female. Most of the participants had a college-level education (27% [11/41] were college graduates and 59% [34/41] had attended some college or technical school). The daily average number of cigarettes smoked was 8.5 (SD 5.7). More than half (23/41, 56%) of smokers were thinking about quitting, and 29% (12/41) had set a quit date. About half (21/41, 51%) of the participants reported a past year quit attempt. Most participants smoked within 30 minutes of waking up (22% [9/41] within 5 minutes and 51% [21/41] within 6-30 minutes). Moreover, 27% (11/41) of smokers had used e-cigarettes some days or every day in the past 30 days. Among smokers who had ever tried e-cigarettes, 59% (17/29) had used e-cigarettes to quit or cut down on smoking (Table 1).

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Table 1. Characteristics of current and former smokers who participated in an online study (N=41).

Characteristic	Value, n (%) or mean (SD)
Gender	
Female	25 (60%)
Male	16 (39%)
Age	
25-34 years	12 (29%)
35-44 years	11 (26%)
45-54 years	10 (24%)
55+ years	8 (19%)
Education	
High school graduate	6 (14%)
College graduate	11 (27%)
Some college or technical school	34 (59%)
How hard is it for you (and your family) to pay for medical care?	
Very hard	7 (17%)
Hard	6 (14%)
Somewhat hard	13 (32%)
Not very hard	15 (37%)
Cigarettes per day, mean (SD)	8.5 (5.7)
Readiness to quit	
I am not thinking about quitting	3 (7%)
I am thinking about quitting	23 (56%)
I have set a quit date	12 (29%)
I quit today	1 (3%)
I have already quit	2 (5%)
Stopped smoking one day or longer in the past 12 months	
Yes	21 (51%)
No	20 (49%)
Past 30-day menthol cigarette use	
Yes	35 (85%)
No	6 (15%)
How soon after you wake up do you smoke your first cigarette?	
Within 5 minutes	9 (22%)
6-30 minutes	21 (51%)
31-60 minutes	4 (10%)
After 60 minutes	7 (17%)
Have you used/ever participated in tobacco counseling before?	
Yes	7 (17%)
No	34 (83%)
E-cigarette use in the past 30 days	
Every day	1 (3%)
Some days	10 (24%)
Not at all	30 (73%)

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Characteristic	Value, n (%) or mean (SD)
Reasons for using e-cigarettes[a]	
To quit/cut down on smoking	17 (59%)
In places I am not allowed to smoke	5 (17%)
Trying it out/experiment with it	7 (24%)

[a] Question asked to smokers who have ever used e-cigarettes at least once (n=31).

Frequencies of Subthemes in Peer-Written Messages

Results are organized via the following themes: behavioral strategies, seeking help, improvements in quality of life, attitudes and expectations, and mindfulness/religious or spiritual practices. Under the *behavioral strategies* theme, distraction strategies were the most frequently suggested behavioral strategies (referenced 84 times in the 318 messages). Other behavioral subthemes included evidence-based treatments/cessation strategies (referenced 41 times), avoidance strategies (referenced 37 times), removal of smoking triggers (referenced 28 times), use of rewards (referenced 34 times), setting restrictions on one's smoking and goal setting (each referenced 23 times), and use of reminders (referenced 17 times). In the *seeking help* theme, subthemes included seeking help or support from family/friends or close social network (referenced 56 times), former smokers (referenced 24 times), and health care professionals (referenced 22 times). Subthemes that emerged from the *improvements in quality of life* theme included concerns about the negative health effects of smoking (referenced 13 times), improving one's health (referenced 22 times), and quality of life (referenced 21 times). Subthemes that emerged from the *attitude and expectations* theme included practicing positive self-talk (referenced 27 times), autonomy/independence from the smoking habit and financial cost of smoking (each referenced six times), and reducing second-hand exposure to others (referenced five times). Within the *mindfulness/religious or spiritual practices* theme, the subthemes included use of self-awareness techniques (referenced 36 times) and religious or spiritual practices to cope (referenced 13 times). Example messages for each subtheme are provided in Textbox 1 and Textbox 2.

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Textbox 1. Themes of behavioral strategies and seeking help, and their subthemes derived from messages (N=318) written by African American smokers who participated in our online study.

Theme: Behavioral Strategies

Subtheme 1: Use of distraction strategies–Behavioral coping strategies or finding healthy ways to pass time (n=84 [number of times the subtheme is referenced in the messages])

Message examples:

- Focus on something else like exercise or reading. Find a relaxing music playlist and turn it on during breaks or at other times when you would smoke.
- Buy sugar free gum, lollipops and a squish ball. When a craving hit take a slow deep breath and then use one of the items listed above to get through the craving.

Subtheme 2: Evidence-based treatments/cessation treatments–Alternatives to smoking and use of treatments (n=41)

Message examples:

- Take smoking cessation medication from the start to help ease into the process of quitting. Use medications to help with cravings, really plan your strategies for difficult situations.
- Purchase gum, mints, cinnamon sticks -- something to use instead of cigarettes. Nicotine patches, or medications, such as Chantix may be helpful.

Subtheme 3: Avoidance strategies–Avoiding places, people, and things that remind one of smoking (n=37)

Message examples:

- People find it helpful to avoid situations in which they might be tempted to smoke, especially in the days right after quitting.
- Stay away from people, places, and things that trigger her to smoke. Now is a time to find new acquaintances. And be honest if they are about to smoke. If they care about what you are attempting to do for self, they won't smoke in front of you. If not, walk away.

Subtheme 4: Use of rewards–Messages focusing on use of rewards (n=34)

Message examples:

- Focus on the reward as a diversion and something to look forward to.
- Remind herself constantly of her reasons for quitting, and put the money she saves aside and plan a vacation or treat for herself to celebrate 1 year of being cigarette free.

Subtheme 5: Removal of smoking triggers–Advice about removing anything that elicits an urge to smoke and/or is associated with the smoking habit. Done ahead of time, pre-emptively (n=28)

Message examples:

- Remove all cigarettes, ash trays, and lighters. Every single lighter needs to be removed even the lighters in all of your purses. Search all of your purses for lighters and matches and spare cigarettes. Get rid of them all.
- Deep clean her house. Wash all of her clothes, ‘cause smoke tends to get trapped in them if you smoke a lot. Remove all ashtrays & lighters. And e-arrange her furniture with a different set up.

Subtheme 6: Setting boundaries/restrictions around the smoking habit–Proactive ways to reduce smoking that limit engaging in smoking (n=23)

Message examples:

- Make your home and your vehicles smoke free zones.
- Travel with less cash or debit card if possible, throughout the day to assist you in not purchasing cigarettes. Maybe keep one cigarette on you during long days out of house.

Subtheme 7: Goal setting (planning)–Messages that focus on preparation to increase chances of success or setting up a plan (prepare for a quit date, prepare rewards/goals, or set a quit date) (n=23)

Message examples:

- You should think about how you will handle situations where you are tempted you will be tempted to smoke.
- Come up with distractions and plans for what to do when a craving hit ahead of time. These could include things like drinking mint tea if you smoked menthols, chewing gum, eating celery or pretzel sticks so your hands do the same movement as smoking. Also calling friends and keeping your hands busy can help.

Subtheme 8: Use of reminders–Remember motivation/reasons/goals around quitting (n=17)

Message examples:

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- Post notes in her home that encourage and remind her of how much she can enjoy life without smoking.
- Keep a small, laminated card in his wallet that reminds him of why he quit and the benefits he is now enjoying.

Theme: Seeking Help

Subtheme 1: Seeking support from family/friends or individuals in social network–Seeking support from friends and family to help quit (n=56)

Message examples:

- Have a list of friends and family to call and talk with for emotional support and encouragement.
- Pull family and friends into the process. Allow them to help you, but also make it clear that they're there for support. It's up to you to define and communicate how you need to be supported. That support need may change over time. Just be clear what you are looking for and what you are not looking for. Example: accountability vs nagging you to death.

Subtheme 2: Seeking support from former smokers–Seeking support from former smokers or smokers trying to quit (n=24)

Message examples:

- I would align myself with other smokers who have gone through the struggle to quit, similar to AA or NA as a support base since they know what you are trying to accomplish and have already been there.
- Find alternate support means such as a group of former smokers or other friends who have previously quit smoking.

Subtheme 3: Seeking help or support from a health care professional–Advice to seek professional support in-person (from physicians) or online to help quit (n=22)

Message examples:

- Ask her physician for help. Talk with her doctor or find a quit line to see what options are available, such as patches or medications that might make it easier to handle cravings.
- Talk to her doctor about the benefits of no smoking. Also get a physical and the doctor can tell her how much quitting can actually benefits her.

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Textbox 2. Themes of improvements in quality of life, attitudes and expectations, and mindfulness/religious or spiritual practices, and their subthemes derived from messages (N=318) written by African American smokers who participated in our online study.

Theme: Improvements in Quality of Life

Subtheme 1: Concerns about the negative health effects of smoking–Conveying smoking health-related concerns (n=13 [number of times the subtheme is referenced in the messages])

Message examples:

- She could live longer and possibly overcome some of her health problems by not smoking.
- It does not actually decrease your anxiety, it does nothing to change the stress you are experiencing, the negative health effects are well documented and affect every part of your body.

Subtheme 2: Improving one’s health–Focusing on improving one’s own health as motivation to quit (n=22)

Message examples:

- You will feel better and your health will improve. You will breathe better. You have more energy through the day. You face will start to look smoother and brighter.
- Thinking about the positive outcome (improved health, relationships) is a great way to stay focused.

Subtheme 3: Improving one’s quality of life–Improving one’s own quality of life as motivation to quit (n=21)

Message examples:

- She can get in tune with her taste buds. Food tastes different once you have quit smoking.
- You smell a lot better and are not self-conscious when stepping into a new crowd. Also, first impression is everything. When going to a job interview, the first scent of you is smoke. That's unattractive and may cost you a great opportunity.

Theme: Attitudes and Expectations

Subtheme 1: Practice positive self-talk–Ways to develop/maintain a positive mindset (n=27)

Message examples:

- Quitting is difficult, take time to congratulate yourself on your success.
- Tell herself that she not weak she can do this. Hype yourself up by telling yourself you got this. You can do it.

Subtheme 2: Autonomy or independence from the smoking habit–Freedom to do what you want and when without being dependent on the smoking habit (n=7)

Message examples:

- Living life on your schedule, not on tobacco bothersome regime.
- Not having to inconvenience yourself to go outside to smoke or wait to smoke in nonsmoking areas, no longer smelling like smoke.

Subtheme 3: Quitting to spend time with family and friends–Highlight improving one’s own health to spend time with family as motivation to quit (n=6)

Message examples:

- If you quit smoking now, you may be able to spend time with your grandkids at a theme park instead of in a hospital.
- Things to me about quitting smoking was how much more quality time I would have with my family.

Subtheme 4: Financial cost of smoking–Messages focused on money spent on cigarettes (n=6)

Message examples:

- The money spent on cigarette is more than the cost of the medications used for smoking cessation. You are literally setting your hard-earned money on fire.
- I was tired of the amount of money that is literally going up in smoke.

Subtheme 5: Reducing second-hand exposure to others–Highlight on harm to family members due to smoking (second-hand smoke health concerns) as motivation to quit (n=5)

Message examples:

- Secondhand smoke has been proven to impact others. Your smoking can harm your family and friends.
- Imagine having lost a pet due to smoking. If your dog develops breathing issues and can no longer leave in the home, you are changing the life of your pet by your habit. It is unfair.

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Theme: Mindfulness/Religious or Spiritual Practices

Subtheme 1: Use of self-awareness techniques–Self-awareness on the smoking habit and/or quitting progress (n=36)

Message examples:

- Keep a journal noting his progress, feeling and other thoughts.
- Sit down and start a daily journal to keep track of her feelings and experiences while she goes through her journey.

Subtheme 2: Use of religious or spiritual practices to cope–Advice referencing use of prayer and/or spiritual practices to cope with cravings/urges and other challenges of quitting (n=13)

Message examples:

- Please pray constantly for the help from God that you will need.
- When you wake-up and pray to God to give you strength to make it through the day.

Discussion

Principal Findings

Our approach to adapting a peer messaging intervention generated a rich set of messages that can be incorporated into text message cessation interventions tailored to support African American smokers. The peer-written messages aligned with evidence-based practices for supporting cessation and corresponded to the following five themes: behavioral strategies; seeking help; improvements in quality of life; attitudes and expectations; and mindfulness/religious or spiritual practices. The themes reflected in the messages described in this paper can be applied to smokers at all stages of behavioral change.

Within the distraction behavioral theme, use of evidence-based treatments/cessation treatment, and avoidance were the most frequently referenced subthemes. Distraction is often suggested as a way to prevent relapse for smokers [26]. Distraction techniques recommended by participants included physical activity and listening to music. Engaging in short bouts of physical activity is associated with a reduction in smoking cravings [27,28]. Listening to music helps participants manage emotional states and cravings that may act as cues to smoke [28]. Participants also suggested use of evidence-based treatment or cessation strategies such as nicotine replacement therapy. African American smokers reported less positive attitudes toward using cessation treatments and are less likely to use a Food and Drug Administration–approved cessation aid compared to White smokers [29]. Increasing the use of evidence-based treatment/cessation strategies among African American smokers is an important research priority in tobacco cessation [30]. Having a peer suggest use of cessation medications may increase the uptake of evidence-based strategies among African American smokers, and this needs further research. Avoiding situations that trigger smoking or peers who smoke is also an often-suggested strategy for smokers interested in quitting [31].

Participants frequently suggested seeking help from family and friends, and health professionals during cessation. Past studies indicated that social network support significantly contributes to cessation in African American individuals who smoke [32,33], and ways to increase this support for cessation need to be explored further [34]. Peers also suggested requesting help from health professionals. Brief interventions from health providers are shown to increase cessation among smokers [35]. However, African American smokers are less likely to receive these interventions [29,36]. Taking the initiative to request for help from a health professional may alleviate differences in receiving cessation advice from providers among African American smokers.

Improvements in the quality of life theme encompassed benefits of quitting and motivations to quit smoking. The most frequent subthemes were (1) improving one’s health and (2) quality of life. Given that the health effects of smoking and benefits of quitting are well-known, peers highlighting the health benefits of smoking may serve as reinforcement to African American smokers. Participants also highlighted several benefits of smoking to improve one’s quality of life, including eliminating the smell of cigarettes, breathing more easily, and having better taste, which are linked to one’s intentions to quit [34]. Smokers are more receptive to information that emphasizes the benefits of quitting [37]. The added benefit of having these messages written by peers is likely to enhance their impact on cessation.

Subthemes under the attitudes and expectations theme included practicing positive self-talk, autonomy/independence from the smoking habit, and the financial cost of smoking. Practicing positive self-talk has been associated with an increase in self-efficacy [38], and in turn, an increase in self-efficacy is associated with smoking cessation [39]. African American smokers are likely to benefit from practicing general self-regulatory activities, including self-talk, as these have been shown to result in smoking fewer cigarettes for up to 15 months [40]. Participants also urged peers to consider the financial costs of smoking as a motivation to quit. Smoking-related cost is an important motivator for cessation among smokers in lower socioeconomic groups [41,42].

Within the mindfulness/religion or spiritual practices theme, smokers were advised to use self-awareness techniques and religious or spiritual practices as coping mechanisms during cessation. In our past work in which we collected messages written mostly by non-Hispanic White smokers (32 out of 39 participants) [14], mindfulness, religious, and spiritual practices did not emerge from the peer-written messages. Although not exclusive to African American communities, use of spiritual and religious practices, as a coping response to health issues,

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is often adopted in this group [40], with positive and promising results in health outcomes [43]. Other health behavior change studies in African American populations have shown more positive outcomes if participants reported having strong ties within a religious congregation [41]. Exploring the use of religious practices for cessation is particularly important for African American smokers, since they are disproportionately impacted by tobacco-related health conditions. Participants also advised use of self-awareness techniques, which are shown to be effective for reducing the number of cigarettes smoked and for relapse maintenance [44,45]. The inclusion of self-awareness messages in cessation messaging interventions will be valuable.

To our knowledge, this is the first study to explore the content (and frequency of the content) of cessation messages developed by African American smokers. Peer-written messages developed in this study can be used to support cessation efforts among smokers motivated to quit, as well as among those less motivated. Smokers who are motivated to quit may experience withdrawal symptoms and smoking cravings during a quit attempt [39]. Messages that highlight distraction and avoidance strategies are therefore relevant to this group. Smokers who initiate quit attempts are vulnerable to declines in motivation, which can lead to resumption of smoking. Messages that highlight healthier lifestyle modifications (eg, engaging in physical activities), along with positive reinforcements, may be particularly helpful for maintaining motivation. For smokers currently not motivated to initiate a quit attempt, challenges, such as low self-efficacy and lack of support, reduce the chances of early quitting success [39]. Messages from peers that highlight ways to increase self-efficacy or ways to tap into sources of social support may be of particular benefit to this group.

This study had some limitations. Recruitment through ResearchMatch resulted in enrollment of highly motivated smokers. Therefore, the subthemes obtained from the peer-written messages may reflect behavioral strategies implemented by highly motivated smokers and could differ from strategies that might be implemented by smokers less motivated to quit. Our sample lacked diversity, as we enrolled a high proportion of female, older, and highly educated current and former smokers. Given that smokers with low socioeconomic status are the most likely population to have difficulty quitting [32] and that smoking is more prevalent in men than women [33], health behaviors observed in our sample could differ from those present in other populations. The meaning of messages may not have corresponded with the coders' interpretations of the messages. We limited the effects of the researchers' perceptions on the study findings by implementing coding protocols that preserved and used original words written by smokers.

Conclusion

For populations experiencing tobacco-related disparities, a reduction in smoking rates may require development of tailored cessation interventions. In this formative work, we were successful in developing a rich set of peer messages written by African American current and former smokers that incorporated many evidence-based strategies and can be used to support both low- and highly-motivated African American smokers. In future research, we plan to assess the impact of these peer-written messages within a technology-assisted intervention for smoking cessation among African American smokers.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Hypothetical scenarios used in data collection of peer-written messages.
[DOCX File , 17 KB - formative_v5i4e21481_app1.docx]

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Abbreviations

OR: odds ratio

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Review

Enabling Guidelines for the Adoption of eHealth Solutions: Scoping Review

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Abstract

Background: Globally, public health care is under increasing pressure, an economic burden currently amplified by the COVID-19 outbreak. With the recognition that universal health coverage improves the health of a population and reduces health inequalities, universal health coverage has been acknowledged as a priority goal. To meet the global needs in a population with increased chronic illness and longer life expectancy, the health care system is in dire need of new, emerging technologies. eHealth solutions as a method of delivery may have an impact on quality of care and health care costs. As such, it is important to study methods previously used to avoid suboptimal implementation and promote general guidelines to further develop eHealth solutions.

Objective: This study aims to explore and thematically categorize a selected representation of early phase studies on eHealth technologies, focusing on papers that are under development or undergoing testing. Further, we want to assess enablers and barriers in terms of usability, scaling, and data management of eHealth implementation. The aim of this study to explore early development phase and feasibility studies was an intentional effort to provide applicable guidelines for evaluation at different stages of implementation.

Methods: A structured search was performed in PubMed, MEDLINE, and Cochrane to identify and provide insight in current eHealth technology and methodology under development and gain insight in the future potential of eHealth technologies.

Results: In total, 27 articles were included in this review. The clinical studies were categorized thematically by illness comparing 4 technology types deemed relevant: apps/web-based technology, sensor technology, virtual reality, and television. All eHealth assessment and implementation studies were categorized by their focus point: usability, scaling, or data management. Studies assessing the effect of eHealth were divided into feasibility studies, qualitative studies, and heuristic assessments. Studies focusing on usability (16/27) mainly addressed user involvement and learning curve in the adoption of eHealth, while the majority of scaling studies (6/27) focused on strategic and organizational aspects of upscaling eHealth solutions. Studies focusing on data management (5/27) addressed data processing and data sensitivity in adoption and diffusion of eHealth. Efficient processing of data in a secure manner, as well as user involvement and feedback, both throughout small studies and during upscaling, were the important enablers considered for successful implementation of eHealth.

Conclusions: eHealth interventions have considerable potential to improve lifestyle changes and adherence to treatment recommendations. To promote efficient implementation and scaling, user involvement to promote user-friendliness, secure and adaptable data management, and strategical considerations needs to be addressed early in the development process. eHealth should be assessed during its development into health services. The wide variation in interventions and methodology makes comparison of the results challenging and calls for standardization of methods.

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KEYWORDS

eHealth; feasibility; global health; implementation

Introduction

Health care constitutes a significant part of public sector expenditure. Total government expenditures among Organisation for Economic Co-operation and Development countries was 41% of the gross domestic product in 2015, and health typically accounts for around 20% of these expenditures [1]. There are several factors hindering efficient improvements in health care services across the globe; one of them is failure to adopt eHealth solutions [2]. With the recognition that universal health coverage improves the health of a population and reduces health inequalities, universal health coverage has been acknowledged as a priority goal of many health systems [3]. As such, the Commission on Social Determinants of Health emphasizes the importance of closing global and national health gaps through enhanced access to a high-quality and safe health supply [3]. As early as 1948, the United Nations declared enhanced access to a high-quality and safe health supply a priority goal [4]. To get around the logistical issues of delivering and receiving health care, both doctors and patients rely on digital communication channels to inform patients and enhance self-management.

Health interventions delivered suboptimally may reduce effective coverage [5]. Although life expectancy has increased globally following the United Nations declaration, the pace of improvement has been slowing down leaving behind large parts of the world's population [6,7]. To achieve the ambitious task of universal health coverage by 2030 as postulated by the World Health Organization and World Bank, radical changes in social and economic trends are necessary [6,7], including improving daily living conditions; addressing inequitable distribution of power, money, and resources; and assessing the impact of action needed [8]. Successful implementation of eHealth solutions requires altering existing health care practices and therefore represents such an opportunity. New approaches delivered by eHealth solutions have the ability to enhance access and quality of care and reduce health care costs [9].

Digitalization, the process of transforming an organization into a digital form, may be considered a driving force in changing health care delivery and may improve accessibility globally [10]. In order to provide equal access to treatment of noncommunicable diseases, which represents the greatest health burden, the possibilities found within digitalization may be substantial [11]. Further, increase in life expectancy is expected to present an influx of patients health care systems are not equipped for. These patients commonly present with complex long-term needs requiring continuity of care, long-term hospitalization, and increased need for individualized care [12]. In addition, the recent COVID-19 pandemic has proved the importance of increased access to care while reducing risk of cross-contamination [13]. As such, several eHealth solutions have been rapidly put into use without a timeframe for tailored implementation or evaluation [14]. For health interventions to maximize benefit, they need to increase service quality and address the imminent needs of the target subpopulation: patients, health providers, and administrators [15].

A high-quality health service can only be achieved if patient outcomes and costs of delivery are addressed [16]. When considering complex health care systems, there are many areas of interest, including legal, organizational, economic, and social aspects, and each needs to be taken into account when looking to implement new technologies [17]. Within these areas, usability of product, learning curve for users, and the need for a recognized standard for patient data security have been highlighted as critical factors in eHealth implementation and scaling [18,19]. Adoption and diffusion of eHealth solutions may be time-consuming and require significant adaptation of work practices [20], and the development and rigorous evaluation of new models of care has been requested [21]. Research has found a discrepancy between the expected value of eHealth and mobile health interventions and the empirically demonstrated benefits [22,23].

In addition to evaluation of eHealth technologies, selection of correct implementation and scaling procedure should be prioritized. Varsi et al [24] found in a review of implementation strategies for eHealth that little attention has been paid to reporting implementation strategies for eHealth and that the feasibility may be compromised as the integration may be perceived as an interruption to existing patient workloads. Implementation processes may be complex as they may concern multilevel organizational structures and involve a wide range of health care stakeholders. A mixed method approach of assessment may be useful when preparing the health care sector for implementation. Applying quantitative methods to explore relationships between digital solutions and disease outcomes may prove useful in enhancing quality of care [25]. In addition, qualitative methods may provide a deeper understanding of contextual factors influencing these relationships and offer information on enablers and barriers to technological implementation globally [26]. This allows for iterative modifications and adaptations from the initial development phase to avoid implementation and scaling of ineffective services. To promote implementation of eHealth solutions with the greatest value to patients, the health care system, and society, we should look at potential value from the very start of the development cycle and throughout testing and implementation [27]. One challenge, however, is that early stages of innovation may suffer from lack of valid data sources.

This study aims to explore and thematically categorize a selected representation of early phase studies on eHealth technologies, focusing on papers that are under development or undergoing testing and assess the studies for common enablers and barriers of eHealth implementation. In summary, through exploring early development phase and feasibility studies we aim to provide applicable guidelines for evaluation throughout the stages of implementation.

Methods

Reporting Standards

The review was structured according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) guidelines [28].

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Selection Criteria

Through two consecutive screenings, we reviewed the articles applying these inclusion criteria: (1) articles reporting some form of early stage eHealth solution (articles were excluded if the intervention or innovation did not consist of eHealth solutions) and (2) articles presenting particular focus on mixed methods to evaluate the feasibility of eHealth (articles were excluded if they did not evaluate the feasibility of eHealth solutions). Detailed inclusion and exclusion criteria can be seen in Textbox 1.

Textbox 1. Selection criteria.

Inclusion criteria:

- Study type
    - Early phase qualitative and mixed method studies
    - Reviews
- Technology (population)
    - eHealth
    - mobile health
- Intervention
    - Apps
    - Sensor technology
    - Virtual reality
    - Television
- Outcome
    - Technological solutions/health care services
    - Methods of evaluation
    - Implementation of eHealth solutions as opposed to specific technologies

Exclusion criteria:

- Study type
    - Language not in English, Norwegian, or Danish
    - Purely quantitative research
    - Published prior to 2008
- Technology (population)
    - No digital innovations
    - Articles deemed not innovative enough
- Intervention
    - Short message (texting) services
    - Interventions not containing digital innovation
- Outcome
    - Articles not falling into categories stated in the inclusion criteria

Outcome Measures

This study aims to explore eHealth technologies under development or undergoing testing to identify enablers and barriers to implementation. We used thematic analysis to categorize the studies according to a preselected thematic framework comprising the following categories: user, technology, analysis, country of origin, and focus point.

Search Strategy

A literature search was conducted in April 2019 using PubMed, Ovid MEDLINE, and Cochrane. The specifics of the search were constructed and performed with the assistance of a librarian

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with experience in systematic search methods. The search was done using a variety of text words and subject headings. The search strategy for MEDLINE was built using the MeSH terms “telemedicine,” “home care services,” “self-help devices,” “communication aids for disabled,” “information technology,” “biomedical technology,” or “telenursing” and synonyms and near-synonyms thereof combined with the text words “technology assessment, biomedical.” The full search strategy can be found in Multimedia Appendix 1.

Selection of Studies

Textbox 1 shows the final inclusion and exclusion criteria agreed upon by the review group. Due to the high number of articles found through the initial search, certain parts of the inclusion criteria were added during the elimination process, mainly in the Intervention category. In addition, we excluded papers published before 2008 partly due to relevance but also to decrease the number of articles. References from each database search were imported into database-specific folders in EndNote (version X9, Clarivate Analytics), and duplicates were eliminated. Abstracts were first assessed by CRW using the selection criteria listed in Textbox 1, and then each of the full-text articles was appraised independently by two reviewers (CRW and LNS). Disagreements were resolved by discussion or by referring to a third author (KJK).

The topic of eHealth solutions is rather broad, and it is challenging to ensure inclusion of all relevant papers within this topic. In an effort to thematically analyze the included studies, the studies were initially thematically categorized in disease groups that represent a great health burden and cost for society, including cardiovascular diseases, cancer, diabetes, and chronic lung disease, as they make the largest contribution to morbidity and mortality [29]. Regarding technology, we focused on commonly used eHealth solutions. However, as the aim of this scoping review was to study barriers and enablers of eHealth implementation, some studies were included as they either focused on specific barriers or enablers of eHealth implementation or evaluated promising technologies less widespread.

The data were extracted by CRW and discussed with LNS. During this process, a framework based on the assessed literature was agreed upon and core themes to answer the research issue were identified. When there was a disagreement among the authors on the appropriate theme, the article was discussed until agreement was achieved. Bibliographic data and study content were collected and analyzed using templates developed iteratively with feedback from the other authors (KJK and LNS).

Data Synthesis and Analyses

Data from the included studies were categorized in Table 1 to provide an overview of the study characteristics for further assessment. Through this categorization and subsequent analysis, we aimed to study barriers and enablers to eHealth implementation.

The data extracted from the included studies were categorized based on Støme et al [30] as follows:

User: Data were categorized by user group targeted by the study: chronic obstructive pulmonary disease (COPD)/asthma, cardiovascular disease, diabetes, elderly adults, and other/not specified.

Technology: Studies were categorized as clinical if a specific technology was applied and divided into four subgroups: apps/web-based technology, sensor technology, virtual reality, and television. Studies were categorized as theoretical if eHealth implementation issues were addressed and divided into the subgroups usability, scaling, and data management.

Analysis: Identified articles were characterized by strategic, economic, and clinical analysis based on the purpose of the analysis and not the analytical approach used, as one analytical approach can be used for different purposes.

Country: Original articles were categorized by country of origin. Reviews were categorized by country of publication or origin of authors. Case studies were categorized by country where study took place.

Focus point: Studies addressing eHealth assessment and implementation were categorized by usability, scaling and data management.

Results

Study Selection

An initial search identified 18,613 studies, and reviewers performed a rough quality assessment by searching through EndNote for the terms “eHealth,” “implementation,” “feasibility,” “early phase” to explore and thematically categorize early phase studies on eHealth technologies under development or undergoing testing. The coarseness of this method was deemed necessary due to the large amount of papers following the initial search. The primary search also included home-hospital services, which did not include eHealth solutions. In the selection of relevant studies for this scoping review, we therefore excluded a large number of studies of moving care to the patients’ home without the use of digitalization or eHealth solutions. Following this method, 628 papers remained. To further narrow the scope, CRW assessed the abstract texts for relevance to the topic, including studies on early phase eHealth development and adoption. Papers published prior to 2008 were excluded as we deemed this to be a suitable breakpoint for technological progress, and articles published prior to this year could have been outdated. Due to the rapid progression of technology development, at a certain point eHealth solutions become outdated when new technology enters the market. Although 2008 is not a year specific for such change, we deemed it adequate to avoid evaluating outdated technology. Following the second assessment, 81 articles remained.

The studies were rigorously assessed, entered on a spreadsheet, and given a general rating based on study design and points of analysis. Relevant stakeholders, advantages of the approach, current research phase, and situational value of the technology were also considered. A focus on variance between papers to gain a holistic view of the topic was an underlying factor for selection. Following this assessment, 27 reviews, pilot studies,

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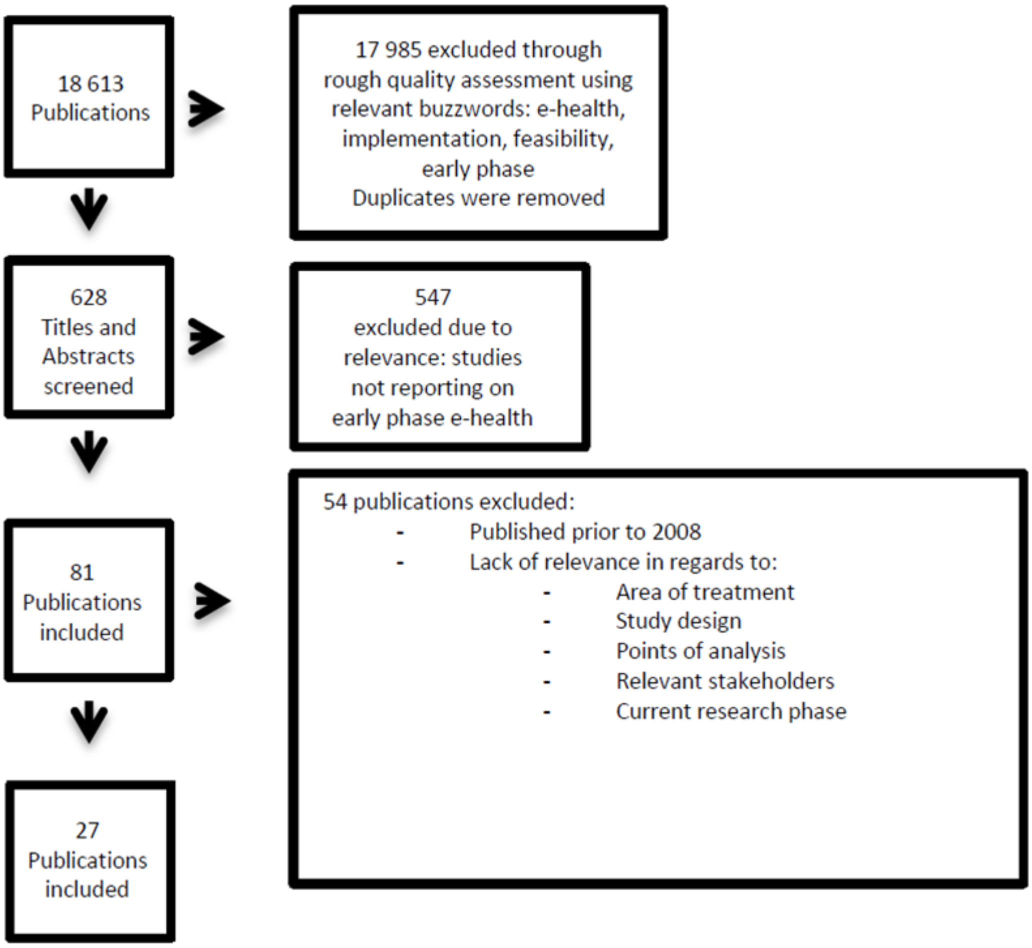
and other forms of research papers were chosen as the basis for this review. The underlying intention behind this review was to identify works of literature and articles addressing both methodological approaches and eHealth solutions in their early phase/concept development/pilot studies. Black et al [22] observed a gap in methodological approaches to studying the empirical evidence concerning the effect of eHealth interventions. Through our search it became apparent that few articles capture implementation and assessment of eHealth. The papers in our review focus on technologies used to treat chronic conditions. An overview of the study selection is shown in Figure 1.

Figure 1. Flow diagram for studies included in the review.



Study Characteristics

The studies selected to undergo a thorough evaluation are shown in Table 1. Enablers and barriers of eHealth implementations will be discussed further in light of findings from these studies. Based on their main focus point, the studies were divided into the categories usability, scaling, or data management. Studies focusing on usability (16/27) mainly addressed user involvement and learning curve in the adoption of eHealth, while the scaling studies (6/27) focused on strategic and organizational aspects of upscaling eHealth solutions. Studies focusing on data management (5/27) addressed data processing sets and data sensitivity in adoption and diffusion of eHealth.

The studies were thematically analyzed and sorted into 5 categories based on illness, although some degree of overlap was found in some studies: patients with COPD/asthma (6/27) [31-35], patients with cardiovascular disease (3/27) [36-38], patients with diabetes (2/27) [39,40], and elderly patients (8/27) [41-48]. While the majority of apps/web-based technology had disease-specific targets, the other technologies were used more frequently with elderly patients. The remaining 8 studies were categorized as other or nonspecified, as illness was not described [49-55] or they focused on issues more relevant from an organizational or caregivers point of view [56,57]. These studies provided theoretical insight into how a given technology may assist in remote treatment and care [49-57].

The majority of the studies were from western countries: 10 studies originated from the United States [33,37,39,44,47-49,51,56,57], 3 from Australia [31,41,55], 4 from England [32,36,45,53], and 3 from Italy [42,43,46]. The remaining 7 studies each took place in Belgium [40], Denmark [35], Japan [34], Malaysia [53], Netherlands [38], Switzerland [54], and Norway [50], respectively.

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Table 1. Description of the data and data analysis.

Author (year)	User	Technology	Focus point	Analysis	Country
Abd Sukor et al (2015) [41]	Elderly adults	Data algorithm	Data management	Clinical analysis	Australia
Aguilar et al (2014) [49]	Not specified	Multifaceted	Scaling	Strategic analysis	US[a]
Angius et al (2008) [42]	Elderly adults	Television	Usability	Strategic/economic analysis	Italy
Arlati et al (2019) [43]	Elderly adults	Virtual reality	Usability	Strategic analysis	Italy
Bartels et al (2017) [44]	Elderly adults	Multifaceted	Scaling	Strategic analysis	US
Burkow et al (2008) [50]	Unspecified chronic disease	Television	Usability	Strategic analysis	Norway
Burrige et al (2017) [36]	Cardiovascular disease	Sensor technology	Usability	Clinical/strategic analysis	England
Cai et al (2015) [45]	Elderly adults	Sensor technology	Usability	Strategic analysis	England
Chi and Demiris (2015) [56]	Chronic disease patients' caregivers	Multifaceted	Usability	Strategic analysis	Primarily US
Ding et al (2012) [31]	COPD[b]	App and web portal	Data management	Clinical/strategic analysis	Australia
Fitzsimmons et al (2016) [32]	COPD	Sensor technology	Usability	Strategic analysis	England
Georgsson and Staggers (2017) [39]	Diabetes	App and web portal	Scaling	Strategic analysis	US
Hui et al (2017) [33]	COPD	App	Usability	Clinical analysis	US
Kamei et al (2012) [34]	COPD	Sensor technology	Usability	Economic/clinical analysis	Japan
Kitsiou et al (2015) [37]	Cardiovascular disease	Multifaceted	Scaling	Strategic analysis	US
Lilhot et al (2015) [35]	COPD	Web-based and tablet technology	Usability	Strategic analysis	Denmark
Mantas et al (2009) [57]	Data security	Data processing algorithm	Data management	Strategic analysis	US
McLean et al (2013) [51]	Not specified	Multifaceted	Scaling	Clinical/economic analysis	US
Monkman (2015) [38]	Cardiovascular disease	App	Usability	Strategic analysis	Netherlands
Mora et al (2018) [46]	Elderly adults	Sensor technology	Data management	Strategic analysis	Italy
Norman et al (2018) [47]	Elderly adults	Multifaceted	Usability	Strategic analysis	US
Sanders et al (2012) [52]	Not specified	Multifaceted	Usability	Strategic analysis	England
Simon and Seldon (2012) [53]	Not specified	App and sensor technology	Data management	Strategic analysis	Malaysia
Tschanz et al (2017) [54]	Not specified	App	Usability	Strategic analysis	Switzerland
Hoecke et al (2010) [40]	Diabetes	App	Usability	Strategic analysis	Belgium
Wade et al (2016) [55]	Not specified	Multifaceted	Scaling	Strategic analysis	Australia
Weiner et al (2016) [48]	Elderly adults	Virtual reality	Usability	Strategic analysis	US

[a] US: United States.

[b] COPD: chronic obstructive pulmonary disease.

Intervention Characteristics

The characteristics of the interventions by technology and illness are summarized in Table 2. The categories were determined following the selection of studies, in an attempt to categorize the studies. The studies were divided into 5 categories based on the type of platform they used, although overlap between technologies was shown in some studies. Among the clinical studies, 8 presented apps combined with web-based technology as their intervention [31,33,35,38-40,53,54]. This was the most common study technology, mainly applied in patients with COPD and asthma. Five studies used sensor intervention, located on the human body or placed indoors in the patients' home [32,34,36,45,46]. Two studies used virtual reality as a method of intervention [43,48]; in the remaining 2, television was tested as a suitable technology [42,50].

Ten studies were categorized theoretical as they did not present a particular technology but focused on general remote care issues [37,41,44,47,49,51,52,55-57]. The studies were placed

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in one of the 3 subcategories: usability [47,52,56], scaling [37,44,49,51,55], and data management [41,57], depending on their primary point of focus. Of these, the majority had communication between patient and practitioner as their primary goal.

Table 2. Study categorization.

Technology/remote care issues	Clinical studies				Theoretical studies			Total
	Apps/web-based technology	Sensor technology	Virtual reality	Television	Usability	Scaling	Data management	
COPD[a]/asthma	4	2	—[b]	—	—	—	—	6
Cardiovascular disease	1	1	—	—	—	1	—	3
Diabetes	2	—	—	—	—	—	—	2
Elderly adults	—	2	2	1	1	1	1	8
Other/not specified	1	—	—	1	2	3	1	8
Total	8	5	2	2	3	5	2	27

[a] COPD: chronic obstructive pulmonary disease.

[b] Not applicable.

Assessment of eHealth Solutions

Early assessment of the potential effect of eHealth solutions was studied in this scoping review with the aim of providing guidelines for evaluation at different stages of implementation. Feasibility can be assessed through qualitative and quantitative methods and may reflect strategic analysis to prepare for implementation or show clinical and safety aspects of the care provided. The feasibility of eHealth interventions was assessed in 6 studies [31,36,41,43,46,50] applying acceptability, usability, and/or utility data from the intervention. Qualitative assessments of the effects of eHealth solutions were also found in this review [32,39,45,47,48,52,54,55]. A Cochrane review [58] identified the need for additional qualitative research to determine if and why particular eHealth interventions are effective. Fitzsimmons et al [32] observed a need to integrate patient satisfaction measures based on patient perceptions of the eHealth technology.

In this review, 2 studies reported on heuristic approaches to evaluation of eHealth solutions [35,38]. These studies emphasized the need to enhance usability in the development and testing of new eHealth solutions. Usability is the extent to which a product or service may be used by a cohort of users to achieve effectiveness, efficacy, and satisfaction in a specified context of use [59]. This may be enhanced by studying users and behavioral data collected during the development of technologies [32]. Such assessments may be time-consuming and resource demanding. Heuristic methods represent a timelier and less expensive approach to assess usability, as user friendliness may be a requirement to achieve full benefit from eHealth solutions in terms of clinical outcomes and patient satisfaction [35].

Discussion

Principal Findings or Summary

This scoping review identified apps/web-based technology and sensor technology as commonly used thematic technologies. Virtual reality, while not as commonly used within eHealth solutions, showed promising results in the studies identified and was included in this study in part due to its wide potential. Television was also found to be used to a somewhat lesser extent, but we included it in this paper due to ease-of-use and high accessibility across patient groups. Within the representative studies assessed in this study, apps/web-based technology had disease-specific targets, while the other technologies were primarily used in elderly patients, where the desire for individualized and tailored care is high [60]. Through analyzing the studies, we identified usability, scaling, and data management as important research areas regardless of eHealth implementation. Studies focusing on usability mainly addressed user involvement and learning curve in the adoption of eHealth, while the majority of scaling studies focused on strategic and organizational aspects of upscaling eHealth solutions. Studies focusing on data management addressed data processing and data sensitivity in adoption and diffusion of eHealth. To explore factors critical for implementation of eHealth based on the studies included in this review, data security and processing, user involvement and feedback, and transitioning from small- to large-scale implementation will be discussed below.

We found that although the emergence of eHealth technologies creates a plethora of innovation opportunities, it is apparent that proper guidelines for evaluating sufficient quality of product are currently not available. This may result in a lack of implementation of new technologies [26,40,43]. As the aim of this study was to explore early development phase and feasibility studies as an intentional effort to provide applicable guidelines for evaluation at different stages of implementation, contributions found in the literature are discussed in this section in the three focus areas: usability, scaling, and data management.

Today, people-centered health care is an increasing ambition [61], and health care is moving toward reduced hospital stays and emphasis on technology-driven solutions to support arena-flexible treatment strategies. Correspondingly, the engagement of end users has become a necessary component in the design and development of future health care [61]. Emphasis is on evidence and outcomes, and the participation

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of users in the provision of their own care has become essential [48]. User-centric design involving patients and health care providers can be employed from the earliest exploratory stages to help understand and design for the needs, goals, limitations, capabilities, and preferences of all stakeholders [62]. Technological development is constantly evolving, and continuous technological adoptions are challenging the identification of valid outcome measurements suitable for assessment of cost and patient benefits [63]. A potential solution may be to integrate an assessment of the whole development cycle, in order to help identify shortcomings and suboptimal parts/areas of innovations. The earlier stages of the development cycle, such as concept stages of innovation, may, however, suffer from lack of valid data sources. This may explain the heterogeneity in the evidence concerning the effect of eHealth interventions in the literature [22,64,65].

Data Management in the Integration of eHealth

Efficient data transfer between parties without compromising the security of sensitive data is important to account for when integrating eHealth solutions. There are vast numbers of requirements for high-security protocols in eHealth. This is obviously due to the sensitive, and in some cases vital, nature of the data and should not be taken lightly [57]. Due to the large amount of data cryptically transferred from patients to practitioners and vice versa, suitable processing technology needs to be incorporated [41]. Especially in the cases of self-measurements, the amount of data is often vast and diluted with errors and noise artefacts since patients are often unaware of what they are supposed to look for [41]. Suitable systems for data processing should therefore be incorporated from an early phase to support the intent of lessening the workload through eHealth [41]. Only through implementing optimal security and processing programs into eHealth can an integrated approach to health care be achieved [27,49]. A summary of guidelines concerning data management in the integration of eHealth can be found in Table 3.

Table 3. Summary of guidelines for eHealth implementation.

Guidelines	Reference	Summary
Data management	[27,41,49,57]	Efficient data transfer between parties without compromising the security of sensitive data. Only through implementing optimal security and processing programs into eHealth can an integrated approach to health care be achieved.
User adaptations	[29,32,39,44,45,66-68]	User involvement may enhance usability and is a significant factor in the implementation of eHealth. The need to account for patient and practitioner adherence was a common feature the reviewed articles reported on. User training programs must provide such information to enhance self-management and goal achievement.
Evaluation and scaling	[23,32-36,38,47,55]	Four critical barriers affecting providers and patients in clinical implementation of eHealth are reported: technological illiteracy and lack of knowledge, awareness, and access to the technology itself. Early stage evaluations of eHealth may reveal hidden factors for successful implementation. Integration of eHealth interventions must be seen as part of a service and not as a standalone system. Two key actions for sustainable implementation are the marketing of eHealth to patients, clinicians, and policymakers and establishing a practice community.

User Adaptations to eHealth Solutions

User involvement may enhance usability and is a significant factor in the implementation of eHealth [66-68]. In the articles reviewed that reported on patient and practitioner feedback, several key points were highlighted and should be accounted for whenever a technological innovation is evaluated. A common feature the reviewed articles reported on was the need to account for patient adherence [29,39]. However, the patients need to understand what to do, why they do it, and how the eHealth solution works to adhere to its use [44]. User training programs must provide such information to enhance self-management and goal achievement [39]. Rigorous training programs may be needed to facilitate successful self-management of the technology [39], as patients vary in understanding and personal motivation. Self-management helps patients gain a better understanding of their condition and enables better communication with their practitioners. This may also ease the intended transparency between patients and practitioners.

Rigorous training may not be enough to ensure uptake of eHealth solutions, and active user involvement in the design of eHealth solutions needs to be perceived as valuable for the participants, such as health care providers. To ensure successful implementation of eHealth, practitioner adherence is also required. Cai et al [45] reported that practitioners involved in the introduction of the technology gain a better sense of the value of the technology they are applying. Studies also highlight positive feedback from patients when the technology facilitates an interactive relationship between patient and practitioner, such as activity planning and communication with practitioners or other health care staff [32]. In this, however, it is increasingly important to uphold a robust level of data security and privacy [69], another factor to be thorough about throughout implementation of any technology [45]. A summary of guidelines concerning user adaptations of eHealth solutions can be found in Table 3.

Evaluation and Scaling of eHealth Solutions

Successful implementation of eHealth solutions may require altering existing health care practices, which may influence patient-provider relationships. Four critical barriers affecting providers and patients in clinical implementation of eHealth are reported: technological illiteracy and lack of knowledge, awareness, and access to the technology itself [32,34]. As these barriers will vary greatly depending on social, geographical,

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and individual situations for patients and caregivers, innovators need to be aware of and make room for individualized alternatives within a given solution. In other words, optional customization within a given eHealth solution to account for each scenario should be included. Timely implementation of eHealth solutions is challenged by lack of early indications of patient benefits and costs. The purpose of this study was to explore how early assessment of eHealth solutions is communicated in the literature to study which markers of eHealth performance could be detected in an early phase. To ensure effective implementation and diffusion of eHealth solutions, each of these barriers needs to be addressed and assessed during the development process of the solution [36]. Early introduction and evaluation of the technology under development is therefore critical. Adaptations to the intervention are still possible in this stage, and barriers to implementation may be identified and eliminated. Early stage evaluations of eHealth may reveal hidden factors for successful implementation. To maximize the benefits associated with eHealth interventions while minimizing risks, evaluations of eHealth interventions should be performed during both design and deployment [70].

Heuristics are decision-making methods that may be applied when faced with short time frames and lack of resources with which to analyze complex data. Although heuristics may be helpful in many situations, the use may also lead to bias, as decisions made using a heuristic approach are likely to be suboptimal [35,38]. As such, to ensure the right eHealth solutions are adopted, increasing the pace of evaluations of eHealth solutions must not sacrifice the quality of scientific findings. Munafò et al [71] call for increased reproducible science and the need to implement measures to improve research efficiency and robustness of scientific findings. The authors argue for the adoption, evaluation, and ongoing improvement of measures to optimize the pace and efficiency of knowledge accumulation.

Evaluating eHealth technologies means evaluating the health care service as a whole. In other words, integration of eHealth interventions must be seen as part of a service and not as a standalone system. eHealth is designed to support the relationship between patients and their health care providers and will never replace the personal interaction between patient and provider [72]. This is why successful implementation requires a holistic approach including the technology, organizational structures, change management, economic feasibility, societal impacts, perceptions, user-friendliness, evaluation and evidence, legislation, policy, and governance [73].

Positive outcomes of any given technology implemented in health care will need to undergo upscaling to suit its intended use and maximize potential benefits. Wade et al [55] developed a qualitative framework for executing large-scale implementation of eHealth solutions. To produce an approach to implementation that ensures sustainable adoption in clinical environments, two key actions were highlighted: marketing of eHealth to patients, clinicians, and policy makers and establishing a practice community. Such leadership support may be vital to large-scale implementation. Policy makers also need awareness of how eHealth aligns with health care policies and how evidence of functionality may best be demonstrated to clinicians [55].

We found large diversity in the studies on the effect of eHealth. To influence policy makers' and clinicians' interpretation of outcomes, research is proposed to be dedicated to understanding optimal strategies for implementation [23,33]. Policy makers and local decision makers may need to adjust their expectations of immediate clinical or economic benefits of eHealth, as it is suggested that the greatest gains may be achieved for patients at highest risk of serious outcomes [47]. A summary of guidelines concerning user adaptations of eHealth solutions can be found in Table 3.

Comparison With Prior Work

Through analysis of the relevant literature we identified several systematic reviews conducted by other research groups. While some of these studies addressed different stages of implementation, others highlighted specific factors of eHealth applications, patient subgroups, or diseases as their focus. Chi et al [56] focused on eHealth experience and innovative potential for patients' caregivers. While this study presented valuable insight into the application of eHealth, it did not provide a full picture of the subsequent effects of eHealth technology. Kitsiou et al [37] provided a broad overview by analyzing several systematic reviews but focused its efforts on patients with chronic heart failure.

Ekeland and Linstad [74] provided valuable insight to different models of eHealth governance but did not give insight into how different technologies may be received by their user groups. Schreiweis et al [75] studied enablers and barriers to eHealth implementation and presented similar conclusions as this study. The literature analysis presents expert discussions to emphasize their findings on enablers and barriers, while this study presents findings on evaluations methods applied in early assessment of eHealth. As such, this study explores the need for early evaluation to communicate the innovative potential in future eHealth research. Ross et al [19] studied eHealth implementation in a comprehensive review of reviews of eHealth and found that a frequent reason for unsuccessful implementation is that the information systems do not fit well with work practices or daily clinical work. Similar to this study, the authors also emphasize the need to focus on reflecting and evaluating the potential benefit of eHealth solutions. For software evaluations, the International Organization for Standardization/International Electrotechnical Commission (ISO/IEC) has defined evaluation methods for the quality of software products and provided common standards called the Systems and Software Quality Requirements and Evaluation series including ISO/IEC 25022:2016 and ISO/IEC 25023:2016 [76]. This quality evaluation framework focuses on metrics such as functional suitability, reliability, performance efficiency, usability, security, compatibility, maintainability, and portability, which are essential to ensure robust eHealth solutions. However, as emphasized above, integration of eHealth interventions must be seen as part of a service and not as a standalone system. As such, there is a need to establish an agreed upon evaluations

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framework to support eHealth solutions throughout the life cycle.

While the previous and related studies show similarities to this study, the focus of this study on the early development phase provides unique insight into factors important to consider when implementing eHealth solutions. Through exploring the early development phase and feasibility studies, this study seeks to provide the groundwork for applicable guidelines for early evaluation of eHealth solutions. As such, this scoping review may be applied as a roadmap to future studies.

Limitations

This scoping review may not have identified all published studies on the feasibility of eHealth, in particular the grey literature. The search strategy may have been compromised by nonstandardization of vocabulary in this relatively new field of research. As the literature search was conducted in two iterations, studies on the feasibility of eHealth may have been involuntarily excluded. As such, the representativeness of the selection of studies evaluating the feasibility of eHealth solutions may have been compromised. In addition, the attempt to draw out representative studies may have inadvertently caused this study to provide a small snapshot of the broad picture that is eHealth implementation. The results from a subset of this small scale may therefore be more fragile to potential outliers, changes in protocol, and new findings emerging in the coming years, as well as findings from the few years since the search was conducted in 2019. Using MeSH terms does not include non-MEDLINE indexed journals, which is a significant subset of PubMed-indexed papers. As such, JMIR Res Protoc or JMIR Formative Res publications were not included in this search, as they were not MEDLINE-indexed 2 years ago. This constitutes a major limitation to the search strategy in this paper. This scoping review did not include specific evaluation frameworks for eHealth components such as software quality but rather focused on evaluation of eHealth as an integrated part of a health system. Despite attempts to adjust the search strategy to several different terms previously used in the literature to describe similar methodologies, other terms may also exist. Although three comprehensive health databases were included in the search (PubMed, Ovid MEDLINE, and Cochrane), searching other databases may have included additional published studies. Our search included only studies in English, Norwegian, and Danish, although only English terms were used in the search. Furthermore, no consultations with stakeholders or experts were included in this review. Finally, although the method was systematically followed by the reviewers, each reviewer subjectively included studies based on the study criteria. Reviewer bias may have occurred in the attempt to include studies that represent a holistic view of eHealth solutions under development and testing. The classification and interpretation of the results were also subject to reviewer bias.

Further Research

As technology continually advances, so does the number of eHealth solutions. Additionally, its infusion into health services is emerging as an active area of research. This was seen in several studies in our literature search. The diversity of studies demonstrated that eHealth is a continually developing field. A large heterogeneity in methodology, sample, interventions, processes, and outcomes was found. It gives an overview of the current broad spectrum of methods but also reflects the broad eHealth scope: to improve health care and enhance quality of care.

Patients also represent diversity, as each of us is different and solutions need to be tailored to the individual. It might also mean that for more robust conclusions to be drawn, improvement related to methodology and standardization is needed. Several studies in this review were not free of bias, reported lack of blinding and related outcomes to the Hawthorne effect. Before a standardized recommendation for methodology concerning assessment and implementation of eHealth can be finalized, more research is needed to systematically validate the methods used for evaluating and implementing eHealth technologies. However, while standardization of methods can achieve better streamlining of new technologies, it is important to keep in mind that diversity and innovation within methodologies can also lead to improvement of innovative methods. Standardization of methodology, with sequential adaptations to new practices, may be a suitable way to optimize eHealth implementation methods. One approach for determining best practice may be to conduct mini case studies on the different methods of implementation and potential subsequent merging methods.

Conclusion

In conclusion, eHealth interventions have considerable potential to improve lifestyle changes and adherence to treatment recommendations, at least in the short term. While apps may support patients with self-management and increased adherence to treatment recommendations, sensor technology may provide additional use and data generation in the health care sector. Virtual reality has a role as a tool to support patient engagement, as well as providing a social platform for isolated patients. The use of television as a medium for system design may help alleviate barriers to user friendliness, as it has been a common household accessory for a long time. However, individualization, data management, and user-friendliness are important factors for use, and technical challenges need to be overcome for full integration to succeed. In terms of providing guidelines for evaluation at different stages of implementation, we found that usability, data management, and scaling strategies should be enhanced in early stage evaluations of future eHealth solutions. Evaluating an eHealth solution still under development may provide continuous information on the performance of the intervention in different development and pilot stages. As such, ineffective solutions may be rejected at an early stage, making room for innovations that provide the most benefit for society. The wide variation in interventions and methodology makes comparison of the results challenging and calls for standardization of methods. A stepwise approach by using subgroup analysis may be one solution that may allow us to understand patient characteristics, behavior, needs, and preferences, allowing us to tailor interventions to those patterns and achieve improved health outcomes while reducing costs. Follow-up, long-term interventions, and analysis of cost-effectiveness need to be included in future research.

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eHealth has the potential for refinement and personalization of existing health care practices and may be of great value. However, user involvement, training, and scaling strategies are important features to implement from the initiation of the development process.

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Authors' Contributions

LNS and CRW conceived and designed the study. LNS and CRW analyzed the data. LNS authored the manuscript. KJK critically reviewed the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy Ovid MEDLINE.
[DOC File , 30 KB - formative_v5i4e21357_app1.doc]

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Abbreviations

COPD: chronic obstructive pulmonary disease
IEC: International Electrotechnical Commission
ISO: International Organization for Standardization
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

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Review

Recommendations for Health Equity and Virtual Care Arising From the COVID-19 Pandemic: Narrative Review

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Abstract

Background: The COVID-19 health crisis has disproportionately impacted populations who have been historically marginalized in health care and public health, including low-income and racial and ethnic minority groups. Members of marginalized communities experience undue barriers to accessing health care through virtual care technologies, which have become the primary mode of ambulatory health care delivery during the COVID-19 pandemic. Insights generated during the COVID-19 pandemic can inform strategies to promote health equity in virtual care now and in the future.

Objective: The aim of this study is to generate insights arising from literature that was published in direct response to the widespread use of virtual care during the COVID-19 pandemic, and had a primary focus on providing recommendations for promoting health equity in the delivery of virtual care.

Methods: We conducted a narrative review of literature on health equity and virtual care during the COVID-19 pandemic published in 2020, describing strategies that have been proposed in the literature at three levels: (1) policy and government, (2) organizations and health systems, and (3) communities and patients.

Results: We highlight three strategies for promoting health equity through virtual care that have been underaddressed in this literature: (1) simplifying complex interfaces and workflows, (2) using supportive intermediaries, and (3) creating mechanisms through which marginalized community members can provide immediate input into the planning and delivery of virtual care.

Conclusions: We conclude by outlining three areas of work that are required to ensure that virtual care is employed in ways that are equity enhancing in a post–COVID-19 reality.

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KEYWORDS
virtual care; health equity; health disparities; health informatics; COVID-19; telemedicine; telehealth; digital health

Introduction

Background

The COVID-19 health crisis has disproportionately impacted populations who have been historically marginalized in health care and public health, including low-income and racial and ethnic minority groups [1]. In the state of Louisiana in the United States, Black patients made up 59% of deaths related to COVID-19 in the early months of the pandemic despite representing only 33% of the state's population [1]. These disparities in COVID-19 outcomes between Black Americans and White Americans can be observed at a population-wide level [2], and Hispanic and Indigenous American communities have also been disproportionately affected by COVID-19 [3,4]. In the United Kingdom, communities with higher concentrations of racial and ethnic minority groups and lower average income

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have been more likely to have a higher concentration of COVID-19 cases [5]. Outbreaks of COVID-19 have also been documented in homeless shelters in the United States and Canada [6-8], illustrating the challenges in combating the spread of the disease in congregate living settings and especially among under-resourced communities. In addition to the well-documented impact of COVID-19 on vulnerable older adults living in long-term care settings [9], these data demonstrate that COVID-19 has disproportionately affected groups who face systematic barriers to care.

The primary strategy for maintaining access to ambulatory and outpatient health services during the pandemic has been to rapidly virtualize, creating systems of health care that rely on telephone visits, video visits, and methods of asynchronous communication such as email, SMS text message, and patient portal messages [10]. Although there are multiple terms referring to the use of information and communication technologies to deliver health services [11], in this paper we refer to applications of this collection of technologies in health care as “virtual care.” A number of contributions have already been published since the onset of the pandemic proposing strategies to ensure that virtual care technologies do not exacerbate disparities in access to health care and health outcomes [12-15]. A large body of literature illustrates how relying on health-related digital technologies can enhance existing inequities—for example, where people from low-income communities are unable to access needed primary care appointments [16].

We make two primary contributions in this paper. Our first contribution is to summarize literature published in 2020 that is explicitly focused on recommending strategies to promote health equity in the delivery of virtual care in the context of the COVID-19 pandemic. We produce a synthesis of these recommendations and organize them according to the three levels at which they are most relevant: (1) policy and government, (2) organization and health system, and (3) community and patient. Our second contribution is to specifically highlight three strategies arising from this literature that are immediately practical and often neglected in the implementation of virtual care initiatives. We conclude by outlining what we view as the central considerations on which governments and health system leaders will need to focus to ensure virtual care is equitable in a sustainable way after COVID-19. We start by reviewing the concept of the digital divide and its links with virtual care in the context of COVID-19.

The Digital Divide

The concept of the digital divide has been widely discussed in the social science literature; this work outlines three “levels” of the divide that are central to understanding the relationships between social inequalities and information technologies [17]. Although originally used narrowly to refer to the gap between those who had access to technologies and those who did not (the “first-level divide”), the concept of the digital divide has evolved to include disparities in technology literacy (the “second-level divide”) and disparities in outcomes (the “third-level divide”) related to technology use [18]. Specifically, the second-level divide refers to the fact that although some individuals might have access to the internet and digital devices, they might not have the skills and knowledge necessary to use these technologies effectively. The third-level divide indicates that even where some individuals might have sufficient knowledge of how to use the technologies, they might not be able to convert their use of technologies into outcomes that improve their lives. The growing presence of information and communication technologies in health care over the past several years has led to growing attention to the implications of the digital divide for access to, and outcomes of, health care services involving such technologies [19,20].

Reviews of the digital divide in health care have illustrated some important considerations about the role of technologies in either increasing or decreasing disparities in health and health care. Weiss et al (2019) [16] explained that understanding the impact of a health-related technology on health disparities is context-dependent, and requires close attention to particular groups of users and their pathways of access and use. In addition, insights are accumulating regarding strategies to enhance access to, and use of, technologies for health care. A 2017 review of the literature outlined strategies related to increasing access, universal technology design, cultural sensitivity, and efforts to promote participation among underserved groups, all of which are promoted as strategies to reduce technology-related health disparities [19]. We now turn to reviewing applications of this body of knowledge to the COVID-19 pandemic that have been published since the onset of the pandemic in early 2020.

Methods

We completed a narrative review of literature published in 2020 focused on recommendations for the promotion of health equity in the delivery of virtual care as a result of the COVID-19 pandemic. Drawing on methodological guidance for narrative literature reviews related to clarity of focus and transparency of search strategy [21,22], our review focused explicitly on literature that was published in direct response to the widespread use of virtual care during the COVID-19 pandemic, and had a primary focus on providing recommendations for promoting health equity in the delivery of virtual care. Fit with these two criteria formed the inclusion criteria. We did not assess articles for quality, and included all those articles that met the two inclusion criteria. Informed by recent discussions of quality in narrative reviews [21], we provide a detailed representation of our search strategy in Table 1.

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Table 1. Literature search strategy.

Search method	Search details	Number of included papers
MEDLINE	- Search in title, abstract, keywords, and subject headings - Search limited to year 2020 - Search string: [(healthcare ADJ dispar*) OR ("health care" ADJ dispar*) OR (health ADJ dispar*) OR (health ADJ equit*)] AND ["virtual care" OR "digital health" OR "telemedicine" OR "telehealth"]	- Total number of results: 43 - Number excluded on screening (not relevant based on fit with inclusion criteria): 35 - Total included papers: 8
Google Scholar	- General search in Google Scholar - Search limited to year 2020 - Search string: ("healthcare disparities" OR "health disparities" OR "health equity") AND ("virtual care" OR "digital health" OR "telemedicine" OR "telehealth")	- Total number of results (first 5 pages): 50 - Number excluded on screening (not relevant based on fit with inclusion criteria): 45 - Total included papers: 5
Forward and backward reference searching	- Identify highly relevant papers cited by included papers - Identify highly relevant papers that cite included papers	- Total included papers: 2

We selected for inclusion only those publications that met the above two criteria, and extracted information on the following: (1) the framing of the paper, (2) the challenges each paper identified in relation to health equity and virtual care, and (3) the recommendations provided to promote health equity through virtual care. We then classified recommendations according to three levels of intervention: (1) policy and government, (2) organization and health system, and (3) community and patient. We use the findings from this literature search to highlight three important practical strategies that require attention and are at high risk of being overlooked, and then comment on strategies to make equitable virtual care sustainable following the COVID-19 pandemic.

Results

Overview

Our database search strategy yielded a total of 93 articles. A total of 80 articles were excluded for reasons of lack of fit with inclusion criteria, and two additional articles were identified from forward and backward reference searching. The result of the screening and supplementary reference search was a final sample of 15 included articles. Table 2 summarizes the included articles addressing virtual care and health equity during the COVID-19 pandemic, and Table 3 summarizes the findings from each included article according to the following three levels: (1) policy and government, (2) organization and health system, and (3) community and patient.

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Table 2. Description of articles addressing virtual care and health equity during the COVID-19 pandemic.

Reference	Framing	Issues raised	Recommendations
Das and Gonzalez, 2020 [23]	Health care equity (equity in access to health services) is especially important to consider during COVID-19.	• Access to technology (phones, phone lines, devices for virtual care) • Digital literacy • Cultural and linguistic issues • Mistrust in health care systems	• Select phone over video for certain populations • Offer telemedicine outside of usual business hours • Identify reimbursement models with insurers for underserved or marginalized patients • Promote virtual widely to grow awareness among underserved or marginalized communities • Partner with community organizations to provide peer-led technical support
Beaunoyer et al, 2020 [24]	Digital inequalities as a determinant of health. Suggest that digital inequalities enhance susceptibility to contracting COVID-19.	Outline 4 proximal influences on whether people can use technology: • Technical means (the quality of the equipment that one can access, both in terms of hardware and software as well as the power and reliability of internet connection) • Autonomy of use (the location where technology is accessed, and perceived freedom to use it as wanted) • Social support networks (assistance from other experienced users) • Experience (time dimension enabling people to be familiar enough with the technology to retain benefits from its use)	• Increase access to connected devices • Increase digital literacy (eg, educational programs) • Increase access to relevant social support (eg, social support phone lines, user-friendly apps, etc) • Increase diffusion of public health messages (eg, increase redundancy of important messaging) • Increase control over quality of messaging • Increase understandability of messaging • Increase acceptability of messaging
Crawford and Serhal, 2020 [12]	Health equity; digital health innovation should not exacerbate existing health inequities during COVID-19.	• Links between broader social determinants of health and the digital determinants of health • Access to digital resources • Use of digital resources for health seeking • Digital health literacy • Beliefs about potential for digital health to be helpful or harmful • Values and cultural norms or preferences for digital resources • Integration of digital resources into community and health infrastructure	• Equal access to digital health leading to equal outcomes across identity groups • Health providers trained to have competencies to provide equitable digital health care • Measurement of equity-related outcomes • Quality improvement focused on equity-related outcomes • Involvement of people from marginalized groups in leadership, health professions, co-design, and data stewardship
Rodriguez et al, 2020 [15]	Digital divide should be considered in the implementation of recent policy (The 21st Century Cures Act)	• Uptake of digital health tools is lower among marginalized populations • Digital health tools have not been designed for marginalized populations	• Promote access to broadband internet and digital devices • Develop programs to promote digital health literacy • Vendors should use inclusive design strategies • Adopting organizations should embed equity in newly established digital services • Offer digital services to all patients • Government policy should clarify standards for design of digital health innovations
Eberly et al, 2020 [14]	Empirical evaluation of difference between those who completed scheduled telemedicine visits and those who did not. Vulnerable patients may have increased barriers to telemedicine care.	• Findings highlight unique challenges faced by women, those who were non–English speaking, and poorer patients	• Interpretation services • Translation of instructions • Improve distribution of video-enabling devices to those unable to afford them • Payment parity between insurers for video and audio visits

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Reference	Framing	Issues raised	Recommendations
Nouri et al, 2020 [13]	Health equity; relying on telemedicine risks further exacerbating inequities as certain patient groups may experience less access to care.	Reduced access to digital health among people in the following groups: • Rural populations • Older adults • Racial/ethnic minority populations • Low socioeconomic status • Limited health literacy • Limited English proficiency	• Identify disparities in access • Explore potential improvements related directly to existing disparities in access • Mitigate digital literacy and resource barriers • Remove health system barriers (offer video visits to every patient, ensure interpreter services, screen for patient barriers to video visits, offer telephone visits if video visits unavailable) • Increase system leadership awareness of barriers to telemedicine • Advocate changes to support equitable access (enable access to low-cost or free internet, pay parity for telephone and video visits from all payers)
Gray et al, 2020 [25]	Prevent exacerbation of health disparities	• Adverse consequences of the digital divide most prominently affect low-income, rural, disabled, racial/ethnic minority, and older adult populations • Sociocultural barriers to digital health: limited electronic skills, low health literacy, disability, low income, and limited English proficiency • Structural barriers to digital health: geographic isolation, broadband capacity, and technical hardware • Lack of touch also negatively affects communication with patients	• Expand broadband access • Accommodate language, literacy, and disability • Provide telehealth literacy training • Engage community health workers • Promote digital empathy and webside manner
Ramsetty and Adams, 2020 [26]	Disparities in access to telemedicine care among vulnerable patients.	• Lack of access to internet • Cultural expectations of technology and its use in health care • Mistrust of health care or of technology • Literacy regarding digital technologies and digital health • Lack of access to relevant digital devices • Health care systems favoring newer, more expensive technologies	• Combine technology and in-person visits, enabling care for people without access to technology (focused primarily on raising awareness about the digital divide during the pandemic)
Egan, 2020 [27]	An explicit focus on informal carers (known as unpaid caregivers in other contexts) and the challenges of engaging carers via digital health and virtual care.	• A large proportion of carers have some form of disability • A large proportion of carers use digital technologies • Currently very few digital or virtual care initiatives are targeted toward caregivers in particular	• Attention should be paid to providing virtual or digital resources specifically for caregivers
Friis-Healy et al, 2020 [28]	Increasing reliance on digital technologies risks exacerbating the digital divide, with adverse consequences on mental and behavioral health, especially of racialized populations.	• Systemic racism and the pandemic are exacerbating mental health concerns for racialized communities, especially Black and Indigenous communities	• Invest in building real-world evidence for digital mental health • Educate providers and consumers about choice and safety of digital mental health • Prioritize adaptive digital mental health content, allowing tailoring to particular communities • Build digital mental health apps and services for diverse patient populations • Build trust by evaluating and vetting in transparent ways
Jackson et al, 2020 [29]			

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Reference	Framing	Issues raised	Recommendations
	The postpandemic future will see digital technologies dominating health spaces. Public health goal setting must attend to equity in digital health, particularly related to the vision of Health People 2030.	• Persistent disparities exist in relation to internet access, using technology to manage health, online health information seeking, and health literacy	• Ensure that health literacy and digital health objectives are a part of Healthy People 2030 • Enhance data collection on digital health disparities • Convene to critically discuss ideal objectives and strategies to achieve them
Kassamali et al, 2020 [30]	Policies enhancing access to telehealth services will expire at the end of the pandemic, but should persist for the sake of enhancing health equity.	• Minoritized communities have had less access to health care during the pandemic • Minoritized communities have been less able to shelter in place	• Examine in detail how minoritized communities have adopted and engaged with telehealth services to inform equitable policy
Mike and Laroche, 2020 [31]	The pandemic has illustrated health inequities very clearly, and these extend to eye health as well. Short- and long-term actions are necessary.	• Racism and structural inequalities are the causes of health inequities observed during the pandemic	• More strongly incorporate telemedicine into eye care • Advocate for policy changes that lead to insurance coverage for more people • Take longitudinal action to address structural racism by encouraging cultural competence and holistic acceptance in medical education
Ortega et al, 2020 [32]	The pandemic has led to investments in telemedicine around the world. Specific policy considerations must be made to ensure telemedicine promotes health equity.	• Inequitable access to telemedicine is driven by three main barriers: (1) disparities in access to broadband internet and related technology, (2) financial barriers to the reimbursement of telemedicine, and (3) lack of institutional commitment to equity in telemedicine	• Policy must invest in expanding broadband internet access, enhance the availability of virtual care through reimbursement mechanisms, and clarify privacy and security requirements for commercially available platforms • Hospitals should take on responsibility to enhance digital access and literacy
Wood et al, 2020 [33]	Many infectious diseases are disproportionately experienced by people from marginalized communities. The infectious disease community ought to invest in digital health equity.	• Primary issues reducing access to virtual care are lack of technology, internet access, digital literacy, and private space in which to engage	• Expanded reimbursement of telemedicine must continue after the pandemic • Assess patient technical readiness. Provide just-in-time training to patients for access • Provide instruction in preferred language • Conduct a test to confirm capability • Develop programs to offer digital devices to people who do not have access • Offer language interpretation • Design for various languages and cultural preferences • Do not rely solely on electronic record–based portals for video visits • Train clinical staff to consider equity when supporting patients virtually • Track disparities in access and use disparities as a performance indicator

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Table 3. Synthesis of recommendations from select literature on virtual care and health equity during the COVID-19 pandemic.

Level of initiative to enhance health equity in virtual care and general recommendations	Specific recommendations
Policy and government	
Government policy	• Government policy should clarify standards for inclusive design of digital health innovations • Governments should increase access to relevant crisis and social services in support of marginalized communities (eg, social support phone lines) • Governments should invest in maintaining expanded virtual care programs beyond the end of the pandemic
Funder (reimbursement)	• Identify reimbursement models with insurers for marginalized patients that can persist beyond the end of the pandemic • Ensure payment parity between insurers for video and audio visits
Access to devices and internet	• Identify and document disparities in access to virtual care • Promote access to broadband internet, especially among those who cannot afford it • Promote access to digital devices among those cannot afford them (eg, through donations and lending programs at health care sites) • Explore quality improvements related directly to existing disparities in access to digital devices
Public health messaging	• Increase emphasis on and diffusion of culturally relevant public health messages (eg, increase redundancy of important messaging) • Increase control over quality, understandability, and acceptability of messaging about transmission, prevention, treatment, and consequences of COVID-19
Organization and health system	
Organizational (health system or health care organization)	• Measurement of equity-related outcomes such as number of visits using interpreter services • Quality improvement focused on equity-related outcomes • Train health providers to have competencies to provide equitable digital health care • Increase virtual access and use of interpretation services for health care encounters • Translate instructions for accessing virtual care • Increase system leadership awareness of equity-related barriers to virtual care • Offer telemedicine outside of usual business hours • Promote virtual care widely to grow awareness among marginalized communities • Adopting organizations should include equity considerations in newly established digital services • Engage community health workers to provide technical support to patients with low digital literacy • Provide interfaces in languages other than English • Develop programs to lend digital devices to patients who do not have access to such devices during the course of care • Provide access through a variety of programs, not solely through the electronic record system
Clinical	• Select phone over video for individuals who are not comfortable with video visits in the home environment • Offer digital services to all patients • Combine technology and in-person visits, enabling care for people without access to technology • Advocate changes to support equitable access to virtual services at the local level • Provide training and support to patients seeking to access care virtually • Build processes for assessing patient readiness for virtual care • Conduct test visits with patients for troubleshooting prior to scheduled virtual clinical visits
Community and patient	
Community engagement in service planning and delivery	• Partner with community organizations to provide peer-led educational support • Involvement of people from marginalized groups in leadership, health professions, co-design, and data stewardship • Vendors should use inclusive, user-centered design processes
Enhance digital literacy	• Develop programs to promote digital health literacy • Mitigate digital literacy and resource barriers (eg, provide patient education to enhance digital literacy skills, inform patients about free or reduced-cost internet access locations)

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Recommended Strategies to Promote Health Equity

At the level of policy and government, recommendations have focused on strategies for health policy makers and health care funders to enable access both to the infrastructure required for patients to participate in virtual care (ie, inclusive design standards, broadband internet, and digital devices) and the availability of virtual care services to entire populations (eg, by appropriately reimbursing virtual care) [13,15,23,25,30-33]. In addition, policy-focused recommendations have emphasized the clarity of public health messaging about COVID-19 and related restrictions, and the role of digital technologies in enhancing the accuracy and reach of such messaging [24,29].

Recommendations at the level of health care organizations and health systems have been more varied. These have included encouragement to develop quality improvement activities focused on underserved or marginalized communities [12,18,27], educational initiatives for providers and leaders [12,23,29,33], and the collection of metrics that provide insight into equity-related outcomes [12]. Specific advice to clinicians has included strategies such as carefully planning a mix of in-person and virtual visits for clients especially at risk of poor health outcomes during the pandemic [25], and using telephone-based visits (over video visits) when a patient has access to a telephone but not a device that would enable a video visit [25,26,28,29].

At the level of communities and patients, recommendations focused on both the engagement of community members in service development and strategies to enhance digital literacy [13,25,26,29,30]. Specific approaches advocated include developing partnerships with community-based organizations and using inclusive design strategies that involve diverse users in the design of the technology [13,25]. Efforts to enhance digital literacy through particular educational programs during the pandemic were also common across the contributions we reviewed, including for example programs offered through local libraries [12,15].

Together, these recommendations provide a multilevel approach to ensuring that the widespread use of virtual care during the pandemic does not exacerbate disparities in access to care and health outcomes. In the next section of this paper, we outline three strategies that received relatively little attention in the reviewed literature We emphasize these three in particular because they are practically implementable by local health systems and have high potential for impact. Furthermore, these strategies are critical to the sustenance of equitable virtual care beyond the COVID-19 pandemic.

Discussion

In this discussion section, we describe three specific strategies to promote health equity in the delivery of virtual care programs, and then outline three lines of action at the level of health system strategy to ensure these approaches are sustainable in the longer term.

Simplify User Interfaces and Clinical Workflow

The first strategy that we highlight pertains to simplifying interfaces and workflows associated with accessing and using virtual care. Mounting evidence suggests that when innovations such as digital technologies increase the complexity of health care processes, they are more likely to widen existing health disparities [16]. This is because patients with less education, lower income, and a higher burden of negative social determinants of health (eg, food insecurity, precarious employment, etc) are less able to effectively integrate such innovations into their everyday lives or usual care [16]. This point is especially important given the ongoing financial and social challenges faced by marginalized communities during the COVID-19 crisis, which are likely to persist well beyond the end of the pandemic.

One reason for the elevated challenge of accessing and using complex virtual care technologies for marginalized patient groups relates to the technological infrastructure itself. For example, some technologies have high internet bandwidth requirements or are compatible with only a subset of expensive personal devices (eg, some video visit platforms do not run on Android devices). Virtual care strategies that work with simpler technology requirements are more likely to be accessible to people living with lower income, and are therefore more likely to be equity enhancing [16]. Such “upstream” strategies also have the potential to persist long term since they do not require agency on the part of providers or patients to maintain.

Additionally, significant digital literacy skills are necessary to benefit from virtual care technologies; marginalized groups with less technical experience, such as older adults and those of lower socioeconomic status, are less likely to have these skills [19,20]. Accordingly, virtual care platforms with usability challenges, high literacy demands, and complex workflows are more likely to benefit more advantaged users [16,20]. Thus, it is crucial that the design and delivery of technology-enabled services aim to minimize such barriers. This can be done by means such as using sequential rather than hierarchical navigation through the virtual care platform, an approach that reduces the cognitive burden associated with navigating through a computer interface by simplifying the information and number of choices presented to the user at any given time (ie, one choice at a time rather than a list of choices presented in a hierarchy). A second strategy is to reduce context switching, which occurs when the particular task in which the user is engaged (eg, booking a visit) is interrupted to perform a second task (eg, installing new software or opening a second program). More generally, following design guidelines for lower literacy populations (such as the guidelines produced by the United Nations Educational, Scientific and Cultural Organization [UNESCO] on designing inclusive digital solutions and developing digital skills [34]) will enhance the usability of any virtual care technology for all users. Where clinicians and organizations retain a degree of control over the content of virtual care technologies (more likely with larger health systems and organizations), these design-based solutions offer important strategies to promote health equity in the context of virtual care technologies.

Use Supportive Intermediaries to Help Patients Engage With Virtual Care

In the context of the pandemic, many patients have been forced to engage with virtual care for the first time. In some sites, such

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as Federally Qualified Health Centers (FQHC) in the United States and other community-based services internationally, the infrastructure for virtual care might not have existed prior to COVID-19. This means that patients might not have had much opportunity to develop the skills required to engage with technology for their health care, especially among those facing other major financial- or health-related challenges. Moreover, first virtual care visits are not optimal environments for learning, fostering the patient-provider relationship, or managing chronic medical conditions as patients and providers are likely to have more urgent priorities related to addressing acute illnesses [35]. Additionally, reflective of the time pressure facing health care providers and staff, the last author's (TV) experience with studying telehealth implementation in an FQHC shows that when challenges emerge during video visits, the immediate reaction is to switch to telephone calls. This results in far more telehealth visits being implemented via telephone than intended.

To address these challenges, we emphasize the strategy of integrating supportive intermediaries or liaisons within virtual care programs to assist new virtual care users in navigating visits. Human-computer interaction and sociology researchers have explored the use of intermediaries to bridge difficulties in access to and use of technologies among people with limited digital access and skills [36,37]. These intermediaries ideally serve as "warm experts," people with relatively advanced knowledge of technologies who are made readily available to support peoples' use of technology in their daily lives [38]. These supportive intermediaries might be identified in a number of ways. For larger organizations with staff that can be redeployed, team members can be trained in navigating a particular technology and provide intermediation to patients remotely. This model has been employed at the hospital (Women's College Hospital) that is the primary affiliation of the first author (JS) during the COVID-19 pandemic, wherein research staff have been redeployed to support patients as they connect virtually with their health care providers. A second option arises from the suggestion of Gray et al (2020) [25] to enlist the support of community health workers where such workers are active in local communities. Community health workers can engage community members who are seeking out health care and provide direct support to patients as they engage with their care providers virtually. Additional strategies that can be pursued to identify and support intermediaries include hiring new staff to take on the intermediary role in permanent positions to assist beyond the pandemic for the long-term sustainability of health equity, building partnerships with community-based organizations, and collaborating with public libraries or patient advocacy groups to establish intermediary support programs. The creation of new staff roles and partnerships represents an infrastructure that has the potential to remain in place after the COVID-19 pandemic.

Engage Members of Marginalized Communities in Planning and Evaluating Virtual Care

As with any health care innovation, virtual care programs risk overlooking the cultural, linguistic, and economic realities of marginalized communities [16,39]. In these cases, the virtual care program is far less likely to be taken up by marginalized patients, which also increases the risk of worsening health disparities. This point was addressed in many of the papers we reviewed, which advocated for the inclusion of marginalized communities in technology design, virtual care program design, training of health care providers, leadership of virtual care programs, and governance of data arising from such programs [12,15,23,25]. In the remainder of this section, we specify these recommendations by focusing on two practical strategies in particular: establishing a community advisory committee, and evaluating the service from the perspective of marginalized groups.

One practical strategy to engage members of marginalized communities in virtual care program delivery is to establish a community advisory committee that represents the views of marginalized patients. Collaborating with trusted partners who are prominent members of particular racial/ethnic or geographic communities could promote meaningful input into the development and improvement of the virtual care program [39]. Methods derived from community-based participatory research can help to ensure meaningful engagement of marginalized communities. Such engagement and input could have the additional benefit of providing a clearer understanding of the impacts of the social determinants of health during the pandemic, clarifying where interventions that look beyond the individual patient to the entire community are needed. Such input can thereby help health care providers and organizations to better understand the shifting needs of their patient populations and enhance their planning in both short-term and long-term time frames.

Evaluation that addresses the needs of underserved communities requires the identification of measures that matter most to members of these groups. This could also be accomplished through receipt of valuable input from key stakeholders, including patients or a community advisory board [12]. Measures should assess both objective features (such as dropped calls or total time spent interacting with patients) and subjective features of virtual care programs (such as satisfaction with and trust in health care providers). This information can be used to inform future quality improvements to the programs to better serve these diverse patient populations, especially in times of crisis when resources are scarce.

Sustainability of Equitable Virtual Care at the Health System Level

Based on the insights generated through our review of literature, we propose three important lines of action to promote health equity in the delivery of virtual care on a large scale and in a sustainable way beyond the pandemic. First, governments and policy makers will need to navigate the demand for investments in infrastructure related to broadband internet access and the availability of digital devices for those who do not have access. The literature reviewed in our paper calls for programs that make devices available to patients who need them to actively engage with virtual care, which constitutes a unique expense for health systems with unique considerations for implementation. Balancing investments in internet access and the availability of digital devices with the clear need for additional investments in public health and the upstream

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determinants of health will be a central challenge for governments in the years ahead.

Second, health systems and stakeholder groups will need to specify clinical processes and develop effective training for the clinical skills that underpin the equitable delivery of virtual care. This will also require investment in educational programs and curriculum change to enable health care providers to employ virtual care in equitable ways.

Third and finally, health systems will need to invest in developing organizational capacity in health equity as a long-term priority. Where organizations do not already have knowledge of how to deliver equitable care in general, they cannot be expected to deliver virtual care in equitable ways. The development of educational programs such as those focused on anti-racism and anti-oppression initiatives will contribute to enhancing the health equity knowledge and capacity of health care organizations overall. Doing so will build an important foundation for incorporating a stronger focus on health equity into virtual care initiatives well into the future.

Conclusion

The literature on strategies to promote health equity in virtual care programs in the context of COVID-19 presents a strong and comprehensive vision for the ways in which multiple stakeholders can work together to prevent worsening health disparities during the pandemic. However, to ensure that virtual care is employed in ways that are equity enhancing in a post–COVID-19 reality, further work is required. Health system leaders, clinicians, and the research community will need to more deeply engage with the literature summarized in this paper, and shift attention to the practical implementation of these strategies in the longer term.

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Authors' Contributions

JS led the drafting of the manuscript. All authors contributed to the ideas, structure, and editing and gave final approval of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

FQHC: Federally Qualified Health Center

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Original Paper

Concerns Discussed on Chinese and French Social Media During the COVID-19 Lockdown: Comparative Infodemiology Study Based on Topic Modeling

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Abstract

Background: During the COVID-19 pandemic, numerous countries, including China and France, have implemented lockdown measures that have been effective in controlling the epidemic. However, little is known about the impact of these measures on the population as expressed on social media from different cultural contexts.

Objective: This study aims to assess and compare the evolution of the topics discussed on Chinese and French social media during the COVID-19 lockdown.

Methods: We extracted posts containing COVID-19–related or lockdown-related keywords in the most commonly used microblogging social media platforms (ie, Weibo in China and Twitter in France) from 1 week before lockdown to the lifting of the lockdown. A topic model was applied independently for three periods (prelockdown, early lockdown, and mid to late lockdown) to assess the evolution of the topics discussed on Chinese and French social media.

Results: A total of 6395; 23,422; and 141,643 Chinese Weibo messages, and 34,327; 119,919; and 282,965 French tweets were extracted in the prelockdown, early lockdown, and mid to late lockdown periods, respectively, in China and France. Four categories of topics were discussed in a continuously evolving way in all three periods: *epidemic news and everyday life*, *scientific information*, *public measures*, and *solidarity and encouragement*. The most represented category over all periods in both countries was *epidemic news and everyday life*. *Scientific information* was far more discussed on Weibo than in French tweets. Misinformation circulated through social media in both countries; however, it was more concerned with the virus and epidemic in China, whereas it was more concerned with the lockdown measures in France. Regarding *public measures*, more criticisms were identified in French tweets than on Weibo. Advantages and data privacy concerns regarding tracing apps were also addressed in French tweets. All these differences were explained by the different uses of social media, the different timelines of the epidemic, and the different cultural contexts in these two countries.

Conclusions: This study is the first to compare the social media content in eastern and western countries during the unprecedented COVID-19 lockdown. Using general COVID-19–related social media data, our results describe common and different public reactions, behaviors, and concerns in China and France, even covering the topics identified in prior studies focusing on specific

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interests. We believe our study can help characterize country-specific public needs and appropriately address them during an outbreak.

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KEYWORDS

comparative analysis; content analysis; topic model; social media; COVID-19; lockdown; China; France; impact; population

Introduction

Since the identification of the first cases of COVID-19 in Wuhan, China in December 2019, the epidemic has quickly spread throughout China and many other countries worldwide. In response to the rising numbers of cases and deaths, China, followed by many other countries, implemented measures to control the epidemic and preserve their health systems. China enforced the quarantine and lockdown of cities and, subsequently, whole provinces at the end of January 2020. Traffic within urban areas was restricted, and all inner-city travel was prohibited unless permitted. All entertainment venues and public places were closed; all public events were cancelled. Subsequently, the control became more stringent, and a universal and compulsory stay-at-home policy for all residents was adopted [1]. On March 13, 2020, the World Health Organization declared Europe the second epicenter. The most affected countries included Italy, Spain, France, and Germany. Measures have consisted of the closure of borders, the closure of educational institutions, the closure of museums and theaters, the closure of shops and restaurants, restrictions on movement, and the suspension of public gatherings with small groups of people [2].

Control measures have been effective in many countries. Tian et al [3] showed that the lockdown of Wuhan and the national emergency response in China were strongly associated with a delay in epidemic growth during the first 50 days of the epidemic based on statistical and mathematical analyses of the temporal and spatial variation in the number of reported cases. Kraemer et al [4] demonstrated that drastic control measures substantially mitigated the spread of COVID-19 with real-time mobility data and detailed case data, including travel history. Similarly, lockdown measures adopted in Europe dramatically reduced viral transmission in Italy [5], Germany [6], and the United Kingdom [7], resulting in large reductions in the basic reproduction number, R0, from an average of 3.8 prior to the lockdown to below 1 in many countries [8]. France had the most rapid reductions, with an R0 of approximately 0.77 when these measures were lifted [9].

Although these interventions could be implemented with the apparent adherence of the population, it is of interest to the public health community and policy makers to assess public opinions and the impact of such interventions on individuals and populations as expressed on social media [10], which may differ in different countries.

Social media has demonstrated its value for sharing experiences, opinions, and feelings, and for disseminating important public health messages and research findings in emergency situations and during pandemics [11-13]. Here, we present an effort to analyze and compare the evolution of topics discussed on social media during the COVID-19 lockdown in China and in France.

Methods

Social Media Data Collection

We focused on the most commonly used microblogging networks in China and France (ie, Weibo and Twitter, respectively). The Weibo data were extracted using Weibo search engine queries, which return messages containing a specified keyword for a predetermined search period. To gather a maximum amount of data, a query was made for each extraction keyword and for each day of the period of interest. Posts returned by those queries were scraped along with their metadata. Tweets were extracted using the Twitter Search application programming interface (API), which makes it possible to query tweets containing a specific set of keywords and returns the IDs of tweets. Those IDs were then used to collect the tweet content and its metadata using the same API.

Two categories of keywords were considered to extract messages from Chinese and French social media: (1) COVID-19–related keywords (eg, COVID or coronavirus) and (2) lockdown-related keywords (eg, lockdown or lockdown lift). A set of synonymous terms in Chinese and French were identified for each category using an iterative process. All keywords used for extraction are listed in Multimedia Appendix 1.

As global online discourse has shown rapid evolutions over time during the pandemic [14], we considered three periods related to the start and end date of the lockdown in each country to analyze the evolving topics on Chinese and French social media:

1. Prelockdown period: 1 week before the lockdown started
2. Early lockdown period: from lockdown implementation to 10 days after
3. Mid to late lockdown period: from the 11th day after lockdown implementation to the lifting of the lockdown

More specifically, the three periods are (1) January 16-22, (2) January 23 to February 2, and (3) February 3 to April 7 for Chinese Weibo, and (1) March 10-16, (2) March 17-27, and (3) March 28 to May 10 for French tweets.

Data Preprocessing

The first step consisted of filtering posts with respect to the language. For Chinese post extraction from Weibo, all words with Latin characters were removed except the keywords (eg, severe acute respiratory syndrome); for French post extraction from Twitter, we used the Twitter Search API to filter for

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messages in French. Forwarded Weibo messages and retweets were removed. Time stamps and regular expressions of periods of time were tagged. Stop words were removed for both the Chinese and French messages. Stemming was performed using the Porter [15] algorithm for French tweets. Tokenization was carried out for each corpus to split the texts into smaller parts, named tokens, for topic model estimation. Finally, to reduce the sparsity of our data, we chose to keep tokens appearing at least 10 times in the whole corpus. The detailed data preprocessing steps for both languages are shown in Multimedia Appendix 2.

Topic Model

A biterm topic model was used to identify the topics in both corpora without prior knowledge. A topic is defined as a subject of discussion, which amounts to tokens that frequently appear together in a corpus. The biterm topic model considers the whole corpus as a mixture of topics, where each co-occurring pair of tokens (the biterm) is drawn from a specific topic independently. A post is thus represented as a combination of the topics associated with each biterm in the post and at a certain proportion. Since Twitter posts are short, often composed of one sentence, we attributed only the most prominent topic to a post [16]. To maintain a homogenous method, the same restriction was applied for Weibo posts.

A biterm topic model was applied separately to each corpus of the three periods. The number of topics was empirically set to 15 for each period, which balanced the quality of topics and the feasibility of qualitative comparisons.

Qualitative Analysis and Validation

Each topic was interpreted and labeled using the top 20 token terms (the tokens with the highest per-topic probabilities) and at least 60 randomly selected topic-specific posts. With the objective of ensuring high quality labeling, interpretation of the topics was performed by two authors independently for each corpus as follows: authors XC and CF for the Chinese topics and authors MK and CF for the French topics. The labels resulting from each pair of interpreters were integrated, and consensus was reached if necessary.

Moreover, to ensure that all topic labels were explicit, blind validation was performed. For each corpus, two authors, who were different from the interpreters (authors MK and PF for Chinese and authors PF and AM for French), were asked to determine what theme each topic was dealing with based only on the topic label. The interpreters then evaluated their statements. Topic labels that were misunderstood by both guessing authors were renamed.

All topics in both corpora for the three periods were finally summarized into broader categories to facilitate comparisons across the periods and between the two countries.

Results

Social Media Data Collection

A total of 6395; 23,422; and 141,643 unique Chinese Weibo messages, and 34,327; 119,919; and 282,965 unique French tweets were extracted in the prelockdown, early lockdown, and mid to late lockdown periods, respectively, in China and France. An overview of the corpora are shown in Table 1.

Table 1. Extraction overview.

Lockdown period	China (n=171,460)		France (n=437,211)	
	Start and end dates	Messages, n	Start and end dates	Messages, n
Prelockdown $[t_0 - 7, t_0)$[a]	Jan 16-23	6395	Mar 10-16	34,327
Early lockdown $[t_0, t_0 + 10]$[a]	Jan 23 to Feb 2	23,422	Mar 17-27	119,919
Mid to late lockdown $[t_0 + 11, t_1)$[b]	Feb 3 to Apr 7	141,643	Mar 28 to May 10	282,965

[a] t_0 denotes the day on which the lockdown began.

[b] t_1 denotes the day on which the lockdown was lifted.

Topics

The topic labels, proportions, and top terms for each period and each corpus are shown in Multimedia Appendices 3-8. All topics were grouped into four categories according to the theme that they mainly addressed: *epidemic news and everyday life*, *scientific information*, *public measures*, and *solidarity and encouragement*. The first category contains topics that discuss the statistics (prevalence, mortality, etc) and other news and facts about the epidemic, which have been evolving everyday and are highly associated with personal emotions and activities. It is a similar case for the category of *public measures* (ie, people often talked about public measures and their personal opinions on these measures simultaneously). Therefore, in these two categories, we further annotated fact-related topics and more subjective ones.

Qualitative Analysis of Topics on Chinese Social Media

The topics on Chinese social media in all three periods are shown in Figure 1.

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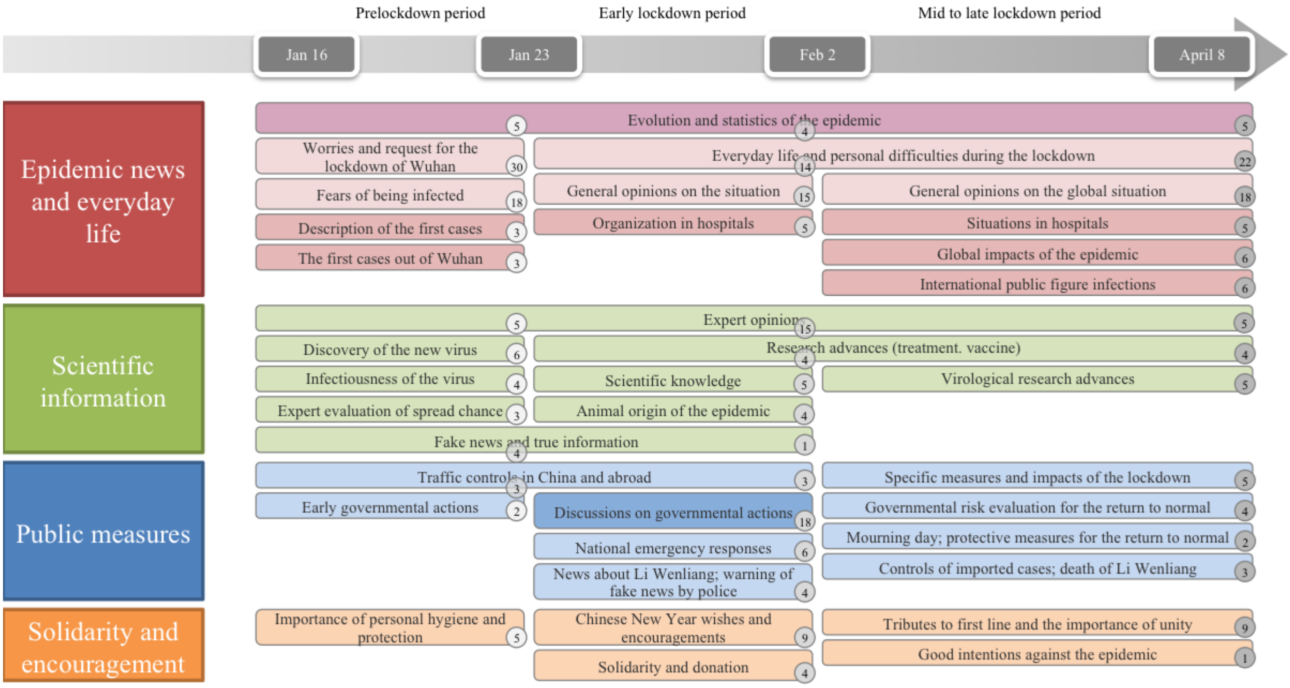
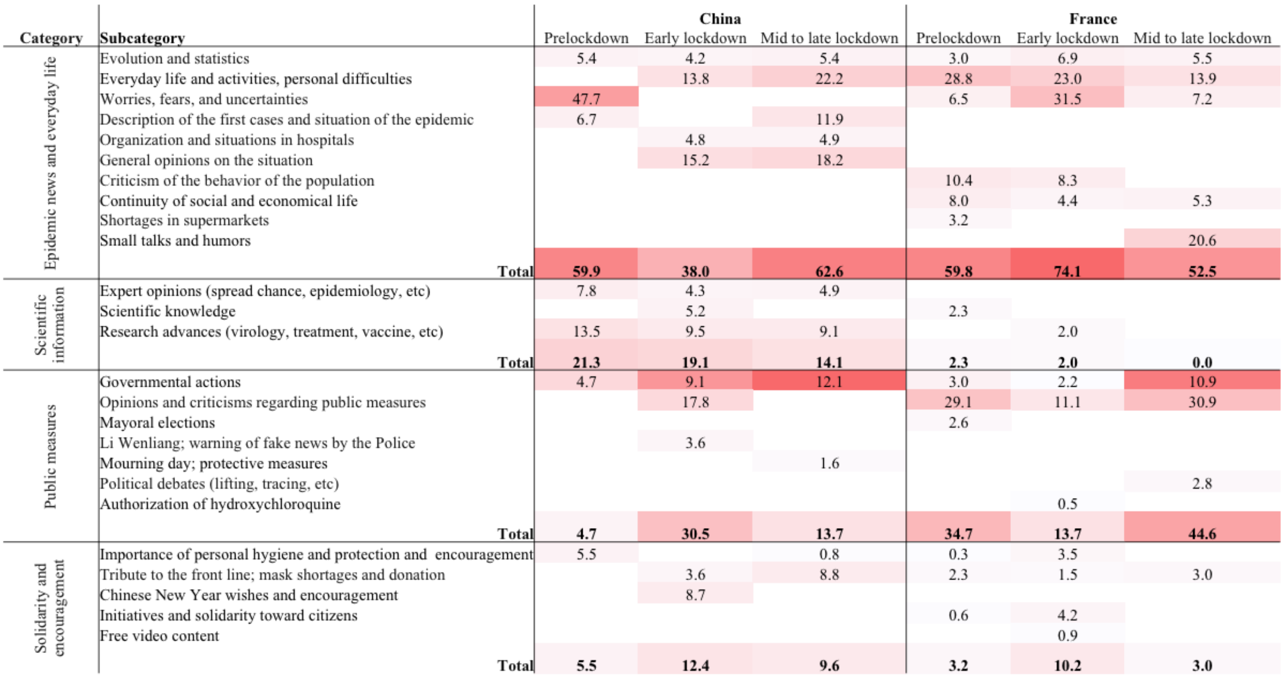
Figure 1. Topics identified on Weibo during the three periods. All topics are colored according to the category and aligned for the three periods. The factual topics are colored in dark red and dark blue, and the subjective topics are colored in light red and light blue for the first and the third category, respectively. The percentage of each topic is indicated in a circle at the bottom right.



The most represented category was *epidemic news and everyday life*, corresponding to 60% (3837/6395), 38% (8900/23,422), and 63% (89,235/14,1643) of the messages in the first, second, and third periods, respectively (Figure 2). Topics related to the evolution of the epidemic were addressed in all three periods. Before the lockdown, the Weibo messages mainly conveyed fears of being infected and worries regarding the spread of the virus, which led to requests for the lockdown of Wuhan by Weibo users and descriptions of the first cases in and outside of Wuhan. After lockdown implementation, users shared more comments and opinions on their everyday lives, the organization in hospitals, the situation of the epidemic, and its impacts in China (early lockdown period) and worldwide (mid to late lockdown period). These impacts included economic difficulties and environmental improvement.

Figure 2. Comparison between topics on Weibo and Twitter. The percentage of messages of each category and subcategory were shown for all three periods in both countries. The color reflected the proportion.



Category	Subcategory	China			France		
		Prelockdown	Early lockdown	Mid to late lockdown	Prelockdown	Early lockdown	Mid to late lockdown
Epidemic news and everyday life	Evolution and statistics	5.4	4.2	5.4	3.0	6.9	5.5
	Everyday life and activities, personal difficulties		13.8	22.2	28.8	23.0	13.9
	Worries, fears, and uncertainties	47.7			6.5	31.5	7.2
	Description of the first cases and situation of the epidemic	6.7		11.9			
	Organization and situations in hospitals		4.8	4.9			
	General opinions on the situation		15.2	18.2			
	Criticism of the behavior of the population				10.4	8.3	
	Continuity of social and economical life				8.0	4.4	5.3
	Shortages in supermarkets				3.2		
	Small talks and humors						20.6
	Total	**59.9**	**38.0**	**62.6**	**59.8**	**74.1**	**52.5**
Scientific information	Expert opinions (spread chance, epidemiology, etc)	7.8	4.3	4.9			
	Scientific knowledge		5.2		2.3		
	Research advances (virology, treatment, vaccine, etc)	13.5	9.5	9.1		2.0	
	Total	**21.3**	**19.1**	**14.1**	**2.3**	**2.0**	**0.0**
Public measures	Governmental actions	4.7	9.1	12.1	3.0	2.2	10.9
	Opinions and criticisms regarding public measures		17.8		29.1	11.1	30.9
	Mayoral elections				2.6		
	Li Wenliang; warning of fake news by the Police		3.6				
	Mourning day; protective measures			1.6			
	Political debates (lifting, tracing, etc)						2.8
	Authorization of hydroxychloroquine					0.5	
	Total	**4.7**	**30.5**	**13.7**	**34.7**	**13.7**	**44.6**
Solidarity and encouragement	Importance of personal hygiene and protection and encouragement	5.5		0.8	0.3	3.5	
	Tribute to the front line; mask shortages and donation		3.6	8.8	2.3	1.5	3.0
	Chinese New Year wishes and encouragement		8.7				
	Initiatives and solidarity toward citizens				0.6	4.2	
	Free video content					0.9	
	Total	**5.5**	**12.4**	**9.6**	**3.2**	**10.2**	**3.0**

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Scientific information was the second most represented topic category, corresponding to 21% (1343/6395), 20% (4684/23,422), and 14% (19,830/141,643) of the messages in the first, second, and third periods, respectively. Topics related to expert opinions were present in all periods. During the prelockdown and early lockdown periods, some topics related to early knowledge about the virus (eg, infectiousness or animal origin) and topics related to the need to distinguish between fake news and true scientific information were shared. Posts like "Be wary of the following fake news:..., and the truth is that..." or "Refute a rumor:..." were often observed. Subsequently, during the second and third periods, the topics shifted to research advances in virology, treatments, and vaccines.

Public measures were intensively discussed in the early lockdown period (7026/23,422, 30%) versus the prelockdown (320/6395, 5%) and mid to late lockdown (19,830/141,643, 14%) periods, and the topics covered early measures such as traffic controls, emergency responses such as home quarantine, and the impact of these governmental actions. Topics related to the lifting of the lockdown were identified during mid to late lockdown (eg, evaluations of the situation by regional governments and preventive measures implemented for the return to normal). Some messages related to Li Wenliang, the Chinese ophthalmologist who issued the alert about mysterious pneumonia cases and subsequently died of COVID-19, were identified during the lockdown as part of topics related to other subjects.

We also identified topics related to *solidarity and encouragement* in all three periods, and such topics represented 5% (320/6395), 12% (2811/23,422), and 10% (14,164/141,643) of the messages in the first, second, and third periods, respectively. These topics were more related to the importance of personal hygiene, protection, and respect for measures at early stages, and to solidarity and donation, the importance of unity, and tributes to frontline workers later on. As the Chinese New Year was the second day after lockdown implementation, one topic related to New Year wishes and hope for the future was identified.

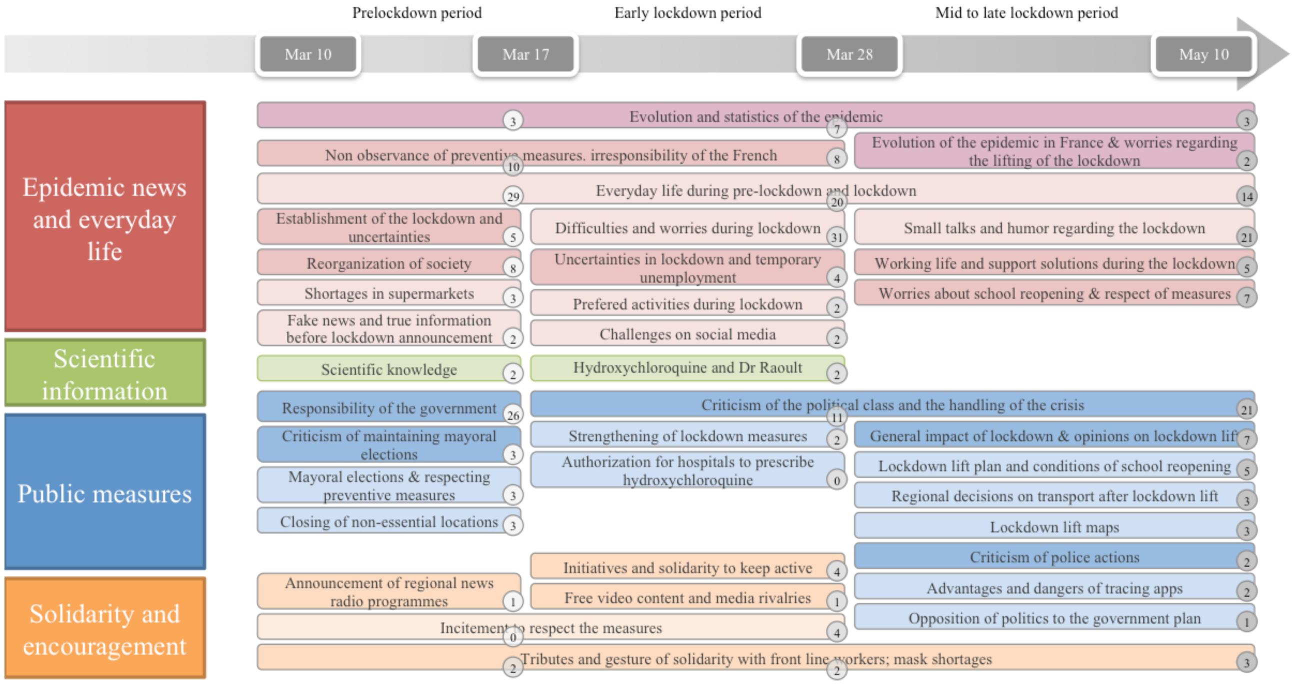
Two irrelevant topics were identified for the prelockdown period due to the polysemy of the Chinese word "隔离," which means not only "quarantine" but also "foundation makeup" or "median barrier." These two topics, related to makeup and traffic accidents, were excluded from our analysis.

Qualitative Analysis of Topics on French Social Media

The topics on French social media are shown in Figure 3.

The most represented category was also *epidemic news and everyday life*, with 60% (20,596/34,327), 72% (86,342/119,919), and 54% (152,801/282,965) of the messages in the first, second, and third periods, respectively. The themes addressed in all three periods included the evolution and statistics of the epidemic, everyday life and activities, the continuity of social and economic life (reorganization of society after the announcement of early measures, temporary unemployment during early lockdown, and working life during mid to late lockdown), and concerns (uncertainties before the lockdown, worries and difficulties during early lockdown, and worries regarding company and school reopenings after the lifting of the lockdown). Fake news regarding the lockdown and criticisms of the lack of respect for preventive measures were identified only at early stages, whereas Twitter users started to share humoristic messages and jokes as the lockdown constraints became more familiar.

Figure 3. Topics identified on Twitter during the three periods. All topics are colored according to the category and aligned for the three periods. The factual topics are colored in dark red and dark blue, and the subjective topics are colored in light red and light blue for the first and the third category, respectively. The percentage of each topic is indicated in a circle at the bottom right.



Regarding *scientific information*, one topic related to the virus and the seriousness of the situation was addressed during the prelockdown period (6865/34,327, 2%), and one topic related to the controversy surrounding the use of hydroxychloroquine in France was addressed during early lockdown (23,984/119,919, 2%).

As the lockdown was implemented in France after public discussions and the official announcement by President Macron, *public measures* were more represented before the lockdown (12,014/34,327, 35%) than in the early lockdown period (16,788/119,919, 14%), and they were extensively discussed again with regard to the lifting of the lockdown during the mid to late lockdown period (127,334/282,965, 45%). Political criticisms and opinions were addressed in all three periods, as well as lockdown measures (the closing of nonessential locations during prelockdown, the strengthening of measures such as curfews in certain cities during early lockdown, and lockdown lift measures during mid to late lockdown). Specific criticisms of police actions, discussions of measures for the return to normal and the general impact of the lockdown (eg, economy and pollution), and debates regarding tracing apps were addressed during mid to late lockdown. People also shared comments about specific events such as the holding of mayoral elections that were scheduled just before the lockdown (including the preventive measures established) and the authorization of the prescription of hydroxychloroquine in hospitals.

Regarding *solidarity and encouragement*, most messages were about solidarity with frontline workers, especially in the context of mask and medical material shortages, and the importance of respecting preventive measures. Initiatives by organizations for citizens were publicized through Twitter over the three periods, such as regional news programs to inform people and organize solidarity, and initiatives to stay active personally and professionally. We also identified a topic related to free video content and media rivalries, as some media offered video content for free during the lockdown, but some of these actions were involved in copyright disputes and led to media rivalries.

Comparison

The comparison of topics between Chinese and French social media is summarized in Figure 2.

The common topics related to *epidemic news and everyday life* that were discussed in both countries included the evolution and statistics of the epidemic, everyday life, and personal difficulties and concerns. However, the concerns were not similar: Chinese users feared being infected and consequently asked for the lockdown of Wuhan, whereas French users were more concerned about the socioeconomic consequences and the enforceability of public measures. Similar topics were also addressed in regard to the *public measures* (eg, the chronology of measures) and *solidarity and encouragement* (eg, the importance of preventive measures and solidarity with health workers) categories. Notably, misinformation circulated through social media in both countries; however, it was more concerned with the virus and epidemic in China, whereas it was more concerned with the public measures before the lockdown announcement in France (eg, rumors about a general curfew for the whole country).

Moreover, we identified several dissimilar topics in all categories. The *epidemic news and everyday life* category included descriptions of early cases and situations in hospitals in China, in contrast to messages about shortages in supermarkets and criticisms of the behavior of the population in France. *Scientific information* was shared far more on Weibo in all three periods, covering virology, pathology, epidemiology, treatments, and vaccines, whereas in France, only one topic related to the virus and one topic related to hydroxychloroquine were identified at early stages. More criticisms were identified in French tweets than on Chinese Weibo in regard to the *public measures* category; such criticisms were directed toward the government, the political class, police, etc. Some country-specific subjects (eg, the day of mourning in China and mayoral elections in France) were also identified. News and discussions regarding tracing apps were addressed in French tweets; in addition to the advantages for controlling the epidemic after the lifting of the lockdown, people shared concerns about data privacy.

Discussion

Strengths and Limitations

Social media has demonstrated its value in helping people stay connected, delivering important public health messages, and disseminating important research findings in emergency situations. Building on our previous experience collating social media posts for pharmacovigilance monitoring [17], we present an analysis and comparison of the evolution of topics discussed on social media during the COVID-19 lockdown in China and France. Biterm topic modeling was used to identify topics in both corpora because of its superior performance on short texts from microblogging websites [18]. This automated approach enabled us to cluster and analyze the content of a data set that was much larger than in manual studies. Moreover, this comparative study was conducted by a multidisciplinary and bilingual team, the topics in each corpus were analyzed separately by two interpreters, and the final topics were assigned after alignment between the two countries and consensus of all interpreters. The qualitative analysis was completed through a rigorous two-step validation process. However, some limitations inherent to all studies using social media material remain. No medium has been proven to be representative of the general population; for example, only 56% of Chinese people use Weibo actively, and 34% of French internet users use Twitter actively [19]. In addition, there are some limitations related to the texts, such as the differences in the length of the messages on Twitter and Weibo and the presence of polysemic terms in the Chinese corpus.

Interpretation of the Differences of Topics on Chinese and French Social Media

The use of social media has evolved rapidly and varies across different countries and cultural contexts. As one of the largest social media platforms in China, Weibo attracts not only ordinary users but also representatives from different sectors,

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such as celebrities, media, and government authorities. As of December 2019, there are 139,000 institutional government Weibo accounts, and public security agencies are the most representative government agencies on Weibo [20]. Moreover, as it dropped its 140-character limit in 2016, it has been largely used as an information source in recent years. Twitter is the most used microblogging platform in France; it still has a strict 280-character limit and has 34% of internet users aged 16-64 years as monthly active users [19]. In France, it is mainly considered a platform for sharing personal experiences and opinions. These different characteristics and cultural uses of Weibo and Twitter can partially explain the differences in the proportions of *scientific information* topics between China and France.

Another contributing factor is the different timelines of the evolution of the COVID-19 epidemic between December 2019 and May 2020. In late January, the prelockdown and early lockdown periods in China corresponded to the early stage of the new virus's discovery, and less was known. When all European countries were affected by COVID-19 in early March, although they benefited from the knowledge and experiences acquired by Asian countries to control the epidemic, no treatment was then available. These elements could explain why some messages focusing on Dr Li Wenliang in China (who gave an alert about the first cases) and on Dr Didier Raoult in France (controversy over hydroxychloroquine) circulated.

The cultural context could also have an impact on the topics addressed. China is traditionally described as a country with a high tendency toward collectivism [21-23], which implies that harmony tends to prevail over personal opinions. In contrast, France has a strong culture of political debate, criticism, and opinion sharing. This tendency has already been observed on social media, as a previous study comparing the behavior of Twitter and Weibo users concluded that Weibo users tended to talk more positively about people than Twitter users [24]. These aspects may help to partly understand the different proportion of topics related to criticisms and debates regarding people's behavior and politics. Moreover, the censorship exerted on social media in China [25] to comply with government requirements may have led to post deletions, which might have had an impact on the data collected and the topics addressed.

Comparison With Prior Work

We searched MEDLINE via PubMed for evidence available by August 31, 2020, using combinations of the following terms: ("COVID-19" OR "lockdown") AND ("social media" OR "Twitter" OR "Weibo") AND ("topic model" OR "content analysis"). The search retrieved 9 relevant studies [26-34] among 20 published articles. We further identified 1 more relevant study [10] by screening bibliographies and "similar articles" suggested by PubMed.

Regarding the objective, most of the content analyses focused on a specific interest related to COVID-19, including public engagement and government responsiveness in Chinese Weibo during the early epidemic stage [26,27], nursing appeals on Twitter and Instagram in Brazil [28], pharmacists' perception on social media in Jordan [29], the reason for not following the orders of the authorities [30], the self-reported symptoms [31], and the misinformation about a particular subject, like 5G spreading COVID-19 in the United Kingdom [32] or general misinformation fueled by rumors, stigma, and conspiracy theories [33]. In these cases, the identified content patterns or topics were related to the specific interest. For example, in the self-reported symptoms–related study [31], the identified topics included reports of symptoms, lack of testing, recovery discussion, and negative diagnosis. There are only 2 studies with general interest on COVID-19–related topics, 1 on Chinese Weibo [34] and the other on English Twitter [10].

For the design and settings, most research efforts have been devoted to the early stage of the epidemic [26,27,34] or focused on a short period of 2 or 3 weeks [28-32], without a particular interest in the evolution of the topics addressed during the lockdown. Most of these prior studies considered messages in one social media platform or in one language, most often English Twitter followed by Chinese Weibo, except for the general misinformation-related study [33], which identified 2311 reports of rumors, stigma, and conspiracy theories in 25 languages from 87 countries.

With regard to the method, except for the general topic study [10] that used the latent Dirichlet allocation model and the self-reported symptom–related study that used the biterm topic model [31] to automatically group social media posts into topic clusters, most of the other studies performed a manual content analysis, which limited the size of the data set.

In terms of the results, the topics discussed in Chinese Weibo were similarly identified in prior studies [26,34], which are comparable to our results on Chinese Weibo during the prelockdown and early lockdown periods. Our results even covered many of the topics identified in those studies with a specific interest. For example, in the nursing appeals–related study [28], the emerged thematic categories of #stayathome and #whereismyPPE were also identified through our analysis and overlapped with some topics in the *solidarity and encouragement* category. Another example, the study exploring why people ignore the orders of the authorities [30] revealed reasons such as information pollution on social media, the persistence of uncertainty about the rapidly spreading virus, the impact of the social environment on the individual, and fear of unemployment. All these aspects were addressed in our results. The public engagement and government responsiveness discussed by Liao et al [26] and the significance of regulating misinformation highlighted by Ahmed et al [32] and Islam et al [33] also emerged in either Chinese topics, French topics, or both through our analysis. Comparing with the general topic study on English tweets [10], which identified topics and determined the sentiment (positive or negative) for each topic, although the mean sentiment was positive during the period between early February and mid-March 2020 (10 topics out of 12), 2 topics conveyed specific concerns about the deaths caused by COVID-19 and increased racism. Contrasting with these findings, we did not identify any topic about racism in Chinese Weibo nor in the French messages. In China, instead of racism, regional discrimination against people from Wuhan was discussed in several Weibo messages (eg, some hotels refused to accept guests from Wuhan). These messages were clustered into the topic related to personal difficulties during the

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lockdown. In French social media, tweets related to group conflict were more about discriminatory actions by the police against homeless people, criticisms of privileged people who left big cities for their secondary house and may have spread the epidemic in preserved regions (in particular criticism of the Parisians who left Paris at the beginning of the lockdown), and criticisms of people from deprived neighborhoods (sometimes described as people with immigrant backgrounds) for not respecting the lockdown. These messages were clustered into other topics, like "criticism of police actions" and "non-observance of preventive measures, irresponsibility of the French."

Implications for Public Health Policies and Perspectives

In contrast to the expected value of social media in sharing information about the epidemic and assessing public needs and opinions in emergency situations, our study has also identified several common risks of Chinese and French social media. The main risk is the widespread sharing of fake news (eg, regarding the virus and public measures), which can lead to mistrust, fear, and improper actions. Even premature findings that have not yet been validated but that spread quickly and widely on social media can cause problems, such as self-medication with unproven treatments (efficacy and safety) and drug shortages (Shuanghuanglian in China and hydroxychloroquine in France). Moreover, scientific information conveyed to the public in an inappropriate way can lead to misunderstandings and unnecessary panic (eg, transmission via aerosols in China). These common risks highlight the importance for institutions to establish an effective communication system to provide reliable, appropriate, and understandable information.

Moreover, our study revealed several different concerns expressed by the public through Weibo and Twitter that may be addressed by Chinese and French policy makers. In China, worries about this new virus and disease, combined with fears of being infected, led to numerous requests for the lockdown of Wuhan on Weibo before the lockdown was implemented. As a result, the lockdown decision was welcomed by many Weibo users in China. In contrast, in France, worries about socioeconomic consequences, impacts on everyday life, and concerns about food shortages in supermarkets were frequently expressed in French tweets. Regarding scientific information, the lack of established knowledge about the new virus and disease led to two different types of messages: the sharing of scientific information among Weibo users, on the one hand, and opinions and controversies about treatment and hydroxychloroquine in France, on the other hand. Ultimately, concerns regarding tracing apps and data privacy were identified in the French tweets, underlining the need for institutions to provide a clear regulatory framework and appropriate messages to the population so that these technologies are trusted and widely spread. These different concerns suggest country-specific needs that should be sufficiently addressed by decision makers.

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Authors' Contributions

SS, AB, and XC contributed to the study design. AM, CF, and XC contributed to the literature review. PF, CF, MK, and XC contributed to the data collection and analysis. CF and XC contributed to the design and drawing of the figures. PF, CF, AB, and XC drafted the manuscript. All authors contributed to the data interpretation and critical revision of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Keywords for extraction.
[XLSX File (Microsoft Excel File), 32 KB - formative_v5i4e23593_app1.xlsx]

Multimedia Appendix 2
Preprocessing.
[XLSX File (Microsoft Excel File), 45 KB - formative_v5i4e23593_app2.xlsx]

Multimedia Appendix 3
Chinese topics in the prelockdown period.
[XLSX File (Microsoft Excel File), 70 KB - formative_v5i4e23593_app3.xlsx]

Multimedia Appendix 4
Chinese topics in the early lockdown period.
[XLSX File (Microsoft Excel File), 11 KB - formative_v5i4e23593_app4.xlsx]

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Multimedia Appendix 5
Chinese topics in the mid to late lockdown period.
[XLSX File (Microsoft Excel File), 11 KB - formative_v5i4e23593_app5.xlsx]

Multimedia Appendix 6
French topics in the prelockdown period.
[XLSX File (Microsoft Excel File), 44 KB - formative_v5i4e23593_app6.xlsx]

Multimedia Appendix 7
French topics in the early lockdown period.
[XLSX File (Microsoft Excel File), 11 KB - formative_v5i4e23593_app7.xlsx]

Multimedia Appendix 8
French topics in the mid to late lockdown period.
[XLSX File (Microsoft Excel File), 44 KB - formative_v5i4e23593_app8.xlsx]

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Abbreviations

API: application programming interface

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Original Paper

Psychological and Coping Strategies Related to Home Isolation and Social Distancing in Children and Adolescents During the COVID-19 Pandemic: Cross-sectional Study

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Abstract

Background: In December 2019, a novel coronavirus called SARS-CoV-2 was identified as the cause of a cluster of pneumonia cases in Wuhan, China. It rapidly spread due to human-to-human transmission, resulting in a global pandemic. Nearly every country, including Qatar, has established guidelines and regulations to limit the spread of the virus and to preserve public health. However, these procedures have been associated with negative effects on the psychological and intellectual well-being of individuals, including children and adolescents.

Objective: The objective of this study was to determine the psychological influence of home isolation and social distancing on children and adolescents during the COVID-19 pandemic in Qatar, and the strategies used to cope with these measures.

Methods: This cross-sectional study was undertaken using an online questionnaire administered through SMS text messaging. All home-isolated children and adolescents registered at the Primary Health Care Corporation aged 7-18 years were invited to participate in the study. Children and adolescents with intellectual disadvantages were excluded. A *P* value of .05 (two-tailed) was considered statistically significant.

Results: Data were collected from 6608 participants from June 23 to July 18, 2020. Nearly all participants adhered to the official regulations during the period of home isolation and social distancing; however, 69.1% (n=4568) of parents believed their children were vulnerable to the virus compared to 25% (n=1652) who expressed they were not vulnerable at all. Higher levels of anger, depression, and general anxiety were prevalent among 1.3% (n=84), 3.9% (n=260), and 1.6% (n=104) of participants, respectively. The mean score for the emotional constructs anger and depression decreased with increased compliance with regulations (*P*=.04 and *P*=.11, respectively). The differences in mean score for all psychological and coping strategies used among participants across the 3 levels of vulnerability to SARS-CoV-2 were statistically significant. The mean score varied little with increasing reported vulnerability to the virus. This mild variation can make a difference when the sample size is large, as is the case in this study.

Conclusions: Screening for psychological and social disruptions is important for the development of strategies by schools and health care providers to assess and monitor behavioral changes and negative psychological impact during post–COVID-19 reintegration. Participants experiencing higher levels of anxiety should be given more attention during reintegration and transitional phases in schools. Although electronic devices and social media platforms may have lowered anxiety levels in some cases, it is important to address how they are used and how content is tailored to children and adolescents. It is also important to maintain an active lifestyle for children and young persons, and encourage them not to neglect their physical health, as this promotes a better psychological state of mind.

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KEYWORDS

COVID-19; coronavirus; pandemic; psychological; coping strategies; children; adolescents; Qatar

Introduction

Coronaviruses are pathogens of humans and animals. In December 2019, a novel coronavirus was identified as the cause of a cluster of pneumonia cases in Wuhan, Hubei Province, China. It spread rapidly, resulting in an epidemic throughout China, followed by an increasing number of cases in other countries due to human-to-human transmission and leading to a global pandemic. In February 2020, the World Health Organization named the disease COVID-19. This pandemic affected almost all members of societies in all countries around the world, including the elderly and children. Fortunately, the rate of vulnerability and cases is lower among children [1,2].

The pandemic caused devastation across the globe, affected the daily lives of millions, and left a deep mark on people's minds. However, historically during difficult times such as wars, humans have exhibited resiliency over time to cope with the effects of such tragedies. In recent times, social media has played a key role in enabling both our interconnectedness with family, friends, and colleagues, as well as a less-welcomed 24-hour reinforcement of our anxieties [3].

Almost all countries around the world, including Qatar, have established guidelines and regulations for the public to follow, in order to limit the spread of the virus and to preserve the health of community members and families. These regulations and instructions focused not only on closing schools and outdoor activities but also imposed measures like homeschooling, home isolation, social distancing, and quarantine. Unfortunately, these procedures are often associated with some negative effects on the psychological and intellectual well-being of people, including children and adolescents [4,5]. These negative psychological and intellectual effects among children include confusion, stress, anger, detachment from others, irritability, insomnia, poor concentration, deteriorating educational performance, reluctance to work, predictor of posttraumatic stress and depressive symptoms, trauma-related mental health disorders, emotional disturbance, low mood, emotional exhaustion, fear, nervousness, sadness, fulfilling basic needs/services, boredom, lack of peer contact [4,6-14].

Although research on the implications of trauma-related events on children is expanding, studies on response and coping strategies remain scarce. Coping is an act (behavior) and effort (cognitive) to prevent or diminish threat, harm, and loss, or to reduce the distress that is often associated with stressful experiences [15]. We can say that stress exists whenever people face situations that exceed their ability to manage them [16]. Some theorists limit the concept of coping to voluntary responses [17]. Others include automatic and involuntary responses as well [18]. There are several taxonomies developed to identify coping strategies in the literature such as adaptive and maladaptive, problem-focused, emotion-focused, social support, cognitive reframing, and religious and spiritual coping [19,20]. Although the appropriateness of the strategies differs according to the type of stressor, strategies in general are considered functional if they succeed in diminishing or reducing the threat of the situation whether it is internal or external [20,21].

In Qatar, home isolation and social distancing regulations have been in effect since early March 2020. Taking into consideration the level of impact this virus has had and how it spreads, a national strategy was considered to mitigate transmission, by enforcing home isolation and social distancing regulations, following the recommendation of the National Crisis Committee led by the Ministry of Public Health.

Several measures were taken nationally, such as closing cinema theaters, malls, public transportation, children's public playgrounds, gyms, and wedding venues, including those in hotels. In addition, the Ministry of Public Health called upon the public to avoid crowded places and postpone social gatherings. Entry into the country was suspended for all those wishing to travel from certain countries. For children and adolescents, the main measure involved suspending studies in school and switching to remote education from home [22-24]. Elderly people and those with chronic health conditions were advised to avoid going out unless necessary, as they are more susceptible to infections. Further precautions included taking care and applying simple preventive measures to protect against infection, such as washing one's hands often, using hand sanitizers and masks, and maintaining a safe distance from people with symptoms of illness [22]. In addition, a COVID-19 contact center accessible around the clock was established for any reports or inquiries regarding the virus via a toll-free phone number (hotline: 16000) [22] .The National Crisis Committee set a 4-stage strategy for reopening the country, with stage 1 starting on June 15, 2020, and stage 4 to start in early September 2020. Each stage was expected to take 1 month, and increases in COVID-19 cases would be the key factor impacting the move from one stage to the next.

This study assessed how children and adolescents (7-18 years) reacted to changes in their daily routines and their behaviors due to the COVID-19 pandemic in Qatar. In particular, the study focused on the psychological influence of home isolation and social distancing on children and adolescents, and the strategies used to cope with the pandemic. In order to shed light on psychological impact, specific diagnoses were selected for this research: depression, general anxiety, separation anxiety, anger, and adjustment disorder.

Methods

Study Design

This is a cross-sectional study implemented on a national level to screen for a selected number of psychological changes in children and adolescents in Qatar during the COVID-19 crisis. While it is acknowledged that challenges may arise from the lack of standardized teleassessment methods, which can affect the means to identify psychological disorders in larger populations, it is important that measures be taken into

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consideration to address them, especially when some disorders have established procedures for assessment like in-person consultations [25].

An online questionnaire was introduced as a screening method to shed light on select psychological changes and their relation to adherence to national regulations and level of participant vulnerability to the virus. We also aimed to identify adaptive coping strategies practiced by children, adolescents, and their parents during the COVID-19 epidemic in Qatar. Sociodemographic characteristics were taken into consideration in relation to adherence to national regulations and vulnerability to the virus.

Adherence to national regulations and restrictions were used as an outcome measure since it represents a unified method for families to prevent the spread of COVID-19, as indicated by studies and guidelines by the World Health Organization. Since we focused on psychological changes in children and adolescents, it was also important to determine the extent to which this group is vulnerable to COVID-19, which was added as the second main outcome measure in the study. Approval from the ethical committee at the Primary Health Care Corporation (PHCC) was obtained to conduct this study.

This study tested the following hypotheses:

1. Is there an association between following the official regulations during home isolation and social distancing due to the COVID-19 pandemic with the sociodemographic characteristics of participants, final psychological diagnoses, and coping strategies used by children and adolescents?
2. Is there an association between the perceived level of vulnerability to SARS-CoV-2 during home isolation and social distancing due to the COVID-19 pandemic with sociodemographic characteristics of participants, final psychological diagnoses and coping strategies used by children and adolescents?
3. Is there any difference in the mean score of selected final psychological diagnoses and coping strategies used across the 3 levels of compliance with official regulations among children and adolescents during home isolation and social distancing due to the COVID-19 pandemic?
4. Is there any difference in the mean score of selected final psychological diagnoses and coping strategies used across the 3 perceived levels of vulnerability to SARS-CoV-2 among children and adolescents during home isolation and social distancing due to the COVID-19 pandemic?
5. Is there an association between the study population's age and final psychological diagnoses?
6. Is there an association between the study population's age and coping strategies?

Study Population

All home-isolated children (7-12 years old) and adolescents (13-18 years old) registered at PHCC and living in Qatar during the COVID-19 pandemic (n=~170,000) were eligible to participate in the study. Children and adolescents with intellectual disadvantages (eg, being unable to communicate their thoughts) were excluded. While obtaining consent from parents to participate in the questionnaire, it was clarified that they must exclude children and adolescents who met the exclusion criterion.

PHCC is a government agency that provides primary health care services to the community in Qatar. Thus, it is the first point of contact between patients and health care providers.

Sample Size and Technique

The research team shared the questionnaire with PHCC's Health Information Management (HIM) department both in Arabic and English, and provided an explanatory introduction of the research and its objectives, including an approval form for consent to participate in the research. The HIM department developed an electronic questionnaire and consent form. It was sent to parents' mobile phones on file at PHCC. Data was collected from 6608 participants from June 23 to July 18, 2020.

Data Collection Tools

The approach of developing the questionnaire took into consideration several assessment tools to screen for anxiety (General Anxiety and Separation Anxiety and Spence Children's Anxiety Scale [SCAS]), depression (Kutcher Adolescent Depression Scale [KADS]), and anger (Clinical Anger Scale [CAS]). Questions that were considered irrelevant to the COVID-19 pandemic and home isolation were disregarded.

For anxiety, the subscale calculation in SCAS was reviewed, and researchers disregarded questions that were meant to assess panic disorder/agoraphobia, obsessive compulsive disorder, social phobia, and anxiety of physical injury [26]. The local context of social distancing and home isolation enforcement by the National Crisis Committee was taken into consideration. Thus, questions on anxieties related to environments outside the home, such as schools, public spaces, public toilets, and transportations, were excluded. Questions related to general anxiety and separation anxiety were retained. We aimed to screen for the effects on children and adolescents caused by being separated from their parents during the pandemic, by taking into consideration its relation to the two outcome measures, vulnerability of children and adolescents to the virus as assessed by parents and older siblings leaving home on an occasional basis, and the level of adherence to regulations by parents and guardians who chose to leave home.

KADS was used as a basis for the questions used to screen for depression. Researchers customized the questions and simplified them for two main reasons: (1) to screen rather than diagnose and (2) to simplify them for comprehension by children by minimizing complex wording and assuring their suitability as addressed in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5). We refrained from using the diagnostic symptom of suicidal ideation, since the assessment was not performed in a clinical setting [27,28].

Although anger is not an explicit diagnosis in the DSM-5, several formally identified disorders reflect enduring and dysfunctional anger. The inclusion of anger in the questionnaire was to distinguish between aggression, indecisiveness, low concentration, distrust, and other symptoms related to depression and anxiety that the targeted population may express. The CAS is an objective, validated self-report measure of psychological

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symptoms, including anger, irritation, social interference, decision interference, and thinking interference [28-30].

According to the DSM-5, adjustment disorder is present when abnormal, emotional, or behavioral symptoms occur in response to stressful events such as a natural disaster (in this case, the event is a pandemic). Stressors may affect single individuals, an entire family, or larger community groups. Following the diagnostic criteria, questions were addressed to screen for emotional and behavioral symptoms developed within months of the start of the pandemic like change in sleep routine, boredom, wanting to be alone, stress and feeling upset, change in the rate of electronic device usage, and overall rate of daily activity. The symptoms identified do not meet criteria pertaining to other disorders collectively, where the stressor (home isolation) is considered an essential factor [28].

It is fundamental to identify coping subcategories since there are no specific strategies observed or a particular belief that can be reliably reported [31]. The literature argues that coping is considered an organizational construct, where it is practiced to manage stressful experiences. It is considered changeable and fixable according to the type of stressor and culture [31]. According to Aldwin [19], culture can affect the way stressors are reacted to and generally affect the choice of coping strategies adopted. Thus, 8 different practices applicable to the lifestyle of children and adolescents in Qatar were selected, with this research aiming to identify the level of adaption of these specific practices during the pandemic.

As far as categorizing coping practices, Edge and Sherwood [31] argue that a hierarchical view of coping can be useful to determine the link between the type of coping and adaptive coping to innumerable situation-specific responses. There is a strong correlation between adaptive coping practices and mental health; both general coping styles and specific strategies are significant in mediating the effects of stressful experiences and the development of psychological disorders. According to Edge and Sherwood [31], “a category is functionally homogenous to the extent it is defined so that all ways of coping it includes serve the same set of functions, ways of coping that are functionally homogenous should be able to be substituted for each other, thus are included within the same category”. The 8 adaptive strategies selected were categorized into 4 themes—spiritual/emotional, physical, social, and cognitive—as Likert-scale questions, for the purpose of measuring level of practice involvement and to identify how different strategies can influence, moderate, and reduce the effects of the pandemic.

The activities selected within those 4 subthemes were taken into consideration to shed light on how often participants prayed, were physically active, socialized with their parents, engaged in at-home activities, etc, and their correlation to the selected diagnoses to be screened for. As it is evident that physical activity and social engagement can reduce depression, and praying and emotional care can reduce symptoms of anger, we aimed to identify the level of practice associated with these coping strategies, in order to advise parents and guardians of the importance of these practices in reducing the symptoms of some psychological effects [19,20].

The T-scores of all tools previously mentioned were reviewed, and all questions were compared to the diagnostic criteria and symptoms of each diagnosis in the DSM-5. The time period of questionnaire distribution was also considered after regulations and mandates on home isolation and social distancing were enforced. Thus, we screened for persistent symptoms in children and adolescents, lasting at least 2 months. The scoring method was linked to the scoring system of the tools mentioned above and comparable to the severity levels of each diagnosis in the DSM-5 (mild, intermediate, or severe). The final scoring system of the questionnaire was standardized across all screening questions to ensure quality of screening and participants’ ability to answer them [28].

Data Analysis

Frequencies with percentages were calculated for categorical variables, and mean (SD) values were calculated for discrete variables. Chi-square tests were used to check associations between categorical variables and the main variables of adherence to regulations and level of vulnerability to SARS-CoV-2. One-way ANOVA (analysis of variance) with post hoc analysis (Bonferroni) was used for continuous variables with adherence and vulnerability. Pearson correlation coefficients were calculated to assess the correlation among the final psychological diagnoses (anger, adjustment disorder, depression, general anxiety, and separation anxiety) and the 4 coping strategies (spiritual/emotional, social, physical, and cognitive). A *P* value of .05 (two-tailed) was considered to indicate statistical significance. SPSS (version 23.0, IBM Corp) was used for the statistical analysis.

Results

The total number of participants in this study was 6608 children and adolescents aged 7-18 years (3.9% of the invited population of 170,000). The data collection period was from June 23 to July 18, 2020, during the period of home isolation and social distancing enforced due to the COVID-19 pandemic.

As shown in Table 1, the distribution of sociodemographic characteristics, final psychological diagnoses screened, and coping strategies used varied between children and adolescents. Adolescents comprised approximately one-third of the sample, and children made up two-thirds. Approximately half were male, and the other half were female. Nearly half of the participants were in primary school and about three-quarters came from middle-income families. Almost all the participants adhered to the official regulations during the period of home isolation and social distancing. A total of 69.1% (n=4568) of parents stated that their children were vulnerable to the virus, compared to 25% (n=1652) who expressed no vulnerability. Most psychological effects were mild among the participants, who used various coping strategies to manage psychological changes. The strategies included were spiritual/emotional, cognitive, social, and physical forms of coping.

Each main variable associated with psychological impacts and coping strategies was divided into 3 to 4 or more subcategories for an in-depth understanding of the main variables as shown in Tables 2 and 3.

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Table 1. Frequency distribution of sociodemographic characteristics, final psychological diagnoses, and coping strategies used among children and adolescents during home isolation and social distancing due to the COVID-19 pandemic in Qatar in 2020 (N=6608).

Variable	Frequency, n (%)
Language	
English	2983 (45.1)
Arabic	3625 (54.9)
Age (years)	
7-12	4148 (62.8)
13-18	2460 (37.2)
Gender	
Male	3354 (50.8)
Female	3254 (49.2)
Nationality	
Qatari	1374 (20.8)
Non-Qatari Arab	2237 (33.9)
South Asian	1907 (28.9)
Other	1090 (16.5)
Education	
Primary	3220 (48.7)
Middle	1733 (26.2)
Secondary	1355 (20.5)
Completed secondary	300 (4.5)
Income (QR[a])	
Up to 5000	627 (9.5)
5001-10,000	1443 (21.8)
10,001-20,000	2034 (30.8)
20,001-40,000	1448 (21.9)
40,001-60,000	598 (9)
≥60,001	458 (6.9)
Adherence to official regulations	
Not following instructions	84 (1.3)
Following instructions exactly	4981 (75.4)
Doing more than what was instructed	1543 (23.4)
Perceived level of vulnerability to SARS-CoV-2	
Not vulnerable at all	1652 (25)
As vulnerable as an average person	4568 (69.1)
Extremely vulnerable	388 (5.9)
Anger	
None	4784 (72.4)
Mild	1740 (26.3)
Severe	84 (1.3)
Adjustment disorder	
None	1349 (20.4)
Mild	4396 (66.5)

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Variable	Frequency, n (%)
Moderate to severe	863 (13.1)
Depression	
None	3760 (56.9)
Mild	1927 (29.2)
Moderate	661 (10)
Severe	260 (3.9)
General anxiety	
No	2646 (40)
Mild	3285 (49.7)
Intermediate	573 (8.7)
Severe	104 (1.6)
Separation anxiety	
None	5077 (76.8)
Possible	1531 (23.2)
Spiritual/emotional coping strategy	
Did not use	508 (7.7)
Felt somewhat comfortable and maintained practice	2439 (36.9)
Always felt comfortable and maintained practice	3661 (55.4)
Cognitive coping strategy	
Did not use	701 (10.6)
Felt somewhat comfortable and maintained practice	4220 (63.9)
Always felt comfortable and maintained practice	1687 (25.5)
Physical coping strategy	
Did not use	1931 (29.2)
Felt somewhat comfortable and maintained practice	3539 (53.6)
Always felt comfortable and maintained practice	1138 (17.2)
Social coping strategy	
Did not use	379 (5.7)
Felt somewhat comfortable and maintained practice	2260 (34.2)
Always felt comfortable and maintained practice	3969 (60.1)

[a] QR: Qatari Rial. 1 USD=3.64 QR.

Table 2. Frequency distribution of symptoms related to each final psychological diagnosis among children and adolescents during home isolation and social distancing due to the COVID-19 pandemic in Qatar in 2020 (N=6608).

Main variable and subcategory	None of the time, n (%)	Rarely, n (%)	Some of the time, n (%)	Often, n (%)	All the time, n (%)
Anger					
Became more aggressive	1697 (25.7)	1399 (21.2)	2622 (39.7)	703 (10.6)	187 (2.8)
Able to deal with one's own emotion	1138 (17.2)	2057 (31.1)	2379 (36.0)	771 (11.7)	263 (4.0)
Thinking clearly	1496 (22.6)	2232 (33.8)	2079 (31.5)	641 (9.7)	160 (2.4)
Having no trust in what people say about the virus	1400 (21.2)	1540 (23.3)	2440 (36.9)	913 (13.8)	315 (4.8)
Having trouble making decisions	1280 (19.4)	1787 (27.0)	2425 (36.7)	794 (12.0)	322 (4.9)
Adjustment disorder					
Increased use of electronic devices	102 (1.5)	197 (3.0)	995 (15.1)	2334 (35.3)	2980 (45.1)
Being less active during the day	461 (7.0)	874 (13.2)	2070 (31.3)	2153 (32.6)	1050 (15.9)
Feeling relaxed	897 (13.6)	1817 (27.5)	2470 (37.4)	1054 (16.0)	370 (5.6)
Feeling upset all the time	1323 (20.0)	1987 (30.1)	2101 (31.8)	832 (12.6)	365 (5.5)
Feeling like being alone	2838 (42.9)	1454 (22.0)	1454 (22.0)	559 (8.5)	303 (4.6)
Feeling bored almost all the time	567 (8.6)	1233 (18.7)	2128 (32.2)	1538 (23.3)	1142 (17.3)
Sleeping during the day and staying up during the night	2175 (32.9)	1088 (16.5)	1385 (21.0)	1125 (17.0)	835 (12.6)
Depression					
Eating more fast food	1315 (19.9)	2139 (32.4)	2012 (30.4)	831 (12.6)	311 (4.7)
Feeling optimistic about the future	1715 (26.0)	1784 (27.0)	2063 (31.2)	698 (10.6)	348 (5.3)
Feeling hopeless	3328 (50.4)	1612 (24.4)	1189 (18.0)	324 (4.9)	155 (2.3)
Feeling tired	1323 (20.0)	1921 (29.1)	2297 (34.8)	738 (11.2)	329 (5.0)
Cannot concentrate when talking to people	1713 (25.9)	1920 (29.1)	1961 (29.7)	764 (11.6)	250 (3.8)
Not feeling like doing any sports or physical activities	1554 (23.5)	1393 (21.1)	1967 (29.8)	1092 (16.5)	602 (9.1)
Feeling that things will never be the same again	1662 (25.2)	1311 (19.8)	1826 (27.6)	1161 (17.6)	648 (9.8)
Generalized anxiety					
Wanting to be a better person	1715 (26.0)	1884 (28.5)	2024 (30.6)	630 (9.5)	355 (5.4)
Worrying about things	434 (6.6)	1148 (17.4)	2820 (42.7)	1513 (22.9)	693 (10.5)
Making sure that things are done correctly	328 (5.0)	865 (13.1)	1653 (25.0)	1819 (27.5)	1943 (29.4)
Having nightmares	2843 (43.0)	1994 (30.2)	1227 (18.6)	395 (6.0)	149 (2.3)
Thinking one did not do well in school	2269 (34.3)	1540 (23.3)	1732 (26.2)	737 (11.2)	330 (5.0)
Separation anxiety					
Feeling afraid of being alone at home	2373 (35.9)	1445 (21.9)	1244 (18.8)	746 (11.3)	800 (12.1)
Worrying about being close to people other than one's own parents	1421 (21.5)	1496 (22.6)	1715 (26.0)	1206 (18.3)	770 (11.7)
Worrying that something will happen to him/her	2105 (31.9)	1854 (28.1)	1721 (26.0)	612 (9.3)	316 (4.8)

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Table 3. Frequency distribution of symptoms related to each coping strategy used among children and adolescents during home isolation and social distancing due to the COVID-19 pandemic in Qatar in 2020 (N=6608).

Main variable and subcategory	None of the time, n (%)	Rarely, n (%)	Some of the time, n (%)	Often, n (%)	All the time, n (%)
Spiritual/emotional coping strategy					
Practicing prayer and religious worship more often	374 (5.7)	541 (8.2)	1460 (22.1)	2001 (30.3)	2232 (33.8)
Asking for support from people who care about them and understand his/her feelings (eg, parents, teachers, academic advisors, school administrative staff)	429 (6.5)	667 (10.1)	1404 (21.2)	1713 (25.9)	2395 (36.2)
Cognitive coping strategy					
Choosing to receive accurate information from parents and official channels instead of rumors from peers	165 (2.5)	304 (4.6)	916 (13.9)	1965 (29.7)	3258 (49.3)
Limiting using of electronic devices	1825 (27.6)	2221 (33.6)	1838 (27.8)	516 (7.8)	208 (3.1)
Social coping strategy					
Spending more time with family	89 (1.3)	330 (5.0)	958 (14.5)	1803 (27.3)	3428 (51.9)
Doing at-home activities with the family, such as cooking a meal or playing board games	326 (4.9)	857 (13.0)	2254 (34.1)	1939 (29.3)	1232 (18.6)
Physical coping strategy					
Doing more exercise	896 (13.6)	1947 (29.5)	2280 (34.5)	1006 (15.2)	479 (7.2)
Creating a sleep schedule	1160 (17.6)	1460 (22.1)	1805 (27.3)	1337 (20.2)	846 (12.8)

Having understood the relative proportion of the study factors, the association of the study variables with the two main variables (ie, adherence to official regulations and perceived level vulnerability to the coronavirus) among the participants during home isolation and social distancing was tested; the results are presented in Tables 4 and 5.

The association between the different levels of adherence to official regulations and perceived levels of vulnerability to the virus and sociodemographic factors, clinical outcome, and coping strategies used by participants were shown to be statistically significant ($P \leq .05$) in most cases.

As shown in Table 6, the difference in mean score of psychological changes and coping strategies used by the participants across the 3 levels of compliance with official regulations were observed. These results were clinically insignificant, except in a few cases. Table 6 shows that respondents who followed instructions reported lower anger and depression scores compared to those who did not follow them.

Unlike the previous two constructs, the mean percentage of general and separation anxiety continuously increased with increasing level of adherence to regulations. Similarly, the mean score for coping strategies used by participants increased significantly among those who followed official instructions. However, the mean score for adjustment disorder increased among the people who followed the exact instructions than those who did not (from 46.4% to 49.4%) and decreased slightly among those who did more than what was prescribed (48.3%).

Table 7 shows that the difference in mean score for all psychological changes and coping strategies used among the participants across the 3 levels of vulnerability to the coronavirus were statistically significant. There was no obvious trends between clinical outcomes and perceived vulnerability. However, the mean score increased with increases in the level of vulnerability in the case of anger and separation anxiety.

As the study population is actually very diverse in terms of age group, ranging from 7 to 18 years, Tables 8 and 9 show the differences in the relationship between different age categories and study outcomes. The differences across age groups were moderate in most cases.

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Table 4. Association between adherence to official regulations and sociodemographic characteristics of participants, final psychological diagnoses, and coping strategies used by children and adolescents in Qatar in 2020 (N=6608).

Variable	Have not been following instructions, n (%)	Have been following instructions exactly, n (%)	Have been doing more than what was instructed, n (%)	*P* value
Language				.15
English	34 (40.5)	2222 (44.6)	727 (47.1)	
Arabic	50 (59.5)	2759 (55.4)	816 (52.9)	
Age				.59
7-12 years	54 (64.3)	3142 (63.1)	952 (61.7)	
13-18 years	30 (35.7)	1839 (36.9)	591 (38.3)	
Gender				.35
Male	45 (53.6)	2503 (50.3)	806 (52.2)	
Female	39 (46.4)	2478 (49.7)	737 (47.8)	
Nationality				.001
Qatari	38 (45.2)	1018 (20.4)	318 (20.6)	
Non-Qatari Arab	15 (17.9)	1743 (35.0)	479 (31.0)	
South Asian	22 (26.2)	1454 (29.2)	431 (27.9)	
Other	9 (10.7)	766 (15.4)	315 (20.4)	
Education				.02
Primary	36 (42.9)	2439 (49.0)	745 (48.3)	
Middle	28 (33.3)	321 (26.5)	384 (24.9)	
Secondary	13 (15.5)	1018 (20.4)	324 (21.0)	
Completed secondary	7 (8.3)	203 (4.1)	90)5.8)	
Income (QR[a])				.001
Up to 5000	14 (16.7)	449 (9.0)	164 (10.0)	
5001-10,000	12 (14.3)	1095 (22.0)	336 (21.8)	
10,001-20,000	17 (20.2)	1551 (31.1)	466 (30.2)	
20,001-40,000	11 (13.1)	1134 (22.8)	303 (19.6)	
40,001-60,000	13 (15.5)	430 (8.6)	155 (10.0)	
≥60,001	17 (20.2)	322 (6.5)	119 (7.7)	
Anger				.001
No	53 (63.1)	3614 (72.6)	1117 (72.4)	
Mild	26 (31)	1316 (26.4)	398 (25.8)	
Severe	5 (6)	51 (1)	28 (1.8)	
Adjustment disorder				.01
None	21 (25)	968 (19.4)	360 (23.3)	
Mild	56 (66.7)	3362 (67.5)	978 (63.4)	
Moderate to severe	7 (8.3)	651 (13.1)	205 (13.3)	
Depression				.04
None	35 (41.7)	2831 (56.8)	894 (57.9)	
Mild	38 (45.2)	1444 (29)	445 (28.8)	
Moderate	7 (8.3)	512 (10.3)	142 (9.2)	
Severe	4 (4.8)	194 (3.9)	62 (4)	
General anxiety				.76

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Variable	Have not been following instructions, n (%)	Have been following instructions exactly, n (%)	Have been doing more than what was instructed, n (%)	*P* value
No	42 (50)	2006 (40.3)	598 (38.8)	
Mild	32 (38.1)	2492 (50)	761 (49.3)	
Intermediate	8 (9.5)	408 (8.2)	157 (10.2)	
Severe	2 (2.4)	75 (1.5)	27 (1.7)	
Separation anxiety				.36
None	70 (83.3)	3825 (76.8)	1182 (76.6)	
Possible	14 (16.7)	1156 (23.2)	361 (23.4)	
Spiritual/emotional coping strategy				.001
Did not use	16 (19)	377 (7.6)	115 (7.5)	
Felt somewhat comfortable and maintained practice	38 (45.2)	1884 (37.8)	517 (33.5)	
Always felt comfortable and maintained practice	30 (35.7)	2720 (54.6)	911 (59)	
Cognitive coping strategy				.001
Did not use	31 (36.9)	516 (10.4)	154 (10.0)	
Felt somewhat comfortable and maintained practice	44 (52.4)	3242 (65.1)	934 (60.5)	
Always felt comfortable and maintained practice	9 (10.7)	1223 (24.6)	455 (29.5)	
Physical coping strategy				.01
Did not use	36 (42.9)	1469 (29.5)	426 (27.6)	
Felt somewhat comfortable and maintained practice	33 (39.3)	2691 (54)	815 (52.8)	
Always felt comfortable and maintained practice	15 (17.9)	821 (16.5)	302 (19.6)	
Social coping strategy				.001
Did not use	17 (20.2)	269 (5.4)	93 (6.0)	
Felt somewhat comfortable and maintained practice	37 (44)	1752 (35.2)	471 (30.5)	
Always felt comfortable and maintained practice	30 (35.7)	2960 (59.4)	979 (63.4)	

[a] QR: Qatari Rial. 1 USD=3.64 QR.

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Table 5. Association between the perceived level of vulnerability to corona virus during home isolation and social distancing because of the COVID-19 pandemic with sociodemographic characteristics of participants, final psychological diagnoses and the coping strategies used among children and adolescents in Qatar in 2020 (N=6608).

Variable	Not vulnerable at all, n (%)	As vulnerable as an average person, n (%)	Extremely vulnerable, n (%)	*P* value
Language				.001
English	642 (38.9)	2027 (44.4)	314 (80.9)	
Arabic	1010 (61.1)	2541 (55.6)	74 (19.1)	
Age				.01
7-12 years	1022 (61.9)	2854 (62.5)	272 (70.1)	
13-18 years	630 (38.1)	1714 (37.5)	116 (29.9)	
Gender				.58
Male	849 (51.4)	2317 (50.7)	188 (48.5)	
Female	803 (48.6)	2251 (49.3)	200 (51.5)	
Nationality				.001
Qatari	412 (24.9)	945 (20.7)	17 (4.4)	
Non-Qatari Arab	582 (35.2)	1592 (34.9)	63 (16.2)	
South Asian	454 (27.5)	1239 (27.1)	214 (55.2)	
Other	204 (12.3)	792 (17.3)	94 (24.2)	
Education				.001
Primary	778 (47.1)	2254 (49.3)	188 (48.5)	
Middle	495 (30.0)	1125 (24.6)	113 (29.1)	
Secondary	305 (18.5)	980 (21.5)	70 (18.0)	
Completed secondary	74 (4.5)	209 (4.6)	17 (4.4)	
Income (QR[a])				.001
Up to 5000	209 (12.7)	377 (8.3)	41 (10.6)	
5001-10,000	375 (22.7)	936 (20.5)	132 (34.0)	
10,001-20,000	478 (28.9)	1449 (31.7)	107 (27.6)	
20,001-40,000	347 (21.0)	1023 (22.4)	78 (20.1)	
40,001-60,000	130 (7.9)	447 (9.8)	21 (5.4)	
≥60,001	113 (6.8)	336 (7.4)	9 (2.3)	
Anger				.02
None	1246 (75.4)	3261 (71.4)	277 (71.4)	
Mild	382 (23.1)	1252 (27.4)	106 (27.3)	
Severe	24 (1.5)	55 (1.2)	5 (1.3)	
Adjustment disorder				.001
None	428 (25.9)	825 (18.1)	96 (24.7)	
Mild	1020 (61.7)	3124 (68.4)	252 (64.9)	
Moderate to severe	204 (12.3)	619 (13.6)	40 (10.3)	
Depression				.001
None	1013 (61.3)	2497 (54.7)	250 (64.4)	
Mild	435 (26.3)	1410 (30.9)	82 (21.1)	
Moderate	147 (8.9)	474 (10.4)	40 (10.3)	
Severe	57 (3.5)	187 (4.1)	16 (4.1)	
General anxiety				.001

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Variable	Not vulnerable at all, n (%)	As vulnerable as an average person, n (%)	Extremely vulnerable, n (%)	*P* value
None	732 (44.3)	1763 (38.6)	151 (38.9)	
Mild	729 (44.1)	2347 (51.4)	209 (53.9)	
Intermediate	161 (9.7)	393 (8.6)	19 (4.9)	
Severe	30 (1.8)	65 (1.4)	9 (2.3)	
Separation anxiety				.01
None	1286 (77.8)	3517 (77)	274 (70.6)	
Possible	366 (22.2)	1051 (23)	114 (29.4)	
Spiritual/emotional coping strategy				.001
Did not use	112 (6.8)	362 (7.9)	34 (8.8)	
Felt somewhat comfortable and maintained practice	551 (33.4)	1759 (38.5)	129 (33.2)	
Always felt comfortable and maintained practice	989 (59.9)	2447 (53.6)	225 (58)	
Cognitive coping strategy				.001
Did not use	171 (10.4)	494 (10.8)	36 (9.3)	
Felt somewhat comfortable and maintained practice	983 (59.5)	3022 (66.2)	215 (55.4)	
Always felt comfortable and maintained practice	498 (30.1)	1052 (23)	137 (35.3)	
Physical coping strategy				.001
Did not use	447 (27.1)	1392 (30.5)	92 (23.7)	
Felt somewhat comfortable and maintained practice	826 (50)	2507 (54.9)	206 (53.1)	
Always felt comfortable and maintained practice	379 (22.9)	669 (14.6)	90 (23.2)	
Social coping strategy				.002
Did not use	107 (6.5)	253 (5.5)	19 (4.9)	
Felt somewhat comfortable and maintained practice	515 (31.2)	1630 (35.7)	115 (29.6)	
Always felt comfortable and maintained practice	1030 (62.3)	2685 (58.8)	254 (65.5)	

[a] QR: Qatari Rial. 1 USD=3.64 QR.

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Table 6. The difference in the mean score of selected final psychological diagnoses and coping strategies used across the 3 levels of compliance with the official regulations among children and adolescents during home isolation and social distancing due to the COVID-19 pandemic in Qatar in 2020 (N=6608).

Variable	Total, mean (SD)	Have not been following instructions (n=84), mean (SD)	Have been following instructions exactly (n=4981), mean (SD)	Have been doing more than what was instructed (n=1543), mean (SD)	*P* value
Anger	37.3 (16.9)	41.1 (19.5)	37.5 (16.5)	36.7 (17.9)	.04[a]
Adjustment disorder	49.1 (17.7)	46.4 (18.2)	49.4 (17.5)	48.3 (18.3)	.05
Depression	35.7 (17.7)	37.8 (18.4)	35.9 (17.6)	35.0 (18.0)	.11
General anxiety	42 (15.6)	39.5 (16.9)	41.9 (15.4)	42.5 (16.0)	.15
Separation anxiety	37.1 (23.1)	30.7 (22.1)	36.9 (23.0)	38.0 (23.6)	.01[b]
Spiritual/emotional coping strategy	69.2 (24.4)	57.6 (27.4)	68.9 (24.1)	70.8 (24.8)	.001[c]
Cognitive coping strategy	55.5 (19.5)	40.3 (22.2)	55.2 (19.2)	57.3 (20.1)	.001[d]
Social coping strategy	70.9 (21.9)	58.3 (27.4)	70.6 (21.4)	72.7 (22.8)	.001[e]
Physical coping strategy	45.2 (24.0)	39.1 (24.8)	44.9 (23.9)	46.6 (24.2)	.01[f]

[a] Have not been following instructions vs have been following instructions exactly, *P*=.15; have not been following instructions vs have been doing more than what was instructed, *P*=.59; have been following instructions exactly vs have been doing more than what was instructed, *P*=.37.

[b] Have not been following instructions vs have been following instructions exactly, *P*=.04; have not been following instructions vs have been doing more than what was instructed, *P*=.01; have been following instructions exactly vs have been doing more than what was instructed, *P*=.26.

[c] Have not been following instructions vs have been following instructions exactly, *P*=.001; have not been following instructions vs have been doing more than what was instructed, *P*=.001; have been following instructions exactly vs have been doing more than what was instructed, *P*=.02.

[d] Have not been following instructions vs have been following instructions exactly, *P*=.001; have not been following instructions vs have been doing more than what was instructed, *P*=.001; have been following instructions exactly vs have been doing more than what was instructed, *P*=.001.

[e] Have not been following instructions vs have been following instructions exactly, *P*=.001; have not been following instructions vs have been doing more than what was instructed, *P*=.001; have been following instructions exactly vs have been doing more than what was instructed, *P*=.003.

[f] Have not been following instructions vs have been following instructions exactly, *P*=.08; have not been following instructions vs have been doing more than what was instructed, *P*=.01; have been following instructions exactly vs have been doing more than what was instructed, *P*=.05.

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Table 7. The difference in the mean score of selected final psychological diagnoses and coping strategies used between the 3 perceived levels of vulnerability to the coronavirus among children and adolescents during home isolation and social distancing due to the COVID-19 pandemic in Qatar in 2020 (N=6608).

Variable	Total, mean (SD)	Not vulnerable at all (n=1652), mean (SD)	As vulnerable as an average person (n=4568), mean (SD)	Extremely vulnerable (n=388), mean (SD)	*P* value
Anger	37.3 (16.9)	34.9 (18.1)	38.1 (16.3)	38.5 (17.2)	.001[a]
Adjustment disorder	49.1 (17.7)	47.2 (18.8)	50.1 (17.2)	46.0 (17.8)	.001[b]
Depression	35.7 (17.7)	33.5 (18.2)	36.6 (17.4)	34.5 (18.0)	.001[c]
General anxiety	42 (15.6)	40.7 (16.9)	42.5 (15.0)	41.3 (15.7)	.001[d]
Separation anxiety	37.1 (23.1)	34.9 (24.1)	37.5 (22.7)	41.6 (22.8)	.001[e]
Spiritual/emotional coping strategy	69.2 (24.4)	70.9 (24.6)	68.5 (24.2)	70.5 (25.2)	.01[f]
Cognitive coping strategy	56.7 (20.5)	56.7 (20.5)	54.7 (19.0)	59.6 (20.8)	.001[g]
Social coping strategy	70.9 (21.9)	72.3 (22.6)	70.2 (21.5)	73.7 (22.4)	.001[h]
Physical coping strategy	45.2 (24.0)	48.0 (25.6)	43.9 (23.2)	48.8 (24.4)	.001[i]

[a] Not vulnerable at all vs as vulnerable as an average person, *P*=.001; not vulnerable at all vs extremely vulnerable, *P*=.001; as vulnerable as an average person vs extremely vulnerable *P*>.99.

[b] Not vulnerable at all vs as vulnerable as an average person, *P*=.001; not vulnerable at all vs extremely vulnerable, *P*=.71; as vulnerable as an average person vs extremely vulnerable *P*=.001.

[c] Not vulnerable at all vs as vulnerable as an average person, *P*=.001; not vulnerable at all vs extremely vulnerable, *P*=.98; as vulnerable as an average person vs extremely vulnerable *P*=.06.

[d] Not vulnerable at all vs as vulnerable as an average person, *P*=.001; not vulnerable at all vs extremely vulnerable, *P*>.99; as vulnerable as an average person vs extremely vulnerable *P*=.36.

[e] Not vulnerable at all vs as vulnerable as an average person, *P*=.001; not vulnerable at all vs extremely vulnerable, *P*=.001; as vulnerable as an average person vs extremely vulnerable *P*=.002.

[f] Not vulnerable at all vs as vulnerable as an average person, *P*=.002; not vulnerable at all vs extremely vulnerable, *P*>.99; as vulnerable as an average person vs extremely vulnerable *P*=.36.

[g] Not vulnerable at all vs as vulnerable as an average person, *P*=.001; not vulnerable at all vs extremely vulnerable, *P*=.02; as vulnerable as an average person vs extremely vulnerable *P*=.001.

[h] Not vulnerable at all vs as vulnerable as an average person, *P*=.002; not vulnerable at all vs extremely vulnerable, *P*=.73; as vulnerable as an average person vs extremely vulnerable *P*=.006.

[i] Not vulnerable at all vs as vulnerable as an average person, *P*=.001; not vulnerable at all vs extremely vulnerable, *P*>.99; as vulnerable as an average person vs extremely vulnerable *P*=.001.

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Table 8. Association between age categories in the study population and the final psychological diagnoses (clinical outcomes) (N=6608).

Variable	Age category			*P* value
	7-12 years, n (%)	13-18 years, n (%)	7-18 years, n (%)	
Anger				.001
None	3007 (72.5)	1777 (72.2)	4784 (72.4)	
Mild	1105 (26.6)	635 (25.8)	1740 (26.3)	
Severe	36 (0.9)	48 (2)	84 (1.3)	
Adjustment disorder				<.001
None	915 (22.1)	434 (17.6)	1349 (20.4)	
Mild	2797 (67.4)	1599 (65)	4396 (66.5)	
Moderate to severe	436 (10.5)	427 (17.4)	863 (13.1)	
Depression				<.001
None	2435 (58.7)	1325 (53.9)	3760 (56.9)	
Mild	1203 (29.0)	724 (24.4)	1927 (29.2)	
Moderate	377 (9.1)	284 (11.5)	661 (10.0)	
Severe	133 (3.2)	127 (5.2)	260 (3.9)	
General anxiety				<.001
No	1685 (40.6)	961 (39.1)	2646 (40.0)	
Mild	2071 (49.9)	1214 (49.3)	3285 (49.7)	
Intermediate	347 (8.4)	226 (9.2)	573 (8.7)	
Severe	45 (1.1)	59 (2.4)	104 (1.6)	
Separation anxiety				<.001
None	2990 (72.1)	2087 (84.8)	5077 (76.8)	
Possible	1158 (27.9)	373 (15.2)	1531 (23.2)	

Table 9. Association between age categories in the study population and the coping strategies used (N=6608).

Variable	Age category			*P* value
	7-12 years, n (%)	13-18 years, n (%)	7-18 years, n (%)	
Spiritual/emotional coping strategy				<.001
Did not use	259 (6.2)	249 (10.1)	508 (7.7)	
Felt somewhat comfortable and maintained practice	1409 (34.0)	1030 (41.9)	2439 (36.9)	
Always felt comfortable and maintained practice	2480 (59.8)	1181 (48.0)	3661 (55.4)	
Cognitive coping strategy				<.001
Did not use	360 (8.7)	341 (13.9)	701 (6.6)	
Felt somewhat comfortable and maintained practice	2590 (62.4)	1630 (66.3)	4220 (63.9)	
Always felt comfortable and maintained practice	1198 (28.9)	489 (19.9)	1687 (25.5)	
Physical coping strategy				.001
Did not use	1148 (27.7)	783 (31.8)	1931 (29.2)	
Felt somewhat comfortable and maintained practice	2264 (54.6)	1275 (51.8)	3539 (53.6)	
Always felt comfortable and maintained practice	736 (17.7)	402 (16.3)	1138 (17.2)	
Social coping strategy				<.001
Did not use	160 (3.9)	219 (8.9)	379 (5.7)	
Felt somewhat comfortable and maintained practice	1265 (30.5)	995 (40.4)	2260 (34.2)	
Always felt comfortable and maintained practice	2723 (65.6)	1246 (50.7)	3969 (60.1)	

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Discussion

Principal Findings

In response to the COVID-19 pandemic, the education authorities in Qatar ordered a nationwide school closure as an emergency measure to prevent transmission of the infection per the mandates implemented by the National Crisis Committee and international procedures. Children and adolescents during the COVID-19 pandemic expressed psychological changes not limited to fears, uncertainties, and physical and social isolation, and may miss school for a prolonged period as a result. Understanding their reactions and emotions is essential to properly address their needs.

This study's sample is representative of the Qatari population in a number of ways. The preliminary results indicated that there was no gender bias, making our sample an acceptable representative for the subsequent analysis of the outcomes. The educational level of the participants and their ages were in line with our expectations. This will assist in developing better reintegration strategies and treatment programs among students in schools. The nationality distribution of participants in this study aligned with the characteristics of the population distribution in Qatar, and this in turn indicates that this sample truly represents the population. The percentage of Qatari participants in this study was relatively higher than their percentage in the population, and this is mostly due to their positive response to participating in the study [32]. Furthermore, this distribution is considered a good representation of the population's income level in Qatar.

Despite variation in sociodemographic characteristics, almost all the respondents (n=6524, 99%) took the required steps and followed the official regulations to safeguard themselves and their family members from the COVID-19 pandemic. This is indicative of the community's awareness regarding the importance of following official guidelines, which are in line with the directives issued by the World Health Organization and the Ministry of Public Health in Qatar [33,34]. Due to the importance of following these instructions, we have relied on them to measure the outcomes of this study [35].

The parents of most participants identified reported that their children were either not vulnerable to the coronavirus or as vulnerable as an average person (n=6220, 94%). Adequate care and standard operating procedures need to be employed for the vulnerable group (n=388, 6%). This result positively coincides with a study in China, which reported that 75.2% of participants were worried about their family members contracting COVID-19 [2].

Clinical outcomes of this study had varying prevalence and levels of severity, which ranged from mild to severe. Higher prevalence was seen for adjustment disorder and general anxiety. These findings were partially supported by other studies [35,36]. In one study, 54% of participants rated the impact of the outbreak on their mental health as moderate to severe, with depressive symptoms and anxiety being the conditions most often stated [35].

A little more than one-quarter of the participants in this study reported anger as one of the psychological changes witnessed during home isolation. This was also observed in a study from the United States [37]. Mild adjustment disorder was prevalent in 66.5% (n=4396) of our sample; this may indicate that when children are out of school, they tend exhibit changes in behaviors and lifestyle pattern, are physically less active, and have more screen time and sleep disruptions [38].

In this study, 35.3% (n=2334) and 45.1% (n=2980) of participants increased use of electronic devices often or all the time, respectively. This was also seen in a study from China where internet and smartphone addiction had increased during the COVID-19 pandemic compared to the period before the pandemic [36]. Due to limited physical and social encounters with other individuals in the community such as friends and relatives, children increasingly reached out to new contacts and groups online, as seen by various other studies [8,12,36,39,40]. It can also be interpreted as causation for introducing virtual learning during home isolation and social distancing regulations [39]. In a study from China, 78.33% admitted that the main purpose of spending time online during the COVID-19 crisis was related to studies compared to 57.1% before the crisis [36]. This may be seen as a positive aspects of the current pandemic as indicated by related studies [41,42]. On the other hand, reports indicated that the distribution of child sexual exploitation materials online; cyberbullying; online risk-taking behaviors; potentially harmful content; inappropriate collection, use, and sharing of data; and ransomware appear to be on the increase [39,40]. Hence, it is important to know how children and adolescents deal with electronic materials and devices, especially during the COVID-19 pandemic, as more than 80% of this study's participants reported an increase in the use of these devices more often or all the time. There is a need to support and empower children, providing them with safe online learning experiences and making online platforms safe and accessible to them [39].

About 30% (n=1960) of our participants reported disturbance in sleep schedule all the time or often. This was also seen in a study where approximately 21% of participants had sleeping disorders [12]. Another study showed that insomnia was prevalent during quarantine [37]. In our study, participants had nightmares in some of the time (n=1227, 18.6%), often (n=395, 6%), and all the time (n=149, 2.3%), compared to less than 15% in a study from China [12].

On the other hand, home isolation proved to have some positive outcomes during the pandemic. For example, many participants in this study and in other studies stated having more time for rest and relaxation [41]. Several factors can be attributed to this, such as the disappearance of external stressors (the absence of private and business appointments, guests, and business trips), strengthening a sense of community and cohesion. In addition, children troubled in school due to bullying or other stressors may embrace homeschooling and find it relieving since the main stressor in their everyday life no longer exists [35].

Similar to other studies [12,35,43], about 60% (n=3858) of children and adolescents in this study had mild to intermediate levels of general anxiety. Although children seem to be less

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vulnerable than adults to COVID-19, initial reports from China indicated that children and adolescents had been impacted psychologically and developed behavioral problems including anxiety [12]. In our study, the prevalence of general anxiety was relatively equal between children and adolescents, whereas anxiety was more prevalent among adolescents aged 13-18 years compared to children aged 7-12 years in another study [36]. More than 25% of that sample expressed worry, compared to 22.9% (n=1513) and 10.5% (n=693) of our participants who worried about things often and all the time, respectively [12].

On the other hand, separation anxiety has been common during the COVID-19 pandemic, even as most people practice home isolation and teaching is virtual [44]. The impact of having family members working or volunteering and parents going shopping for food and groceries, along with unclear social situations, could increase the level of separation anxiety in children and adolescents [44]. However, the nature of Qatari society and the presence of high levels of social cohesion and family stability could have helped reduce the emergence of separation anxiety in our sample. Regardless, social relations have primarily been limited to close family members, which may negatively impact children and adolescents, given the importance of other family members and peers for well-being [45,46].

During difficult times such as this pandemic, developing depression is highly expected. In line with other studies, about 40% (n=2588) of this study’s participants developed a mild to moderate form of depression [12,35-37,43]. A study from Canada during the severe acute respiratory syndrome (SARS) epidemic showed that 31.2% of 129 participants had depression due to quarantine measures [9]. In our study, some participants experienced loss of concentration when talking to others almost all the time (n=1014, 15.4%) or some of the time (1961, 29.7%). Similarly, children aged 6-18 years in a study from China were more likely to show inattention during the COVID-19 pandemic (P=.049) [12].

About 30% (n=1976) of our study’s population worried often or all the time about being near people other than own parents, with 26% (n=1715) experiencing this feeling some of the time. In line with this finding, another study indicated that clinging was one of the most severe psychological conditions demonstrated by children [12].

In terms of coping, participants in our study used different strategies to face psychological problems resulting from the pandemic. With the combined support of health care professionals, families, and other social connections, including friends and the school environment, children and adolescents can appropriately overcome and stabilize emotionally and physiologically [47-49].

Similar to other related studies, cognitive coping was used by our participants. Media and digital entertainment were used by families to relieve their children’s distress and address their concerns regarding the negative state they were facing. Obsessive requests for updates were identified among almost 30% of participants in one COVID-19 study [12,50]. Choosing to receive accurate information from parents and official channels instead of rumors from peers was practiced widely by about 80% (n=5223) of our study’s population all the time or often. This intervention was advised by a guideline developed for facing the COVID-19 and other crises [35,49].

The spiritual/emotional coping strategy was also used by participants. Close and open communication with children is the key to identifying any psychological issues and to comfort children during prolonged isolation [49,51]. Different types of emotional support from parents and avoidance of gossip about the pandemic can help to decrease the negative impacts of the crisis and in return lower clinical symptoms [50]. Similar to the sample of another study [52], the majority of participants in our study felt comfortable and maintained their practice of prayers and asked support from people who understand their feelings to relieve the negative conditions related to home isolation and social distancing. In addition, intrinsic religiousness has been suggested to help find meaning during a crisis; the relevance of affectivity shows the importance of a positive mood and attitude for stress-related growth [53]. The results of our study have shown that over 64% (n=4233) of the participants maintained their religious practices during isolation.

On a positive note, family cohesion in Qatar may have strengthened families to count on each other for support. Our study showed that more family time was allocated to children and adolescents, with more activities reported to have been practiced with siblings and parents. More time with caregivers can increase a sense of social support, which strengthens resiliency [41]. Thus, we see that social coping strategies represented a third option for the participants in this study in facing the pandemic. A guideline developed during early COVID-19 crisis support has recommended this intervention as an effective option [49].

Maintaining physical activity during home isolation was a critical aspect that was screened for. Adding physical activities during children’s and adolescents’ daily schedules can help maintain their health and fitness during health-related crises [54]. Our study showed that the use of physical activity to overcome negative psychological states was low, with 15.2% (n=1006) of participants reporting doing more exercise than before and only 7.2% (n=479) reporting doing exercise almost all the time. Fear of infection, hot weather, high humidity, and regulations limited movement outside the home, and relative shortage of infrastructure to support exercise and physical exertion may be the main factors behind this limitation. In contrast, a study from China indicated that higher levels of physical activities reached effective and very effective levels of practice (31.72% and 20.06%, respectively) [12].

Strengths and Limitations

This study had various strengths. The results provide essential information to support decision making by education authorities concerned with the psychological state of students during the COVID-19 pandemic or in similar crises in the future. In addition, the age group of our sample is more prone to psychological problems than other age groups. The older groups have a better ability to deal with exceptional periods such as a pandemic; in contrast, younger groups may be less aware of the dangers and psychological changes associated with a pandemic. Additionally, the sample size was relatively large and

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representative, which increases the applicability and generalization of the results. The use of a well-designed questionnaire and standard statistical methods ensured the comparability of the results with other studies.

Several limitations also exist. First, the study was conducted on an age group that may be at risk of information bias. In order to improve the quality of data, the questionnaires were sent to their parents' mobile phones so that they can help their children, especially those in the early childhood age. Specific parts of the questionnaire were answered by children or adolescents with the help of their parents. Second, due to the fear of COVID-19 spreading during the period of data collection, information was collected online, which may affect the quality of the data collected. Therefore, subsequent follow-up studies may be required in which data collection should be face to face. Third, the results of this study were influenced by the time period the research was conducted, the level of adherence to social distancing restrictions by family members, and the level of children and adolescents' vulnerability to the virus.

Conclusion and Recommendation

The purpose of this study was not to provide a final diagnosis of psychological disorders. Rather, it was to establish a sense of what children and adolescents have been facing during home isolation and social distancing in Qatar. Screening for psychological and social disruptions is of importance to develop reintegration strategies in schools, and for health care providers to assess and monitor behavioral changes and negative psychological impacts post–COVID-19. Children and adolescents experiencing higher levels of anxieties should be provided with extra attention during reintegration and transitional phases in schools, as they might express persistent worry, irritability, and perceive situations or people as threatening, which may negatively impact their performance in school and the ways in which they interact with their peers.

Although electronic devices and social media platforms may have lowered anxiety levels in some cases and promoted more interconnectedness during the COVID-19 pandemic among people on a community level, it is important to address how these platforms are used and how content is tailored to children and adolescents. Some platforms may not be well designed for children under 18 years of age; parents and caretakers should not only set boundaries on how much time each child or teenager spends on electronic devices, they should also navigate and audit content accessed online. Another aspect that must be taken into consideration by parents and caregivers is the importance of maintaining an active lifestyle for their children and not neglecting their physical health. This can be activated by following sports enthusiasts and athletes on social media platforms or following fitness channels broadcasting daily in-home exercises. Finally, continuity of care for children and adolescents should be ensured during all phases of the pandemic by parents and health care providers.

Conflicts of Interest

None declared.

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Abbreviations

ANOVA: analysis of variance
CAS: Clinical Anger Scale
DSM-5: Diagnostic and Statistical Manual of Mental Disorders, 5th Edition

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HIM: Health Information Management
KADS: Kutcher Adolescent Depression Scale
PHCC: Primary Health Care Corporation
SARS: severe acute respiratory syndrome
SCAS: Spence Children’s Anxiety Scale

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Original Paper

Estimating the Proportion of COVID-19 Contacts Among Households Based on Individuals With Myocardial Infarction History: Cross-sectional Telephone Survey

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Abstract

Background: Adults with cardiovascular diseases were disproportionately associated with an increased risk of a severe form of COVID-19 and all-cause mortality.

Objective: The aims of this study are to report the associated symptoms for COVID-19 cases, to estimate the proportion of contacts, and to describe the clinical signs and behaviors among individuals with and without myocardial infarction history among cases and contacts.

Methods: A 2-week cross-sectional telephone survey was conducted during the first lockdown period in France, from May 4 to 15, 2020. A total of 668 households participated, representing 703 individuals with pre-existing cardiovascular disease in the past 2 years and 849 individuals without myocardial infarction history.

Results: High rates of compliance with health measures were self-reported, regardless of age or risk factors. There were 4 confirmed COVID-19 cases that were registered from 4 different households. Based on deductive assumptions of the 1552 individuals, 9.73% (n=151) were identified as contacts, of whom 71.52% (108/151) were asymptomatic. Among individuals with a myocardial infarction history, 2 were COVID-19 cases, and the estimated proportion of contacts was 8.68% (61/703), of whom 68.85% (42/61) were asymptomatic. The cases and contacts presented different symptoms, with more respiratory signs in those with a myocardial infarction history.

Conclusions: The telephone survey could be a relevant tool for reporting the number of contacts during a limited period and in a limited territory based on the presence of associated symptoms and COVID-19 cases in the households. This study advanced our knowledge to better prepare for future crises.

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KEYWORDS

COVID-19; survey; myocardial infarction; cases; contacts; household; estimate; cross-sectional; cardiovascular; risk; symptom

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Introduction

With more than 100 million confirmed cases worldwide, COVID-19 has caused more than two million deaths in the world from December 2019 to May 2020 [1]. With the appearance of the first cases on January 24, 2020, the health situation in France rapidly deteriorated as in most neighboring countries. The cumulative incidence rate exceeding 10 COVID-19 cases per 100,000 inhabitants in some areas during the week of March 10, 2020 [2]. The French government announced a strict lockdown period from March 17 to May 11, 2020 (ie, 1 month and 25 days) [3].

The need for early and accurate diagnosis for suspected cases become obvious for effective management and for keeping control of the disease spread [4]. Virological tests (reverse transcription polymerase chain reaction [RT-PCR]) have routinely been used to confirm diagnosis, providing results within a few hours. Recent studies have revealed that the computed tomography (CT) scan of the chest was more sensitive but did not replace the RT-PCR that remained the gold standard (sensitivity about 60%-71%) in diagnosing patients with a COVID-19 infection [5,6]. Although serological tests can inform if individuals were exposed to the virus and if they presumably developed immunity, the poor analytical performance can create confusion and may lead to false reassurances, especially when carried out on large populations that have yet to be exposed to the virus and in the absence of a gold standard comparative method [7] at the time of this study. When a COVID-19 diagnosis has been confirmed, chest CT has a central place in the management of respiratory symptoms but cannot be generalized at the scale of the whole population. Therefore, the need to find a more reliable method for estimating prevalence had to be addressed.

At the time of this study, the potential of population surveys in identifying COVID-19 contacts among households may have been underestimated. Existing surveys were designed to assess qualitative data such as risk perception, social isolation, or behavioral disorders [8,9]. Since the symptoms are now well documented in the literature [10] and the tests are more widespread, telephone surveys could also be useful to estimate symptomatic and asymptomatic COVID-19 contacts. Moreover, the most severe forms of COVID-19 and the overall risk of all-cause mortality were disproportionately associated with older adults because of age and pre-existing conditions [11-14].

The main objective was to report the diagnosed COVID-19 cases and the associated symptoms in households with at least one individual with pre-existing myocardial infarction. The second objectives were to estimate the symptomatic and asymptomatic contacts during the 55-day lockdown period in France (March 17 to May 11, 2020) based on deductive assumptions and to describe the clinical signs and behaviors among individuals with or without myocardial infarction history among the cases and contacts.

Methods

Study Design

A 2-week cross-sectional telephone survey was conducted, from May 4 to 15, 2020, corresponding to the last week of lockdown in France and the 5 following days (the average period of incubation [15]). The sample comprised households with at least one individual with pre-existing myocardial infarction, collected in the *Observatoire des Syndromes Coronariens Aigus du Réseau Cardiologie Urgence (OSCAR, RESCUe)* (OSCAR) registry and occurring in the Auvergne Rhône-Alpes region in France.

Sample Selection

The eligible households were identified through inclusions in the OSCAR registry, a multicentric prospective observational registry of the regional emergency cardiovascular network (RESCUe) [16]. Funded by the Regional Agency for Health (*Agence Régionale de Santé Auvergne Rhône-Alpes*), the network covers 3 million inhabitants located in the second most important region in France, including 10 large volume hospitals, representing more than 400 percutaneous coronary interventions per year. The OSCAR registry was approved by the French National Commission of Informatics and Liberties (Commission Nationale de l'Informatique et des Libertés; number 2013090 v0), and all the participants gave informed and oral consent. Patients included were associated with persistent chest pain with ST segment elevation of at least 2 mm in at least two continuous leads.

In this study, the 1164 myocardial infarctions listed in the OSCAR registry were extracted, which occurred between September 3, 2018, and December 10, 2019, discharged at home, and successfully reached by telephone at least once for cardiological follow-up. With events dating less than 2 years and the inclusion criteria chosen, the chances of successfully reaching households by telephone were increased. The patients discharged to dependent older adult homes were excluded.

Investigator Training

A total of 17 investigators were involved in the telephone interviews. They were trained by a 15-year experienced telephone operator for two 2-hour meetings with practical instructions (see Multimedia Appendix 1) and simulations by role playing exercises. The training sessions included information on the context to setting up the survey, the methodology, the construction of the sampling frame and eligibility criteria, the conduct of the questionnaire, and the contact phase. After a brief presentation of the study, investigators collected the oral consent from the first respondent to allow the collection of anonymous data for all individuals living in the household during the lockdown period. Interviews took place between 10 AM and noon, and between 1 PM and 6 PM. If no response was received, three other telephone attempts were made at different time slots and days.

Ethical Approval

In accordance with French regulations, an individual information note was addressed, after the telephone interview, by email or

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postal mail to the household to explain the purpose of the study and the rights after data collection.

Data Collection

The survey items were elaborated based on a scoping review of the PubMed scientific literature and depending on the World Health Organization symptom list, as updated at the time of the study. The item selection was validated by two emergency physicians, especially the symptoms and the disease's history (see Multimedia Appendix 1). The investigator collected information from the first individual of the household who picked up the phone. This first respondent answered for all the individuals living in the household. The questionnaire comprised of a common part relating to the household in general and another part relating to each individual living in the household during the lockdown period. The common part relating to the household consisted of identifying the place of residence (zip code and city name), the number of individuals, and any possible regular contacts of a third person (home nurse or home helper). In addition to the items on COVID-19 symptoms observed since March 1, 2020, the questionnaire for individuals comprised sociodemographic items (age, sex, weight, height, occupation), the respect of precautionary behaviors (physical distancing, contact outside home, number of outings per week), pre-existing comorbidities and treatments, travels to high risk areas in France or abroad, and the results of nasal or blood testing or chest CT scan. Moreover, it included the delivered, reported, or renounced consultation during the lockdown period and if another individual of the household was hospitalized or deceased from COVID-19.

Definition and Assumptions

When an individual was confirmed to be COVID-19 positive, all the other individuals living in the household were considered as contacts [17,18]. A COVID-19 contact was also defined when they had been in contact with a confirmed case since March 1, 2020, or had a relative from the same household not present at the time of the survey who was hospitalized or deceased from COVID-19.

Statistical and Geographical Analysis

To determine the representativeness of the study sample, the open-source data from the French Institute of Statistics and Economic Studies was used to compare the respondents included in the survey to the inhabitants living in the same area, based on a two-stage approach by age [11] and sex [19].

To report the proportion of COVID-19 cases and to estimate the contacts, baseline characteristics in numbers and percentages were provided for categorical variables and medians and IQRs for continuous variables. Bivariate analyses were assessed using the Fisher exact test for categorical variables and the nonparametric Wilcoxon rank test for continuous variables. Statistical analyses were performed using R 3.6.2 software (R Foundation for Statistical Computing). The level of significance was set at a P value <.05. When frequencies were insufficient (<10) to provide a statistical test value, an em dash was used.

The missing data represented less than 1%, except for the BMI (10.12%). The denominator was specified when different from the total number.

To describe the clinical signs among symptomatic individuals, a network-based approach [20] was used where the nodes represented an association of symptoms (reported by at least two individuals), linked by shared symptoms. Individuals with and without myocardial infarction history were compared. As the small number of observations did not allow for the proposal of a statistical test, a descriptive approach was proposed to represent the common symptoms.

Results

Inclusions

A total of 1164 eligible households from the OSCAR registry were identified. The investigators made 1052 call attempts in a 2-week telephone survey, with an average of 1.63 calls per household. A total of 668 households gave their consent to participate, representing 1552 individuals (Figure 1).

The initial response rate was about 63.49% (668/1052) and the participation rate was about 88.70% (668/753). A total of 134 individuals living alone during the lockdown period (ie, 20.06% of the 668 households) was observed. Additionally, 703 individuals with a myocardial infarction history were reported (ie, 45.30% of the 1552 individuals). The proportions of women (777/1552, 50.06%) and men (775/1552, 49.94%) were balanced. However, the study sample included older individuals compared to the resident households of the area (Figure 2).

The sample of men aged 30-44 years was three times less than the inhabitants of the survey area, and there were twice as many men between the ages of 60-64 years.

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Figure 1. Flowchart of the panel sample selection and the final inclusions households and individuals with myocardial infarction history (patients) and without myocardial infarction history. OSCAR: Observatoire des Syndromes Coronariens Aigus du Réseau Regional Emergency Cardiovascular Network.

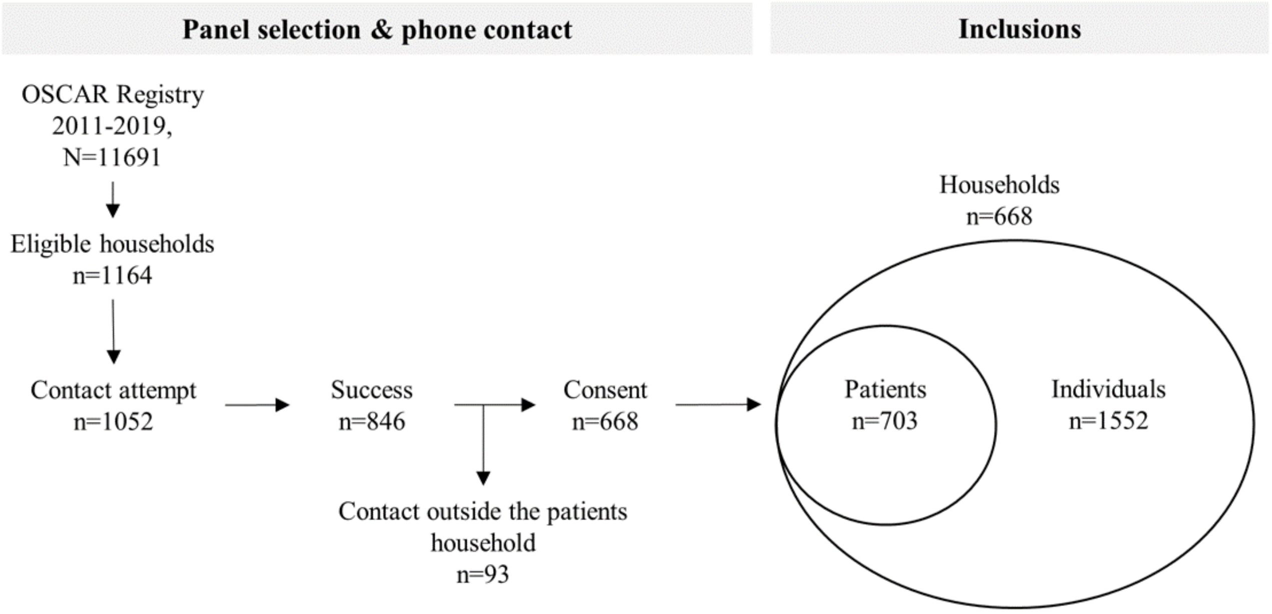

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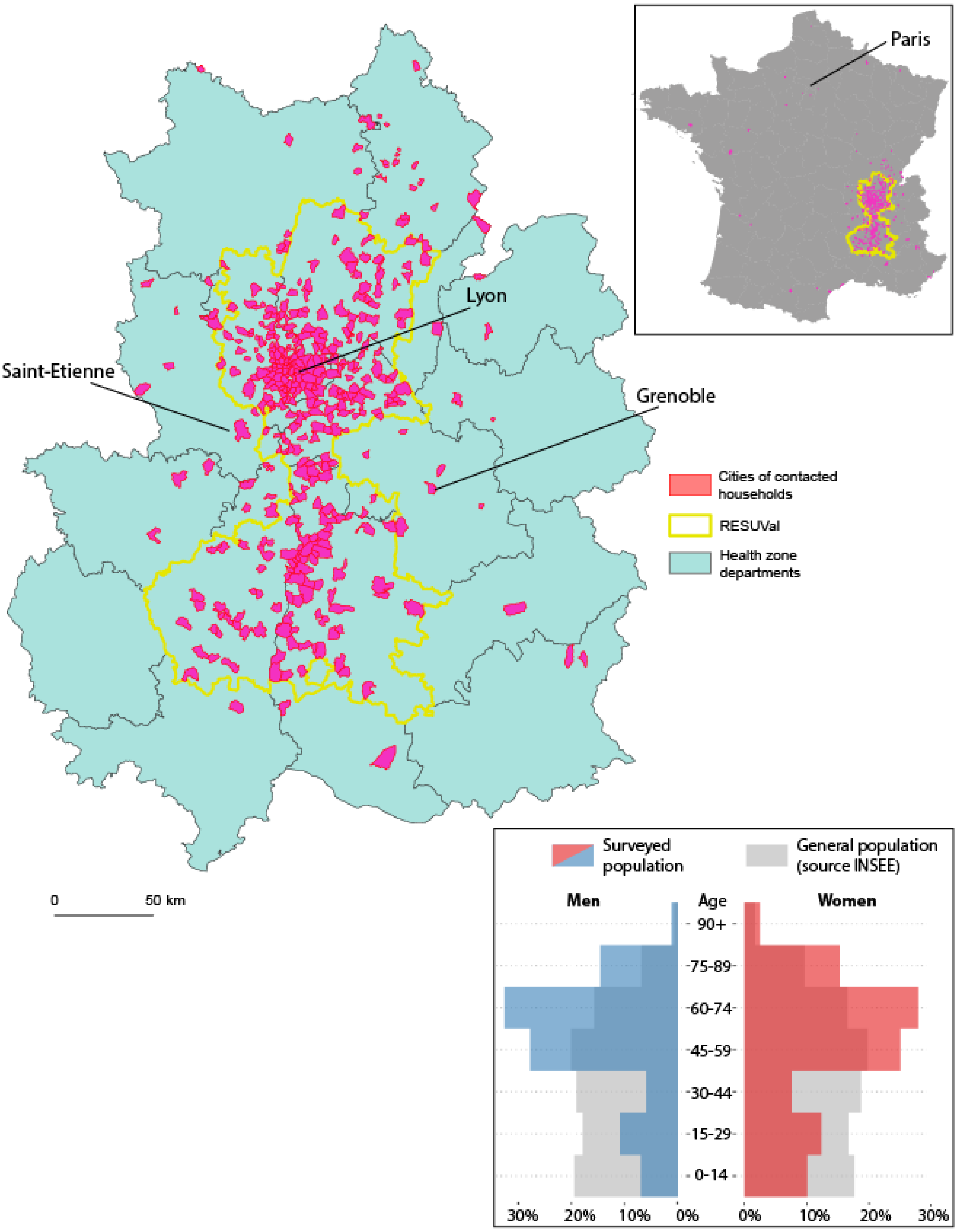
Figure 2. Territorial coverage and age and sex representativeness of the households included in the telephone survey (N=1552 in France for n=1507 in the RESUVal area and its adjacent departments). INSEE: Institut national de la statistique et des études économiques.



Risk Behavior and Risk Factors

High rates of compliance with health measures were self-reported by individuals, regardless of age or risk factors. Among the 1373 individuals who did not work at their usual workplace (ie, 88.47% of the total 1552 sample), 98.69% (n=1355) were confined, 98.69% (n=1355) maintained physical distances, 29.42% (n=404) had no contact with individuals outside their household during the lockdown period, and 23.89% (n=328) went out only once per week. Only 14.2% (n=95) of the 668 households were regularly visited by a caregiver or a nurse. Among the individuals at risk (age ≥60 years with at least one comorbidity; n=709), 98.59% (n=699) complied with the lockdown and 99.15% (n=703) complied with keeping physical distances.

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Less than a third of the 1552 individuals were vaccinated against influenza A H1N1 (n=510, 32.86%). This proportion reached 49.93% (n=351) among the 703 individuals with myocardial infarction history. Nearly a quarter (n=314, 20.23%) of the sample presented at least one COVID-19 symptom. There were more symptomatic individuals with myocardial infarction history observed (169/703, 24.04% vs 143/847, 16.88%; *P*<.001). These groups of individuals were significantly associated with different risk factors and comorbidities (Table 1).

Table 1. Risk factors and history of the 1552 included individuals with and without myocardial infarction history (two missing values).

Characteristics	Without myocardial infarction history		With myocardial infarction history		*P* value for total	*P* value for symptomatic
	Total (n=847)	Symptomatic (n=143)	Total (n=703)	Symptomatic (n=169)		
Risk factors						
Age (years), median (IQR)	49 (19-65)	56 (43-69)	64 (55-74)	63 (55-74)	<.001	<.001
Active smoker (age≥15 years), n/N (%)	138/716 (19.27)	23/137 (16.79)	83/701 (11.84)	24/168 (14.29)	<.001	.63
BMI≥30, n/N (%)	73/733 (9.96)	18/136 (13.24)	92/661 (13.92)	26/162 (16.05)	.02	.51
Hypertension, n (%)	98 (11.57)	22 (15.38)	176 (25.04)	54 (31.95)	<.001	<.001
Diabetes, n (%)	53 (6.26)	12 (8.9)	118 (16.79)	35 (20.71)	<.001	<.001
Heart failure, n (%)	6 (0.71)	4 (2.80)	64 (9.10)	30 (17.75)	—[a]	—
History, n (%)						
Asthma	23 (2.72)	6 (4.20)	17 (2.42)	6 (3.55)	.75	—
Rheumatism/polyarthritis	26 (3.07)	13 (9.09)	35 (4.98)	22 (13.02)	.75	.77
Cancer	23 (2.72)	6 (4.20)	33 (4.69)	8 (4.73)	.04	—
Hypothyroidism	30 (3.54)	13 (9.09)	16 (2.28)	6 (3.55)	.17	—
Stroke/stroke-like	6 (0.71)	3 (2.10)	32 (4.55)	5 (2.96)	—	—
Renal disease	4 (0.47)	2 (1.40)	21 (2.99)	7 (4.14)	—	—
Respiratory failure	7 (0.83)	0 (0.00)	18 (2.56)	8 (4.73)	—	—
Neurologic disease	8 (0.94)	1 (0.70)	13 (1.85)	7 (4.14)	—	—
Chronic obstructive pulmonary disease	5 (0.59)	2 (1.40)	11 (1.56)	4 (2.37)	—	—
Immune disease	5 (0.59)	1 (0.70)	7 (1.00)	2 (1.18)	—	—
Liver disease	3 (0.35)	1 (0.70)	5 (0.71)	0 (0.00)	—	—
Emphysema	2 (0.24)	1 (0.70)	5 (0.71)	1 (0.59)	—	—
Oxygen at home	1 (0.12)	0 (0.00)	4 (0.57)	1 (0.59)	—	—
Other (ie, dyslipidaemia)	39 (4.60)	12 (8.39)	57 (8.11)	14 (8.28)	<.001	>.99

[a] Not available because frequencies were insufficient to provide a statistical test value.

Symptomatology

The proportion of individuals associated with COVID-19–like symptoms was 20.23% (314/1552), of whom 50.3% (158/314) reported only one symptom. Among the 314 symptomatic individuals, the most frequent symptoms were cough (n=93, 29.6%), headaches (n=85, 27.1%), runny nose (n=79, 25.2%), unusual fatigue (n=65, 20.7%), fever (n=58, 18.5%), and sore throat (n=49, 15.6%).

A total of 37 distinct symptom associations were reported by at least two individuals (Figure 3), 20 associations for individuals with myocardial infarction history (n=95), and 17 associations for individuals without myocardial infarction history (n=97).

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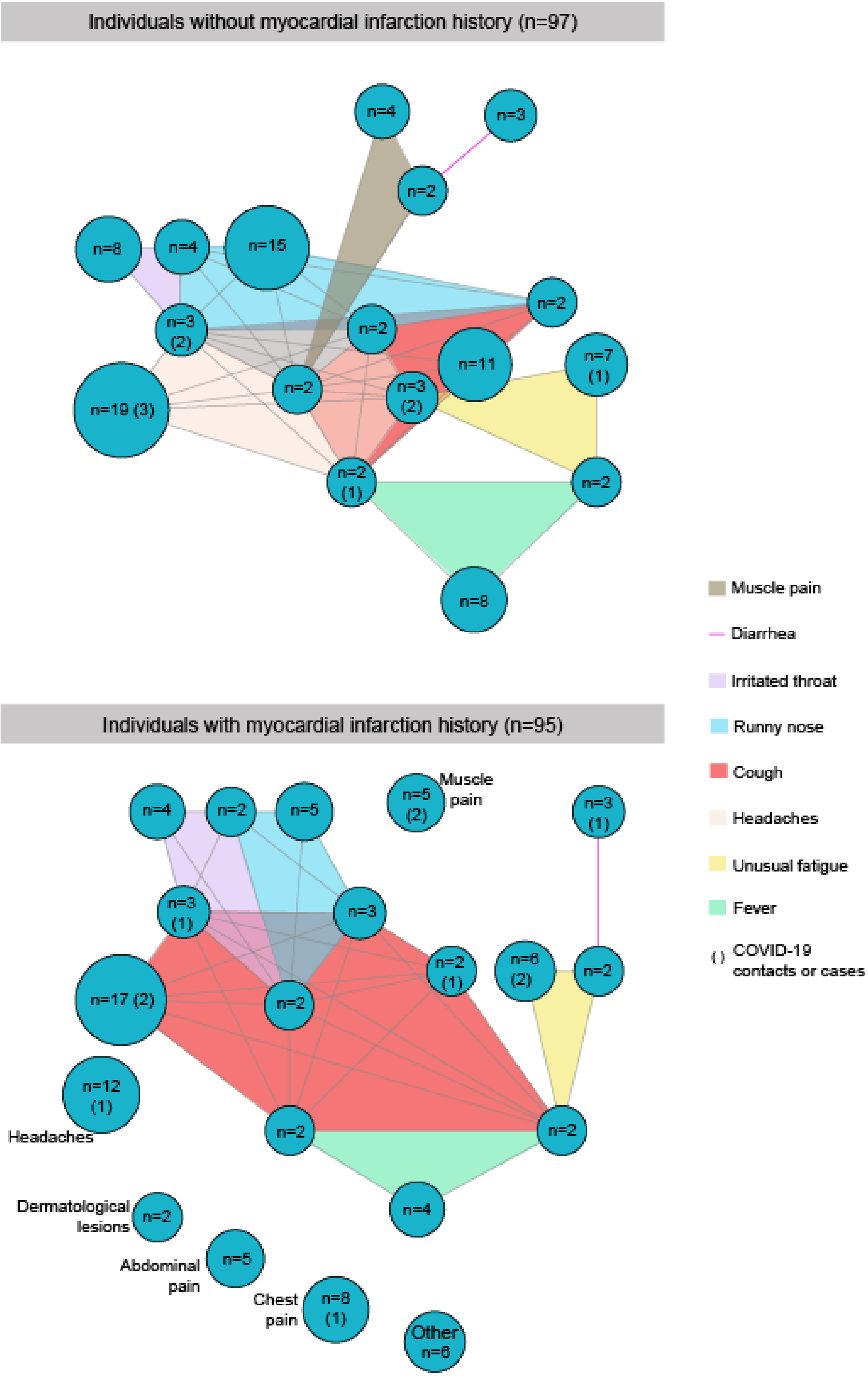
Figure 3. Symptom network of associations reported by at least two individuals: comparison of the reported clinical signs between individuals without myocardial infarction history (n=97) and with myocardial infarction history (n=95).



Individuals with myocardial infarction history were more associated with an isolated symptom compared to other individuals, accounting for 40% (38/95): headache, chest pain, muscle pain, abdominal pain, and dermatological lesions. To illustrate, among individuals without pre-existing myocardial infarction, headaches were frequently associated with other symptoms like runny nose, cough, sore throat, fever, unusual fatigue, or muscle pain. Among individuals with myocardial infarction history, the most associated symptom was cough with sore throat, runny nose, unusual fatigue, and fever. Among the 47 symptomatic individuals (43 contacts and 4 cases), 20 were observed at least twice (in parenthesis in Figure 3).

Consultation and Diagnostic Tests

Only 38.85% (n=122) of the 314 symptomatic individuals consulted a general practitioner during the lockdown period

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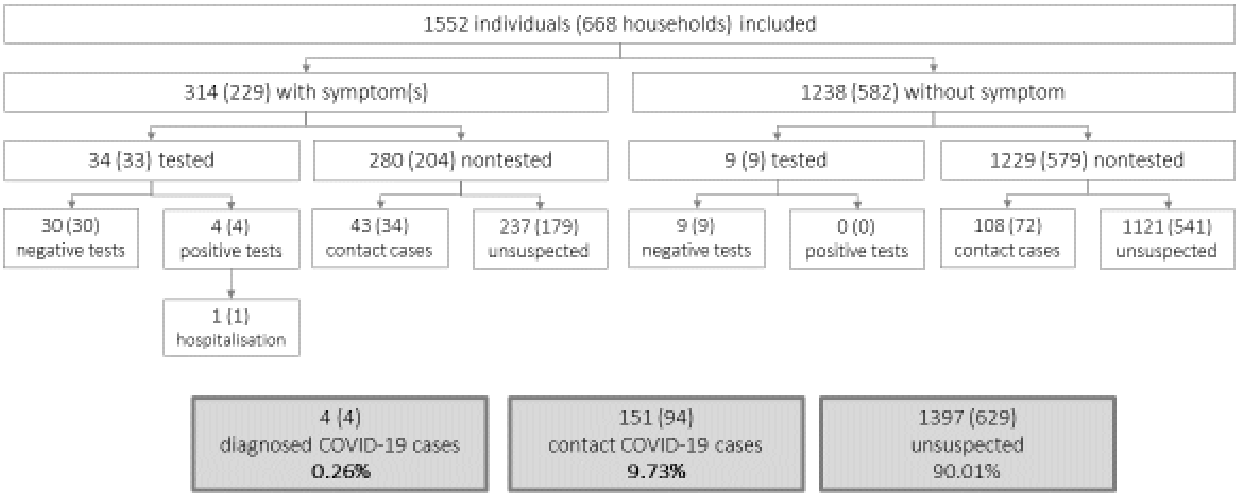
because of their symptoms; 68.03% (83/122) of them went to the doctor's office, 15.6% (19/122) used a telemedicine service, and 16.4% (20/122) visited the emergency department. Only 2.77% (43/1552) of individuals were tested. The test processes were RT-PCR in 56% (24/43), chest CT in 23% (10/43), and blood tests in 44% (19/43). Only 34 (10.83%) tests were performed among the 314 symptomatic individuals with four positive results leading to one hospitalization (Figure 4; 1 by RT-PCR, 1 by blood tests, 1 by chest CT scan, and 1 by all three tests).

Figure 4. Final reporting of the testing process among individuals and households sampled.



The proportion of confirmed COVID-19 cases was 0.26% (4/1552) of individuals, and the proportion of contacts was 9.73% (151/1552), of whom 71.52% (108/151) were asymptomatic (Figure 4). In the subgroup of individuals with myocardial infarction history, two individuals were COVID-19 confirmed among four positive tests, 8.68% (61/703) of contacts, of which 68.85% (42/61) were asymptomatic contacts.

Scheduled Consultations for Patients During the Lockdown Period

Nearly a quarter of individuals (369/1552, 23.78%) had their appointments rescheduled at the physician's initiative, but these delays were more common among individuals with myocardial infarction history (259/703, 36.8% vs 110/847, 13%; *P*<.001). Among them, 7.54% decided on their own to cancel an appointment (vs 3.78%; *P*=.001), and 9.10% decided to report it (vs 2.72%; *P*<.001). In 76.07% (89/117) of those cases, the appointment was related to a medical follow-up (vs 67.27%; *P*=.25).

Discussion

Principal Results

A network-based approach was provided to understand the different clinical signs associated with contacts of COVID-19. Individuals with myocardial infarction history and who were identified as contacts based on deductive assumptions were most likely to have respiratory symptoms such as cough, sore throat, runny nose, and fever, whereas other individuals presented nonspecific signs (eg, headaches or muscle pain).

The initial response rate of 63.49% (668 included households out of 1052 contact attempts) showed that the telephone survey is a suitable and feasible study design to address such a research question in a short period of time [21]. This proportion of participation is probably due to the population availability during the lockdown period and to their high interest in this unprecedented pandemic situation. If a paper questionnaire had been sent by postal envelope or surveyed through an online questionnaire, the participation rate would have been much lower [22]. The period of the survey—the last week of lockdown and first week post lockdown—was considered appropriate to study the lockdown period, as the mean incubation period lasts 5 days [15].

The study sample also provided estimations on adherence to precautionary measures during the lockdown period with a high compliance rate in our high risk population. This compliance with precautionary measures might explain why only one hospitalization was recorded and the absence of death. Relatives that were susceptible had adapted their behavior as to not expose the individual with myocardial infarction history at risk of infection in the household. Nevertheless, it cannot assume that precautions were observed by the whole population, especially among healthier and younger individuals [23].

Limitations

Although the sample was not representative of the inhabitants of the territory, the included population constitutes an exhaustive population of myocardial infarction history, focusing on middle-aged and older adult individuals. The literature has established that the latter are associated with higher mortality compared to young or middle-aged individuals [23]. The sample study would be associated with higher risk of complications or hospitalization if it included 45.30% of individuals with myocardial infarction history. Previous studies stated that

16.40% of the patients hospitalized with COVID-19 were associated with cardio-cerebrovascular diseases [24]. In addition to these risk factors, of the included individuals, 15.60% were active smokers, 11.84% were obese, and 11.03% had diabetes [25-27].

In addition, the public health measures that aim to prevent or control transmission in the community [28] were hammered at the same time by the mainstream media and by health professionals [29], and were compulsory under penalty in public places in France. As a consequence, there might be a bias since respondents may have felt compelled to self-report that they respected them [30].

Comparison With Prior Work

Since the prevalence of COVID-19 is unknown, this cross-sectional survey was considered to be a useful and rapid means of understanding the pandemic situation at a given time and local place [31]. In France, a telephone survey was conducted in an emergency medical dispatching center at the same period of this study, based on COVID-19 cases only, to better characterize the patients managed in an outpatient setting 12 hours after positive testing [21]. Considered as a telemedicine solution, the telephone survey is an alternative to face-to-face consultations during the COVID-19 pandemic [9], and self-reported symptoms are nonetheless clinical signs possibly associated with COVID-19 [32].

Although time series models allow us to understand the trends of the outbreak and to estimate the different epidemiological stages, there is still a need of a reliable and easy to implement solution to evaluate the situation in a high risk population. These findings were not intended to be extrapolated in a predictive model given that the epidemic was spreading unevenly throughout France. Conducted at the end of the lockdown period in France, this survey was presumed to be relevant for a limited area due to the uneven distribution of infection rates across France. Indeed, the Auvergne Rhône-Alpes region was moderately affected compared to the Grand Est and Ile de France regions in the same period [33]. Nevertheless, outcomes such as risk behaviors and symptoms remain declarative responses and subject to approximations.

Conclusions

A cross-sectional telephone survey was conducted by selecting households from a prospective observational registry of individuals with myocardial infarction history. A low proportion of COVID-19 diagnosis tests was observed, with only 10.62% (34/320) of symptomatic individuals who had been tested over the study period. The estimated proportion of contacts was about 8.68% (61/703) of the respondents with prior history of myocardial infarction, of which 68.85% (42/61) were asymptomatic. These estimates were relevant at several levels; first, they showed that a telephone survey could be a relevant tool for rapidly assessing the number of contacts on a limited territory; second, they could be a useful tool for the local institutional structures for advising and reporting the current situation. In addition to keeping a social link during lockdown and with high risk populations in our territory, these estimates advanced our knowledge to better prepare for future crises.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Phone survey.
[DOCX File , 20 KB - formative_v5i4e26955_app1.docx]

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Abbreviations

CT: computed tomography
OSCAR: Observatoire des Syndromes Coronariens Aigus de RESCUe
RESCUe: Réseau Cardiologie Urgence / Regional emergency cardiovascular network
RT-PCR: reverse transcription polymerase chain reaction

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Original Paper

Characterization and Comparison of the Utilization of Facebook Groups Between Public Medical Professionals and Technical Communities to Facilitate Idea Sharing and Crowdsourcing During the COVID-19 Pandemic: Cross-sectional Observational Study

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Abstract

Background: Strict social distancing measures owing to the COVID-19 pandemic have led people to rely more heavily on social media, such as Facebook groups, as a means of communication and information sharing. Multiple Facebook groups have been formed by medical professionals, laypeople, and engineering or technical groups to discuss current issues and possible solutions to the current medical crisis.

Objective: This study aimed to characterize Facebook groups formed by laypersons, medical professionals, and technical professionals, with specific focus on information dissemination and requests for crowdsourcing.

Methods: Facebook was queried for user-created groups with the keywords “COVID,” “Coronavirus,” and “SARS-CoV-2” at a single time point on March 31, 2020. The characteristics of each group were recorded, including language, privacy settings, security requirements to attain membership, and membership type. For each membership type, the group with the greatest number of members was selected, and in each of these groups, the top 100 posts were identified using Facebook’s algorithm. Each post was categorized and characterized (evidence-based, crowd-sourced, and whether the poster self-identified). STATA (version 13 SE, Stata Corp) was used for statistical analysis.

Results: Our search yielded 257 COVID-19–related Facebook groups. Majority of the groups (n=229, 89%) were for laypersons, 26 (10%) were for medical professionals, and only 2 (1%) were for technical professionals. The number of members was significantly greater in medical groups (21,215, SD 35,040) than in layperson groups (7623, SD 19,480) ($P<.01$). Medical groups were significantly more likely to require security checks to attain membership (81% vs 43%; $P<.001$) and less likely to be public (3 vs 123; $P<.001$) than layperson groups. Medical groups had the highest user engagement, averaging 502 (SD 633) reactions ($P<.01$) and 224 (SD 311) comments ($P<.01$) per post. Medical professionals were more likely to use the Facebook groups for education and information sharing, including academic posts ($P<.001$), idea sharing ($P=.003$), resource sharing ($P=.02$) and professional opinions ($P<.001$), and requesting for crowdsourcing ($P=.003$). Layperson groups were more likely to share news ($P<.001$), humor and motivation ($P<.001$), and layperson opinions ($P<.001$). There was no significant difference in the number of evidence-based posts among the groups ($P=.10$).

Conclusions: Medical professionals utilize Facebook groups as a forum to facilitate collective intelligence (CI) and are more likely to use Facebook groups for education and information sharing, including academic posts, idea sharing, resource sharing, and professional opinions, which highlights the power of social media to facilitate CI across geographic distances. Layperson groups were more likely to share news, humor, and motivation, which suggests the utilization of Facebook groups to provide comedic relief as a coping mechanism. Further investigations are necessary to study Facebook groups' roles in facilitating CI, crowdsourcing, education, and community-building.

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KEYWORDS

cognitive intelligence; communication; COVID-19; crowdsourcing; evidence-based; Facebook; Facebook groups; internet; social media; virtual communities

Introduction

SARS-CoV-2, first discovered in Wuhan, China, on December 31, 2019, has quickly spread among >16 million individuals worldwide by June 2020 [1], and has resulted in the disruption of activities of daily life [2,3]. Social distancing has emerged as a method of reducing the transmission of COVID-19 and includes government-recommended or -mandated policies to "remain at home" or quarantine. Strict social distancing measures have led people to rely more heavily on social media as a means of communication and information sharing [4], including crowdsourcing (using resources from many people to obtain a final goal). Forums that facilitate discussion and sharing of ideas, such as Facebook groups, allows for the democratization of information and permits the development of quick collaborations to allow for the allocation of resources and advancement of science and technology. Social media has played a critical role in the COVID-19 pandemic, as multiple social media forums were developed by medical professionals, laypeople, and engineering or technical groups to discuss current issues and possible solutions to the current medical crisis.

However, despite the benefits of message sharing and crowdsourcing on social media platforms, studies have shown that social media platforms can lead to the propagation of misinformation [5]. With the rapid dissemination of information through unregulated forums, it is often difficult to distinguish evidence-based posts and forums from those that are not validated or originate from a credible source. For example, during the COVID-19 pandemic, there has been great debate on whether social media platforms have bred unnecessary fear and facilitated the spread of misinformation [6]. While social media is a powerful medium for communication, it can also result in conflicting information and negative societal impacts. Consequently, it is critical to understand how social media can be used effectively, especially during unprecedented times such as the current COVID-19 pandemic. The CoV-IMPACT consortium has called for "the development of a real-time information sharing system, drawing from data and analyses from a range of social media platforms, in multiple languages and across the global diaspora" [7]. Furthermore, social media has been used by medical professionals and researchers to communicate and form virtual communities through groups. In this study, we aim to characterize Facebook groups formed by laypersons, medical professionals, and technical professionals, with specific focus on information dissemination and requests for crowdsourcing.

Methods

Recruitment

Facebook was queried for user-created Groups with the keywords "COVID," "Coronavirus," and "SARS-CoV-2" at a single time point on March 31, 2020. The characteristics of each group were recorded, including language (ie, English or non-English), privacy setting (ie, public or private), security requirement to attain membership, and membership type (ie, laypersons, medical professionals, or technical professionals). For each membership type, the group with the greatest number of members was selected, and in each of these groups, the top 100 posts were identified using Facebook's algorithm. Each post was characterized by category and subcategory, whether it was evidence-based or crowdsourced, and whether the poster self-identified. The coding scheme for category and subcategory was developed independently by 3 investigators (Table 1). Metrics were also recorded for these groups (ie, number of members and posts, adjusted to time on Facebook) and for posts (number of comments and number of reactions). Posts with duplicated content were discarded to avoid oversaturation of the sample.

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Table 1. Predetermined coding framework for post categories.

Subcategories	Example posts
Education and information sharing	
News	“Official statement from Dr. Peter Tsai, inventor of the electrostatic charging technology that makes the filter media of face masks including medical and N95.”
Academic	“I created these quick sheets (PDF and images) for non-ICU clinicians (medical or surgical) who may find themselves taking care of critically ill patients.”
Question	“Has anyone seen patients whose presenting symptom was only abdominal pain (no diarrhea)?”
Personal experience	“We recently had a COVID patient with a cimino fistula with thrombosis of the fistula.”
Resource	“As you know, the CARES act passed a few days ago and it is 800 pages long. There are a lot of provisions in it that may help you, whether you run a small business or are an employee of a health care facility.”
Movement-based advocacy	“Stay Home Stay Safe.”
Supply and equipment	
Idea sharing	“Here is a link to a google doc on how to make one yourself.”
Request for resources (demand)	“We need a way to make more. Can you help produce these?”
Offer to provide resources (supply)	“I’m in Miami looking to donate some face shields locally does anyone here need?”
Networking	“Anyone here been in touch with the NHS… Any contacts appreciated.”
Opinions	
Professional	“To summarize, treat your patients as individuals. If they have compliant lungs but are hypoxemic, use PEEP cautiously, and if they are not PEEP responsive, don’t persist in trying to treat them for a disease they probably don’t have.”
Layperson	“I have remained fairly calm since January when the news broke, but today I find myself sad and weeping for all that the world has suffered.”
Conspiracy theory	“Russia and anti-vaxxers are spreading disinformation about COVID-19 and 5G.”
Humor and motivation	
Humor	“‘What’s parenting during lockdown like?”
Support for health care workers	“We love you guys....thank you for saving life in this hard time”
Inspiration	“Raise your hand if you know what it’s like to lose everything and rebuild your life from scratch.”
Mental health visibility	“For all the health care providers and unsung heroes on the front lines: nothing can “fix” these feelings, but maybe naming them and noticing them can make them a little easier to bear.”

Statistical Analysis

STATA (version 13 SE, Stata Corp) and Python (version 3.7.7, Python Software Foundation) were used for statistical analysis. Demographic data were tabulated and stratified by the type of group (medical, layperson, or technical). Hypothesis testing was conducted with a Cronbach α of .05. To compare membership volume across Facebook groups, a Mann–Whitney *U* test for nonparametric data was used. A Kruskal–Wallis test was used to compare the volume of reactions and comments for the top 100 posts across various types of Facebook groups. Planned posthypothesis testing was conducted using the Dunn test. Lastly, the chi-square test was conducted to compare evidence basis by group type for the top 100 posts.

Results

Group Characteristics

Our search on March 31, 2020, yielded 257 COVID-19–related Facebook groups (Table 2). Majority of the groups (n=229, 89%) were for laypersons, 26 (10%) were for medical professionals, and only 2 (1%) were for technical professionals. While the mean number of group members was 9203, groups ranged widely in size from 1 to 185,340 members. A Mann–Whitney *U* test indicated that overall, the number of members was significantly greater in medical groups (21,215, SD 35,040) than in layperson groups (7623, SD 19,480) (*P*<.01) (Figure 1 and Table 3). The mean number of group posts per day was 62 (range 0-625). Almost half of the groups were public (n=128, 50%); layperson groups (n=123, 54%) were more likely to be public than medical groups (n=3, 12%; *P*<.001). The majority of groups (n=218, 85%) predominantly operated in English, with no significant difference among layperson, medical, and technical groups (Figure 1).

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Table 2. Characteristics of COVID-19–related Facebook groups (N=257).

Group characteristics	Value
Type of group, n (%)	
Layperson	229 (89)
Medical	26 (10)
Technical	2 (1)
Number of members, mean (range)	9203 (1-185,340)
Number of posts per day, mean (range)	62 (0-625)
Privacy setting, n (%)	
Public	128 (50)
Private	129 (50)
Security requirement to join the group, n (%)	
Yes	121 (47)
Request	114 (44)
No	22 (9)
Language, n (%)	
English	218 (85)
Non-English	39 (15)

Figure 1. Characteristics of COVID-19–related Facebook groups by group type.

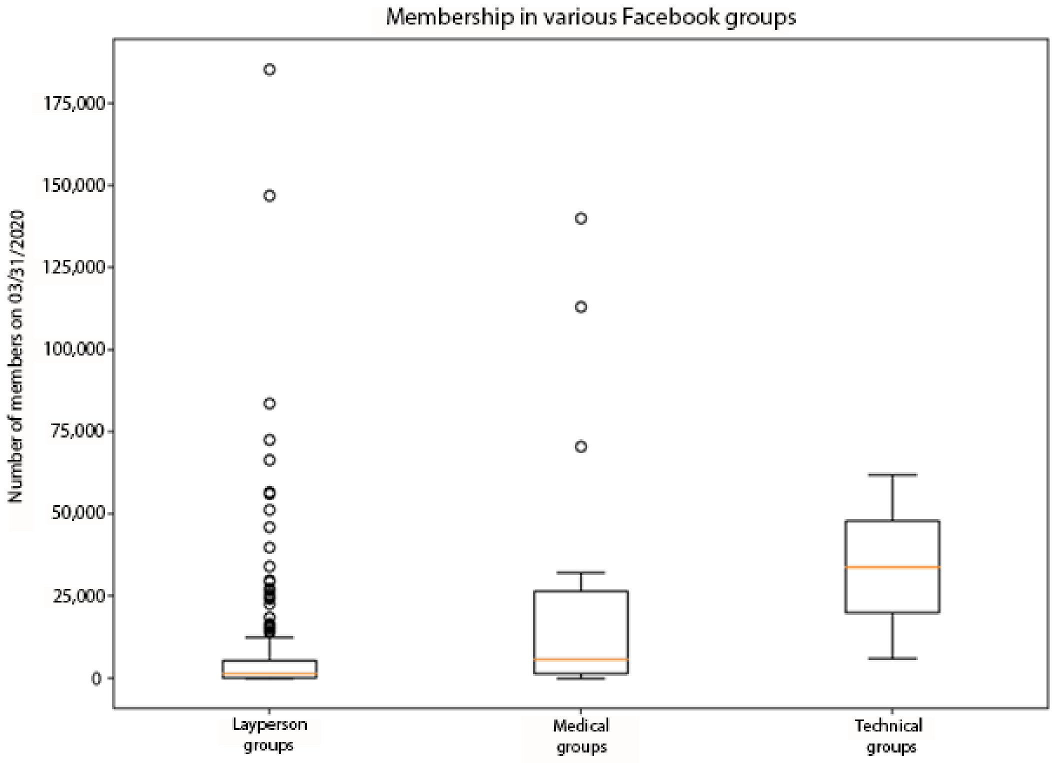

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Table 3. Characteristics of layperson, medical, and technical groups.

Characteristics	Groups		
	Layperson	Medical	Technical
Number of members, mean (SD)	7623 (19,480)[a]	21,215 (35,040)[a]	33,948 (39,578)
Public privacy setting, n (%)	123 (54)[b]	3 (12)[b]	2 (100)
Security requirement to attain membership, n (%)			
Yes	98 (43)[c]	21 (81)[c]	2 (100)
Request	110 (48)	4 (15)	0
No	21 (9)	1 (4)	0
English language, n (%)	193 (84)	20 (77)	2 (100)

[a] Significant difference in the number of members between layperson and medical groups ($P<.01$).

[b] Significant difference in public privacy setting between layperson and medical groups ($P<.001$).

[c] Significant difference in the presence of security requirements to attain membership between layperson and medical groups ($P<.001$).

Nearly all groups required prospective members to submit a request or to answer security questions to attain membership (n=235, 91%) (Figure 1). Medical groups were significantly more likely to require security checks to attain membership (ie, providing practice numbers, identification, verification of physicians, and agreement to the terms of the group) than layperson groups (81% vs 43%; $P<.001$). Among medical groups, the majority were private groups (n=23, 88%) that enforced security settings, with 4 groups (15%) that required requests, and only 1 (4%) that had no security settings. Similarly, both technical groups required security requirements to attain membership (n=2, 100%). In contrast, 98 (43%) layperson groups had security requirements, 110 (48%) had requests to join, and 21 (9%) had no security requirements.

When investigating the gender of the Facebook group creator (male, female, or organization; Figure 2 and Table 4), layperson groups were more likely to be created by a male (n=131, 56.7%) rather than a female creator (n=86, 37.2%) ($P<.001$). Male creators were more common in non-English layperson groups than female creators (66.7% vs 28.2%; $P<.001$). Medical and technical groups were equally likely to be formed by a male or female creator. Facebook groups formed by organizations accounted for 14 (6.1%) layperson groups, 1 (5%) medical group, and no technical group.

Figure 2. Gender of the creator of COVID-19–related Facebook groups by group type.

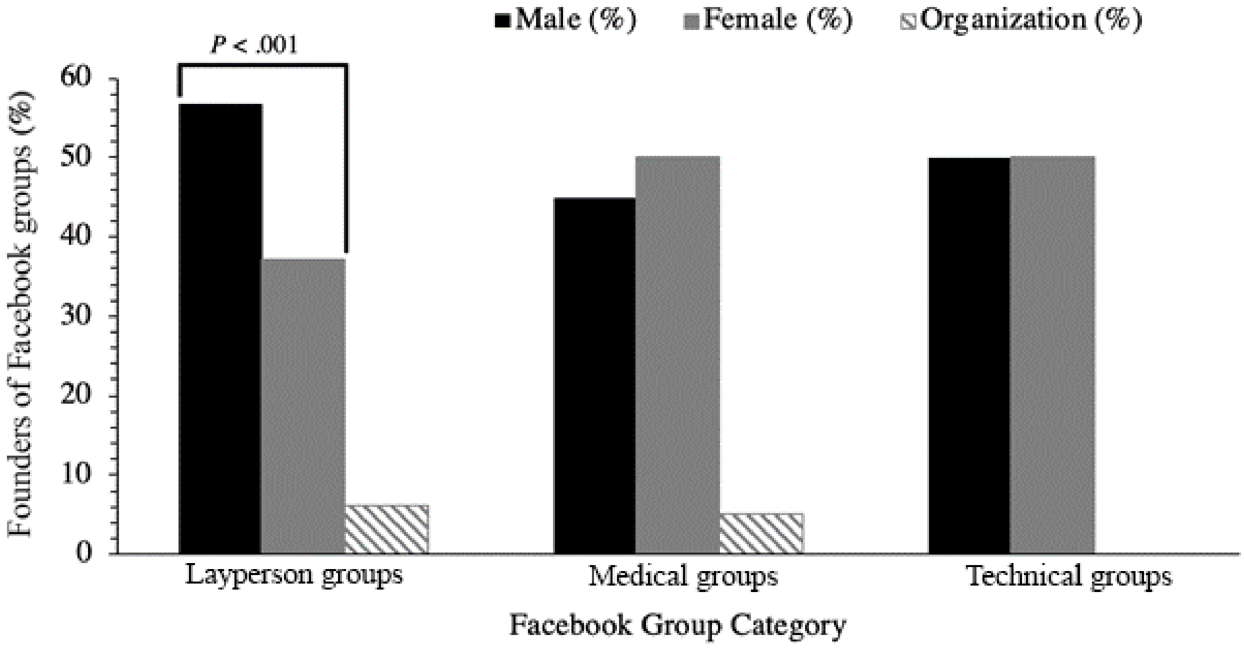

Table 4. Distribution of creator genders (male, female, or organization) among layperson, medical, and technical groups.

Groups	Creator gender		
	Male, n (%)	Female, n (%)	Organization, n (%)
Layperson	131 (56.7)	86 (37.2)	14 (6.1)
Predominantly English language	105 (54.7)	75 (39.1)	12 (6.3)
Predominantly non–English language	26 (66.7)	11 (28.2)	12 (6.3)
Medical	9 (45.0)	10 (50.0)	1 (5.0)
Technical	1 (50.0)	1 (50.0)	0 (0.0)

Post Characteristics

The largest layperson group (CoronaVirus International) was formed in late January 2020, while the largest medical (COVID-19 USA Physician/APP Group) and technical (Open Source COVID19 Medical Supplies) groups were formed in mid-March 2020. As of this writing, CoronaVirus International had 185,340 members, averaged at 333 posts per day, operated predominantly in English, and required answering security questions to attain membership. COVID-19 USA Physician/APP Group had 140,018 members, averaged at 100 posts per day, operated predominantly in English, and required answering security questions to attain membership. Open Source COVID19 Medical Supplies had 61,935 members, operated predominantly in English, and required security questions to attain membership.

Medical groups had higher user engagement, averaging at 502 (SD 633) reactions (*P*<.01) and 224 (SD 311) comments (*P*<.01) per post than layperson (182, SD 265 reactions and 104, SD 207 comments per post) and technical (165, SD 216 reactions and 80, SD 86 comments per post) groups (Figure 3 and Table 5).

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Figure 3. Average number of reactions and comments among the top 100 posts of COVID-19–related Facebook groups by group type.

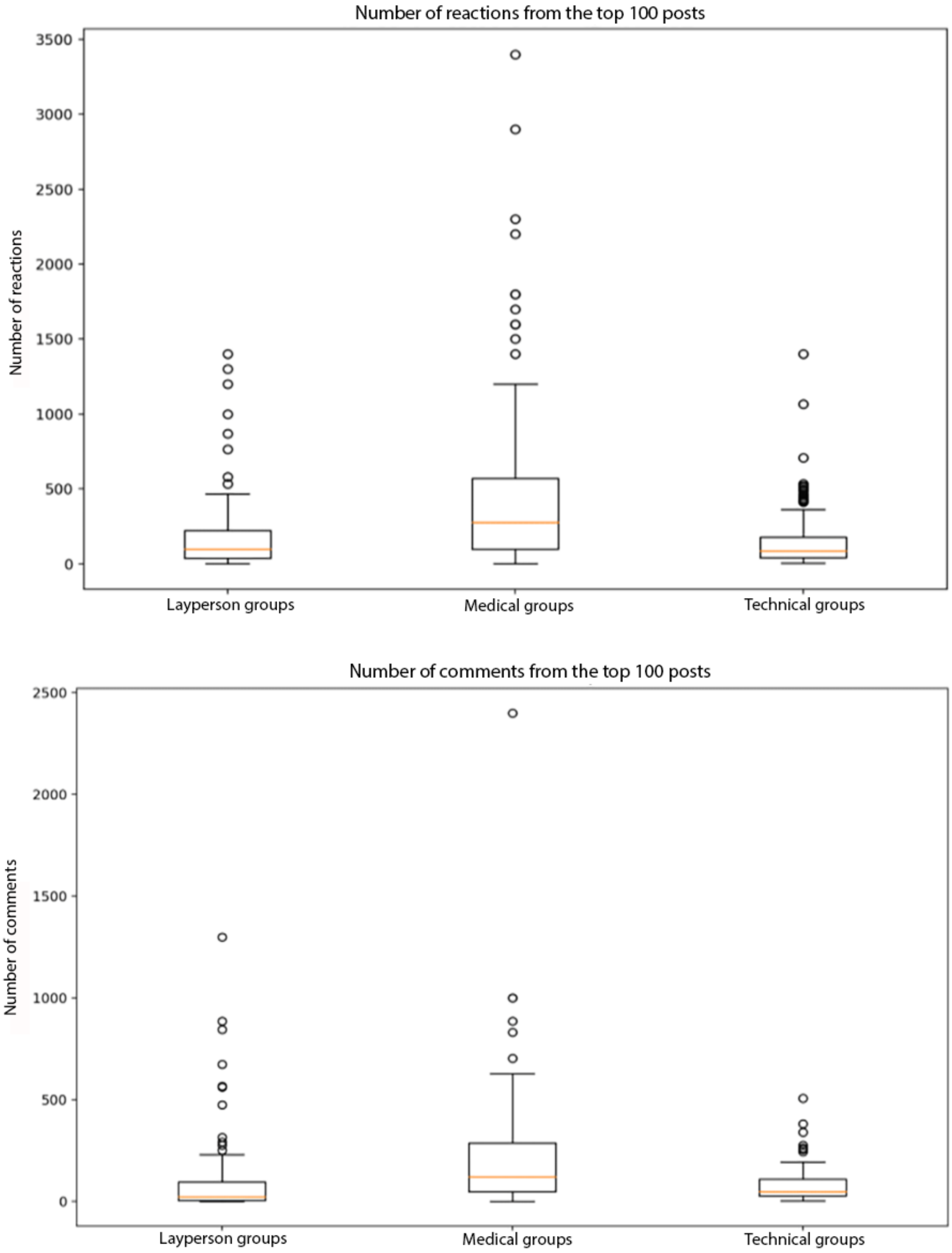

Table 5. Member engagement in layperson, medical, and technical groups.

Engagement types	Groups			*P* value[a]
	Layperson	Medical	Technical	
Number of reactions, mean (SD)	182 (265)	502 (633)	165 (216)	<.01
Number of comments, mean (SD)	104 (207)	224 (311)	80 (86)	<.01

[a] *P* values for comparisons between layperson and medical groups.

On comparing the characteristics of the posts by groups (Table 6), layperson and medical groups had predominantly education and information sharing posts. Layperson groups had more posts that shared news about COVID-19 (31 vs 10; *P*<.001), while medical groups had more evidence-based posts (21 vs 4; *P*<.001). Technical groups predominantly contained posts related to supply and equipment sharing (n=99) compared to layperson and medical groups (*P*<.001), the majority sharing ideas (n=72), followed by posts related to networking (n=11), requests for resources (n=9), and offers to provide resources (n=7). Medical groups had more posts related to supply and equipment than layperson groups (17 vs 3; *P*<.001), including posts sharing ideas (11 vs 1; *P*<.001). Medical groups provided more professional rather than layperson opinions (18 vs 0; *P*<.001), while layperson groups provided more layperson opinions (12 vs 1; *P*<.001). For each layperson or medical

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professional group, there was only one post. Layperson groups were more likely to share posts related to humor and motivation than medical groups (29 vs 3; *P*<.001), including humor (21 vs 0; *P*<.001) and inspiration (4 vs 0; *P*<.001).

Medical group posters were significantly more likely to self-identify (91 vs 1; *P*<.001), and more likely to request crowdsourcing in the group (38 vs 19; *P*<.001) than their counterparts in layperson groups. There was no significant difference in the number of evidence-based posts among the 3 group types, with 28 evidence-based posts in layperson groups, 39 in medical groups, and 42 in technical groups (*P*=.10).

Table 6. Comparison of the characteristics of the top 100 posts by group type.

Types of posts	Groups			*P* value[a]
	Layperson	Medical	Technical	
Categories, n				
Education and information sharing	55	60	1	.48
News	31	10	0	<.001
Academic	4	21	0	<.001
Question	11	14	1	.52
Personal experience	5	7	0	.55
Resource	1	8	0	.02
Movement-based advocacy	3	0	0	.08
Supply and equipment	3	17	99[b]	<.001
Idea sharing	1	11	72	.003
Request for resources (demand)	2	2	9	.99
Offer to provide resources (supply)	0	1	7	.32
Networking	0	2	11	.16
Opinion	13	20	0	.18
Professional	0	18	0	<.001
Layperson	12	1	0	.002
Conspiracy theory	1	1	0	.99
Humor and motivation	29	3	0	<.001
Humor	21	0	0	<.001
Support for health care workers	4	2	0	.41
Inspiration	4	0	0	.04
Mental health visibility	0	1	0	.32
Evidence-based, n				.10
Yes	28	39	42	
No	72	61	58	
Crowdsourced, n				.003
Yes	19	38	42	
No	81	62	58	
Poster self-identified, n				<.001
Yes	1	91	12	
No	99	9	88	

[a] *P* values for differences between layperson and medical groups.

[b] *P*<.001 on comparing between layperson and medical groups.

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Discussion

Background

Information sharing on social media has become mainstream during the COVID-19 pandemic. In a matter of weeks, over 257 new groups were formed on Facebook, including those formed by laypersons, medical professionals, and technical professionals. In this study, we characterize how Facebook group activities surrounding the COVID-19 pandemic differ among layperson, medical, and technical groups, including members, user engagement, and types of posts.

Principal Findings

Medical groups are more likely to be private, and require security questions and agreement with group policies, and posters were more likely to self-identify (providing details including their name, specialty, and location of practice) in accordance with the community rules, which is suggestive of a more professional community compared to layperson groups. Despite the heavier security, medical groups on average had more members than layperson groups (Figure 1 and Table 3) and higher engagement, with a larger number of reactions and comments per post (Figure 3 and Table 5). Strikingly, when characterizing the top 100 posts by group type, medical professionals were more likely to use Facebook groups for education and information sharing, including academic posts (P<.001), posts sharing ideas (P=.003), posts sharing resources (P=.02), and professional opinions (P<.001). Medical professionals were also more likely to request crowdsourcing than laypersons, asking questions about patient management and resources such as personal protective equipment. Together, this evidence suggests that medical professionals intentionally utilize Facebook groups as a forum to facilitate collective intelligence (CI) to compensate for the dynamic and unfamiliar evidence and guidance surrounding COVID-19 and associated treatments. CI is the “wisdom of crowds” [8], which refers to collective insight obtained from these groups [9-11], and has the potential to generate more accurate information or medical decision-making than individuals [12-14]. While previous studies on CI in medicine include activities such as case conferences and tumor boards [8], social media has been proposed as a facilitator of health information sharing [15] and CI across geographic distances [16]. Our findings highlight the power of social media to facilitate CI not only beyond geographic distances but also across additional physical barriers of strict social distancing practices owing to the COVID-19 pandemic, and intellectual barriers where conventional avenues of information searching and consulting are not yet available. Further studies are necessary to investigate whether participation in Facebook groups improves the knowledge base of medical professional participants and whether Facebook group CI influences decision-making.

However, layperson groups were more likely to share news (P<.001), humor and motivation (P<.001), and layperson opinions (P<.001) than medical groups. Layperson groups were less likely to crowdsource, and only 3% of posts were related to movement-based advocacy (such as “#stayathome”). This suggests that laypersons utilize the Facebook groups to form a community to share emerging news and share humor and inspiration, potentially to provide comedic relief as a coping mechanism. The COVID-19 pandemic has resulted in drastic shifts in day-to-day living for many individuals, including measures such as working from home, social isolation, adoption of hand hygiene, and wearing masks. These changes were rapid and may result in anxiety and distress among laypersons. Humor has been well evidenced as an adaptive mechanism for stress [17] and to reduce anxiety [18,19], enhance mood [19], and as a potential tool for psychotherapy [20-25]. The role of news sharing and providing humor and inspiration is analogous to that of a virtual support group, with the potential to connect individuals and foster reflections and conversations [26,27]. Consequently, it may be important for health care professionals to utilize these layperson Facebook groups to communicate with and educate laypeople and to understand their perspectives and experiences during the COVID-19 pandemic, provide supporting resources, and potentially facilitate grassroot movements (such as “#stayathome” and “#wearamask”).

The technical groups assessed in this study are a unique example of using Facebook groups for crowdsourcing, idea sharing, and networking worldwide. In total, 99 of the 100 top posts in the technical group analyzed herein were in regard to supply and equipment, 72 of which were related to idea sharing, such as open-sourcing designs for personal protective equipment, progress in designs for ventilators and ventilator splitters, etc. These groups had more evidence-based and crowdsourced posts than medical and layperson groups. The technical group serves as an example of the benefits and new standard of using Facebook groups for crowdsourcing and CI to cope with challenging times.

Layperson groups were significantly more likely to be formed by males. Surprisingly, this was not the case in medical and technical groups, where the group creators displayed an equal male:female gender distribution. This suggests that despite gender disparities in social media leadership positions globally, this gender gap is not evident in social media usage among medical professionals. Previous studies have reported that women in medicine in particular turn to social media for mentorship and networking [28,29] and that social media is a potential gender equalizer in medicine [30]. However, this does not discount persistent biases that may persist in Facebook group interactions. Consequently, additional studies are required to investigate how social media interactions occur and influence gender roles in medicine.

Comparison With Prior Studies

Recent studies evaluating the utility of information sharing on social media have focused on negative effects including rapid dissemination of false information [5,7,9,10]. Misinformation propagated by social media is not unique to the COVID-19 pandemic. Previous studies have reported that only 53% of health-related posts by medical professionals on Twitter are supported by medical evidence [10]. Additionally, studies of social media posts related to the Ebola pandemic in 2014 reported a similar rate of false information [9,11]. Our study similarly reveals a small fraction of posts that are evidence-based, with an equal likelihood of a layperson’s post

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versus a medical professional's post to be evidence-based (28 vs 39; *P*=0.10). Only 1% of posts from both medical and layperson groups were conspiracy theories, suggesting that a potential paucity of information surrounding the COVID-19 pandemic may explain the low number of evidence-based posts. Regardless, the potential to rapidly propagate misinformation on social media could be dangerous, in both medical professional and layperson groups. Layperson groups in particular, may benefit from a moderator or peer "champions" [31] to encourage evidence-based discussions and respectful user engagement.

Previous studies have also described the potential of Facebook groups as support groups and for community-building among patients [31-33], or the medical community as an educational tool to facilitate discussion, community-building, material sharing [34], and mentorship [35]. Our study complements this body of literature and highlights that virtual community-building on Facebook groups is accelerated during unprecedented times, such as the current COVID-19 pandemic. However, future studies are required to understand virtual community interactions and recommendations for the formation of impactful and secure Facebook groups.

Limitations

A potential limitation to our study is the assumption that our findings are representative of the global culture of Facebook groups or other social media forums. We recognize that our study merely involves a small sample from among immensely diverse Facebook groups and the different communities that contribute to each group and the resulting culture. Furthermore, as a cross-sectional study, our data represent only 1 time point of the dynamic content on the social media platform. Our findings serve as a beachhead to establish the importance of understanding social media responses to the COVID-19 pandemic and its potential to facilitate CI, crowdsourcing, and community-building.

Conclusions

In this study, we characterize how Facebook group activities surrounding the COVID-19 pandemic differ among layperson, medical, and technical groups. Medical professionals utilize Facebook groups as a forum to facilitate CI and are more likely to use the Facebook groups for education and information sharing, including academic posts, idea sharing, resource sharing, and professional opinions. Our findings highlight the power of social media to facilitate CI not only beyond geographic distances but also across additional physical barriers of strict social distancing practices resulting from the COVID-19 pandemic. Layperson groups were more likely to share news, humor, and motivation, which suggests the utilization of Facebook groups to provide comedic relief as a coping mechanism. Further studies are required to study the role of Facebook groups in facilitating CI, crowdsourcing, education, and community-building.

Conflicts of Interest

None declared.

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Abbreviations

CI: collective intelligence

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Original Paper

Transitioning to Remote Clinic Visits in a Smoking Cessation Trial During the COVID-19 Pandemic: Mixed Methods Evaluation

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Abstract

Background: The pandemic of SARS-CoV-2, which causes COVID-19, has caused disruptions in ongoing clinical trials and is expected to accelerate interest in conducting research studies remotely.

Objective: A quasi-experimental, mixed methods approach was used to examine the rates of visit completion as well as the opinions and experiences of participants enrolled in an ongoing clinical trial of smoking cessation who were required to change from in-person clinic visits to remote visits using video or telephone conferencing due to the COVID-19 pandemic.

Methods: For quantitative comparisons, we used a quasi-experimental design, comparing a cohort of participants followed during the pandemic (n=23, COVID-19 cohort) to a comparable cohort of participants followed over a similar time period in the calendar years 2018 and 2019 (n=51, pre–COVID-19 cohort) to examine the rates of completion of scheduled visits and biospecimen collection. For the qualitative component, interviews were conducted with participants who experienced the transition from in-person to remote visits.

Results: Participants in the COVID-19 cohort completed an average of 83.6% of remote clinic visits (95% CI 73.1%-91.2%), which was not significantly different than the in-person completion rate of 89.8% in the pre–COVID-19 cohort. Participants in the COVID-19 cohort returned an average of 93.2% (95% CI 83.5%-98.1%) of saliva specimens for remote clinic visits completed, which was not significantly different than the in-person saliva specimen completion rate of 100% in the pre–COVID-19 cohort. Two broad themes emerged from the qualitative data: (1) the benefits of remote visits and (2) the challenges of remote counseling compared to in-person counseling. Despite limited experience with telehealth prior to this transition, most participants expressed a willingness to engage in remote visits in the future.

Conclusions: Even in the context of a rapid transition from in-person to remote visits necessitated by the COVID-19 pandemic, rates of visit completion and return of biospecimens remained high. Participants were generally accepting of the transition. Further research is needed to identify the optimal mix of in-person and remote visits beyond the pandemic context and to better understand how these changes may impact study outcomes.

Trial Registration: ClinicalTrials.gov NCT03262662; https://clinicaltrials.gov/ct2/show/study/NCT03262662

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KEYWORDS

smoking; cessation; clinical trial; telehealth; COVID-19; coronavirus; telemedicine; conferencing; mixed methods; experience; patient

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Introduction

Recent reviews have examined the growing interest in conducting remote trials for smoking cessation by incorporating existing applications for cell phones and other technology [1-3]. However, transitioning from the more traditional approach, in which study participants return for assessments at a research center, to a more decentralized design raises multiple implementation issues, including study recruitment and screening, completion of informed consent, follow-up assessments, biomarker collection, and medication adherence monitoring [1]. Although technology currently exists to support decentralized assessments, data collection, and other procedures, the processes of these transitions and their impact on participant and clinician experiences remains unclear [4-9].

The SARS-CoV-2 outbreak, which led to the COVID-19 pandemic, has caused disruptions in ongoing clinical trials and is expected to accelerate interest in conducting research studies remotely. Many trials were suspended for varying periods of time, while others were forced to transition from in-person to remote visits. In this context, the COVID-19 pandemic experience provided a unique opportunity to examine quantitative and qualitative data, albeit nonexperimentally, regarding the impact on relevant intermediate study outcomes such as completion of visits and return of biomarker specimens, as well as to consider participant perspectives on the transition and their preferences and recommendations for in-person versus remote visits.

This paper uses a quasi-experimental, mixed methods approach to examine the opinions and experiences of participants enrolled in an ongoing clinical trial of smoking cessation who were required to change from in-person clinic visits to remote visits using video or telephone conferencing due to the COVID-19 pandemic. The quantitative component allows for direct (albeit nonexperimental) comparisons among a group of participants on objective measures of effect, which is complemented by qualitative data regarding the experiences and opinions of research participants. For quantitative comparisons, we used a quasi-experimental design, comparing a cohort of participants followed during the pandemic to a comparable cohort of participants followed over a similar time period in the calendar years 2018 and 2019 to examine rates of completion of scheduled clinic visits and biospecimen collection. We tested whether rates of visit completion and saliva collection were lower for remote visits than for in-person visits. For the qualitative approach, interviews were conducted with a subset of participants who experienced the transition from in-person to remote visits.

Methods

Clinical Trial

Our ongoing randomized clinical trial examines the impact of an alternative varenicline dosing strategy to enhance rates of cessation among treatment-seeking adult cigarette smokers [10]. Following prescreening and completion of a baseline visit, eligible participants are randomized to one of two varenicline dosing regimens and scheduled for 6 clinic visits over a 2-month period, during which survey measures are completed, biospecimens are collected, and brief individual cessation counseling is delivered. Study outcomes include bio-verified continuous abstinence at end-of-treatment and at 6 months; the focus of this paper is on the active treatment phase of the study.

In March 2020, accruals to this trial were on target when the COVID-19 pandemic forced us to rapidly implement changes to our procedures. One of the primary changes involved a transition from in-person counseling to remote counseling via Zoom (Zoom Video Communications, Inc) or telephone calls (when Zoom was not feasible for the participant) for the 23 participants who had already begun the treatment phase but had not yet completed all clinic visits (ie, the COVID-19 cohort).

Study Design

A mixed methods approach, based on a concurrent embedded framework, was used to explore the impact of transitioning to remote clinic visits in a smoking cessation trial during the COVID-19 pandemic. A quasi-experimental design provided quantitative data to compare clinic visit completion rates among the COVID-19 cohort to a comparable cohort of participants with clinic visits that were scheduled during a similar time period in the calendar years 2018 and 2019 (ie, the pre–COVID-19 cohort). Qualitative methods [11] were used to examine the experiences of in-person versus remote clinic visits completed via video or telephone conferencing among a subgroup of participants enrolled in an ongoing clinical trial of smoking cessation. Participants in both cohorts must have had at least one additional clinic visit remaining after having completed a clinic visit during the transitional time period (March-April 2020) or during a parallel interval in 2018 or 2019. Qualitative interviews were conducted with 15 of the 23 participants (65%) in the COVID-19 cohort.

A mixed methods design with a convergent approach was used to inform a more comprehensive understanding of the impact of transitioning from in-person to remote clinic visits by integrating both qualitative and quantitative data instead of only relying on one of these data sources. The quantitative data test the major outcomes of the quasi-experimental condition, while the qualitative data provide important insights about the process from people's experiences [12,13].

Study Participants

The parent research project (ClinicalTrials.gov NCT03262662) continues to enroll eligible treatment-seeking cigarette smokers between the ages of 18 and 70 years in a randomized clinical trial evaluating extended pre-quit varenicline pharmacotherapy for smoking cessation. Following intake and randomization, each clinical trial participant is scheduled to complete 6 in-person clinic visits (at weeks 0, 1, 3, 4, 6 and 8, respectively) as well as 2 follow-up appointments to assess long term abstinence. At each in-person clinic appointment, participants complete blood pressure and exhaled carbon monoxide (CO) assessments, fill out self-administered questionnaires, provide a saliva sample, receive brief behavioral counseling, and receive a supply of study medication.

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COVID-19 Cohort

For the current investigation, we focused on a COVID-19 cohort, defined as participants (n=23) who had completed at least 1 in-person clinic visit in a 2-week transition window immediately before the PAUSE executive order was issued in New York State and had at least 1 of 6 clinic visits remaining (range: 1-5 remaining visits). In other words, these participants completed clinic visit #1, 2, 3, 4, or 5 during the 2-week transition period. The PAUSE executive order, issued in mid-March 2020, suspended 100% of nonessential business activities, including clinical research.

During the transition window clinic visit, participants were provided with their remaining supply of study medication and remote visit packets containing instructions, paper copies of self-administered questionnaires, behavioral counseling handouts, and at-home saliva sample collection kits, along with postage-paid envelopes for returning the surveys and specimens. Procedures for either telephone or Zoom meetings were also briefly reviewed.

For the remaining clinic visits, the questionnaires could be completed by following an email link to the surveys programmed in Research Electronic Data Capture (REDCap) or by filling out paper copies of the measures included in the remote visit packets. Participants received audio (telephone) or audiovisual (Zoom) instructions to guide saliva sample collection. To return the remote clinic visit packet to the study investigators, participants sealed their completed questionnaires and saliva specimen in a large padded envelope with pre-paid postage that could be picked up by their mail carrier.

Pre–COVID-19 Cohort

For comparative purposes, we retrospectively reviewed records to identify a comparator cohort of study participants who had completed an in-person clinic visit during the same 2-week time frame (March 18 to April 2) in the calendar year 2018 or 2019 and had 1 or more (range 1-5) remaining clinic visits scheduled (ie, the pre–COVID-19 cohort). Participants followed during 2018 and 2019 did not significantly differ with regard to demographic or tobacco use characteristics and were combined into a single pre–COVID-19 cohort (n=51).

Measures

Baseline Variables

We examined participant age, sex, race/ethnicity, household income, highest level of education completed, Fagerstrom Test of Cigarette Dependence (FTCD) cigarettes per day at time of enrollment, and baseline exhaled carbon monoxide level across the COVID-19 and pre–COVID-19 cohorts. The FTCD is a 6-item self-reported scale used to assess the severity of dependence on cigarettes; the level of dependence is inversely correlated with the ability to successfully quit [14,15].

Dependent Variables

We focused on the percentage of clinic visits completed and the rates of biospecimen (saliva) collection after the last in-person visit for the COVID-19 cohort and after the comparable in-person visit for the pre–COVID-19 cohort.

Data Analyses

This study relied upon a concurrent design in which quantitative and qualitative data collection and analyses were performed in parallel to yield complementary impressions of the impact of transitioning from in-person interviews and a desire to not burden participants to the extent that it would negatively affect the completion of long-term follow-up visits for participants still participating in the trial [13,16]. Consistent with a contiguous approach to data integration, the quantitative and qualitative results will be reported in different sections, followed by a synthesis of these findings in the *Discussion* section [16].

Quantitative Analyses

Descriptive statistics, t tests, and chi-square tests were used to compare means and categorical distributions by cohort; P values <.05 were considered significant. Analyses were conducted using SPSS, version 26 (IBM Corporation).

Qualitative Analyses

Persons in the COVID-19 cohort were contacted by telephone and invited to participate in a telephone-based structured interview to explore their experiences with transitioning from in-person to remote visits. Interviews were completed shortly after the final scheduled clinic visit (visit #6). Participants were informed verbally of the study aims and provided verbal informed consent; no additional compensation was provided. Interviews were completed by 2 trained research assistants using a structured interview guide. Items in the structured interview addressed how in-person counseling visits compared with remote visits, whether most remote visits were telephone calls or video sessions, desirable and undesirable features of remote visits, challenges encountered during remote visits, experiences with remote survey completion and saliva sample collection, privacy issues regarding in-person and remote visits, prior experience with telemedicine, preferences for remote versus in-person visits, and how changing from in-person to remote visits might have influenced the participant's ability to stop smoking. The interviews lasted an average of 12:48 minutes (range 7:01-26:03), excluding informed consent. Interviews were completed with 15/21 persons (71%); 2 persons did not complete any remote visits and were not contacted, 4 persons declined to participate, and several telephone calls yielded no response for 2 participants. Initial interview audio transcripts were generated by the Zoom software. Individual transcripts were carefully reviewed by a coauthor (NJS), who made minor corrections when necessary to address errors or to improve clarity. This research was approved by the Institutional Review Board (IRB) at the University at Buffalo.

A qualitative descriptive analysis was conducted using a conventional content analysis [17], and ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH) was used for the qualitative coding process. With an inductive approach, each transcript was thoroughly read and coded based on the unit of meanings [18]. Data from all participants were combined and analyzed to identify themes. After the initial coding process, the coding was discussed and reviewed by 2 coauthors (EP and MCM), then grouped and categorized under two main themes: (1) the benefits and (2) the challenges of remote counseling

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compared to in-person counseling. In addition, descriptive statistics were used to report the respondent percentages regarding the platform used (telephone only or video), preferred setting for clinic visits (on-site or remote), previous experiences with telemedicine, future recommendations for visit type, willingness to try telehealth, and the self-perceived impact of remote counseling on quitting success.

Results

Study Participants

Table 1 presents selected demographic, tobacco use, and study completion characteristics for the study participants in the COVID-19 and pre–COVID-19 cohorts (n=23 and 51, respectively). The cohorts were comparable on all demographic and tobacco use characteristics examined. Also, the cohorts did not differ with regard to loss to follow-up (1/23, 4%, vs 0/51, 0%) or withdrawals from the study (1/23, 4%, vs 5/51, 10%).

Table 1. Selected demographic, smoking, and visit attendance characteristics among smoking cessation clinical trial participants by study cohort.

Characteristic	Values		*P* value
	COVID-19 cohort[a] (n=23)	Pre–COVID-19 cohort[b] (n=51)	
Age (years), mean (SD)	53.8 (9.6)	54.8 (9.3)	.68
Female sex, n (%)	10 (44)	28 (55)	.36
Did not self-identify as White, n (%)	7 (30)	12 (24)	.53
Household income <US $50,000, n (%)	9 (39)	19 (37)	.48
High school degree or less, n (%)	9 (35)	15 (29)	.64
Baseline CPD[c], mean (SD)	20.5 (8.4)	19.5 (7.4)	.60
Baseline CO[d], mean (SD)	20.9 (12.1)	16.6 (18.8)	.32
FTCD[e] score, mean (SD)	5.9 (1.8)	6.2 (1.7)	.52
Clinic visits during transition window[f] (range 1-5), mean (SD)	2.8 (1.5)	2.9 (1.4)	.70
Lost to follow-up, n (%)	1 (4)	0 (0)	.13
Withdrew from study, n (%)	1 (4)	5 (10)	.43

[a] COVID-19 cohort: participants with mix of in-person and remote clinic visits due to the COVID-19 pandemic.

[b] Pre–COVID-19 cohort: participants with all in-person clinic visits scheduled during a comparable time period during the calendar years 2018 and 2019.

[c] CPD: cigarettes per day.

[d] CO: exhaled carbon monoxide at baseline visit.

[e] FTCD: Fagerstrom Test for Cigarette Dependence.

[f] Transition window: matching on-site visit during a similar calendar year period in 2018 and 2019.

Quantitative Data

21 of 23 participants in the COVID-19 cohort (91%) completed at least 1 remote clinic visit, while 48 of 51 participants (94%) in the pre–COVID-19 cohort completed at least 1 subsequent in-person visit; withdrawals and loss to follow-up were counted as incomplete visits. As presented in Table 2, participants in the COVID-19 cohort completed an average of 83.6% of their remote clinic visits (95% CI 73.1%-91.2%), which was not significantly different than the in-person completion rate of 89.8% (95% CI 84.0%-94.1%) in the pre–COVID-19 cohort (Table 3). Participants in the COVID-19 cohort returned an average of 93.2% (95% CI 83.5%-98.1%) of saliva specimens for remote clinic visits completed, which was not significantly different from the in-person saliva specimen completion rate of 100% (95% CI 97.4%-100%) in the pre–COVID-19 cohort (see Tables 4 and 5).

When given the option of recommending either in-person or remote clinic visits for a future cessation trial, 11/15 interviewed participants (73%) expressed a preference for a hybrid approach, with 7 participants recommending that future clinic visits be scheduled as a mix of in-person and remote visits and 4 respondents indicating that participants should be permitted to select their own schedule of clinic visits; 3 participants expressed a preference for all in-person visits, and 1 indicated no preference. Also, 13/15 participants (87%) reported that the change from in-person to remote visits had no impact on their ability to stop smoking; 1 participant reported a positive impact, and 1 reported a “potentially negative” impact from this change.

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Table 2. Clinic visit attendance among smoking cessation clinical trial participants for the COVID-19 cohort (n=23).

Last in-person visit	n	Remote clinic visit completion, n (%)[a]					Remote visit attendance (%)
		Visit #2	Visit #3	Visit #4	Visit #5	Visit #6	
Visit #1	5	4 (80)	4 (80)	3 (60)	3 (60)	3 (60)	68
Visit #2	6	N/A[b]	5 (83)	5 (83)	4 (67)	4 (67)	75
Visit #3	4	N/A	N/A	4 (100)	3 (75)	3 (75)	83
Visit #4	4	N/A	N/A	N/A	4 (100)	4 (100)	100
Visit #5	4	N/A	N/A	N/A	N/A	4 (100)	100
Total	23	4 (80)	9 (82)	12 (80)	14 (74)	18 (78)	83.6[c]

[a] Percentages in the Total row are calculated based on the sum of visits in each column.

[b] N/A: not applicable.

[c] 95% CI 73.1%-91.2%.

Table 3. Clinic visit attendance among smoking cessation clinical trial participants by last in-person visit for the pre–COVID-19 cohort (n=51).

Matching in-person visit[a]	n	On-site clinic visit completion, n (%)[b]					On-site visit attendance (%)
		Visit #2	Visit #3	Visit #4	Visit #5	Visit #6	
Visit #1	11	11 (100)	11 (10)	10 (91)	10 (91)	8 (73)	91
Visit #2	9	N/A[c]	7 (78)	7 (78)	7 (78)	7 (78)	78
Visit #3	14	N/A	N/A	14 (100)	14 (100)	13 (93)	98
Visit #4	7	N/A	N/A	N/A	6 (86)	6 (86)	86
Visit #5	10	N/A	N/A	N/A	N/A	10 (100)	100
Total	51	11 (100)	18 (90)	31 (91)	37 (93)	44 (86)	89.8[d]

[a] Matching: on-site visit during a similar period in 2018 and 2019.

[b] Percentages in the Total row are calculated based on the sum of visits in each column.

[c] N/A: not applicable.

[d] 95% CI 84.0%-94.1%.

Table 4. Saliva sample collection rates among smoking cessation clinical trial participants by last in-person visit for the COVID-19 cohort (n=23).

Last in-person visit	n	Remote saliva sample collection, samples/visits completed (%)					Saliva sample collection rate (%)
		Visit #2	Visit #3	Visit #4	Visit #5	Visit #6	
Visit #1	5	3/4 (75)	3/4 (75)	3/3 (100)	3/3 (100)	3/3 (100)	88
Visit #2	6	N/A[a]	5/6 (83)	5/6 (83)	4/4 (100)	4/4 (100)	90
Visit #3	4	N/A	N/A	4/4 (100)	3/3 (100)	3/3 (100)	100
Visit #4	4	N/A	N/A	N/A	4/4	4/4	100
Visit #5	4	N/A	N/A	N/A	N/A	4/4	100
Total	23	3/4 (75)	8/10 (80)	12/13 (92)	14/14 (100)	18/18 (100)	93.2[b]

[a] N/A: not applicable.

[b] 95% CI 83.5%-98.1%.

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Table 5. Saliva sample collection rates among smoking cessation clinical trial participants by last in-person visit in the pre–COVID-19 cohort (n=51).

Matching in-person visit[a]	n	On-site saliva sample collection, samples/visits completed (%)					Saliva sample collection rate (%)
		Visit #2	Visit #3	Visit #4	Visit #5	Visit #6	
Visit #1	11	11/11 (100)	11/11 (100)	10/10 (100)	10/10 (100)	8/8 (100)	100
Visit #2	9	N/A[b]	7/7 (100)	7/7 (100)	7/7 (100)	7/7 (100)	100
Visit #3	14	N/A	N/A	14/14 (100)	14/14 (100)	13/13 (100)	100
Visit #4	7	N/A	N/A	N/A	6/6 (100)	6/6 (100)	100
Visit #5	10	N/A	N/A	N/A	N/A	10/10 (100)	100
Total	51	11/11 (100)	18/18 (100)	31/31 (100)	37/37 (100)	44/44 (100)	100[c]

[a] Matching: on-site visit during a similar period in 2018 and 2019.

[b] N/A: not applicable.

[c] 95% CI 97.4%-100%.

Qualitative Data

Two broad themes emerged from the qualitative data: (1) the benefits of remote visits and (2) the challenges of remote counseling compared to in-person counseling. As presented in Table 6, the benefits of remote clinic visits included not having to travel to in-person appointments (noted by 11 participants), feeling more comfortable in their homes (7 participants), generally easier and more convenient (5 participants), feeling safer staying at home during the COVID-19 pandemic (3 participants) and a greater level of privacy when completing the clinic visits from their homes (3 participants). Challenges associated with the remote visits included less personal interaction and support (noted by 6 participants), challenges with technology (5 participants), less accountability to complete assignments (5 participants), less confidence in their ability to quit smoking (4 participants) and distractions at home (2 participants).

Among the 15 participants interviewed, 8 (53%) reported that the majority of their remote counseling visits were video calls (audio and video communication); a strong preference was expressed for video calls (noted by 7/9 participants, 78%, who completed at least one video call and at least one telephone call), as video sessions were viewed as more personal and interactive (6 participants completed only video calls or only telephone calls). Few participants (2/15, 13%) reported any previous experience with video or audio calls from their health care providers (eg, telehealth visits or virtual visits). Following the experience of these remote visits, 13/15 participants (87%) indicated a willingness to engage in telehealth visits in the future.

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Table 6. Dominant themes and subthemes based on structured interviews with smoking cessation clinical trial participants (n=15) who completed both in-person and remote clinic visits.

Theme and subthemes	n (%)	Illustrative quotes
Benefits of remote clinic visits		
No travel required	11 (73)	• “I guess it saved a little time, didn't have to drive there. But, you know, so it's basically a little more time-consuming to actually go there.” • “Just saves the trip. Don't have to worry about trying to find a place to park or anything.”
Safer	3 (20)	• “With COVID-19 being prevalent, it felt safer…” • “I'm just saying on my behalf, it was better for me to be at home, especially during the pandemic.”
Generally easier/more convenient	5 (33)	• “Of course you got to take the time off to get there.” • “I didn’t have to wait to be seen or anything, when the call came I accepted the call and we went from there.” “It’s just far more easier and convenient.”
More comfortable	7 (47)	• “You’re much more comfortable in your own environments. That’s the way I felt. It’s not that staged clinical setting…there’s comfort in your own home, your own environment is very comforting and calming.” • “You’re a little bit more comfortable with doing things because you know, you’re at home.”
Greater privacy at home	3 (20)	• “Obviously it's more private being at home because you can control, even though I have no issues with privacy when I came to the office.” • “I live alone so nobody else was there. Nobody hearing my thoughts and it felt as if I could express myself a little better, for me.”
Challenges of remote clinic visits		
Less personal/less supportive	6 (40)	• “I think connecting with the counselor was easier in person.” • “It was more personal being there (in-person) compared to doing a Zoom meeting…” • “You lose that factor of like meeting staff and other people there, that was kind of nice you know. Like knowing there’s something behind the program you are in.” • “Sometimes it's easier just explaining things when you're there in person and you can show what kind of stuff.”
Distractions at home	2 (13)	• “I have 3 dogs that are really loud so I have to make sure they are all locked up” • “People at home could, you know, hear my phone call…”
Technology challenges	5 (33)	• “Zoom is new to me. Video conferencing is new to me….” • “I like it a lot better in person because I’m not a technology…”
Less self-confidence in ability to quit	4 (27)	• “I’m at home and I might pick up a cigarette.” • “Probably a little less confident, but I did it. It was like, it's tough when you don't have friends or doctors and people that were rooting you on.”
Less accountability	5 (33)	• “I was preparing a little bit more [for office visits] than I do when just the phone rings.” • “Driving there, part of me quitting is me thinking about quitting and I have spent half an hour to get there you know, and block out a portion of my day, hey, I can't wait to quit because when I do I won't have to do this anymore.” • “For me personally, I tended to work on the homework in between sessions. On days prior to my sessions when it was in-person. At-home visits, I just didn't feel the accountability to do that at the at-home visits.”

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Discussion

The quasi-experimental component identified no differences between subcohorts in the proportion of participants lost to follow-up or withdrawal from the study. Participants in the COVID-19 cohort completed an average of 83.6% (95% CI 73.1%-91.2%) of scheduled remote clinic visits and returned an average of 93.2% (95% CI 83.5%-98.1%) of saliva specimens, which was comparable to the in-person clinic visit completion rate of 89.8% (95% CI 84.0%-94.1%) and the in-person saliva specimen completion rate of 100% (95% CI 97.4.0%-100%) in the pre-COVID-19 cohort. The qualitative findings suggested two broad themes: (1) the benefits of remote visits, such as convenience, comfort and safety, and (2) the challenges of remote visits, such as less personal interaction with the study staff, struggles with technology, less accountability to complete assignments, and decreased confidence in their ability to quit smoking. There was a strong preference expressed for video calls over telephone calls, as video sessions were viewed as more personal and interactive. Finally, while few participants reported any previous experience with video or audio calls with their health care providers, nearly all participants indicated a willingness to engage in telehealth visits in the future.

The ongoing COVID-19 pandemic has heightened interest in remote, decentralized clinical trials. Dahne and colleagues [1] recently summarized the use of emerging technologies to support the remote implementation of smoking cessation trials, and our study employed several such tools. Their review described ongoing shifts, including use of Facebook or other social media platforms, to support study recruitment. With IRB approval, participants can give consent remotely; for example, REDCap provides the ability to complete the consent process electronically, along with audio or video calls with members of the research team to address questions. Survey instruments can be completed through email or SMS text message links sent to participants [1]. In this study, we used REDCap to send participants links to surveys, including safety monitoring, to be completed electronically as a component of these remote visits. Studies of smoking cessation have typically relied upon biomarker collection at in-person visits to validate smoking status. However, saliva specimens can be successfully collected remotely and mailed back to investigators. Also, it is possible to collect CO measurements using devices connected to smartphones (eg, the iCO Smokerlyzer monitor [19]). During biospecimen collection, video calls or facial recognition software can be used to verify participant identify, and incentives can be credited virtually to a ClinCard account. In this study, we observed specimen collection during most visits via Zoom; remuneration was not credited to a participant's account until the specimen was received. Adherence to study medication can be assessed remotely via saliva specimens or using the Medication Event Monitoring System (MEMS), which records pill container openings. However, direct observation of medication self-administration, along with remote assessments of weight, height, and blood pressure, is potentially more intrusive and introduces several complexities [1]. In this study, we conducted remote medication accountability assessments; however, to make remote visits more feasible, we did not require participants to send back pill containers, and we dropped a number of secondary assessments (ie, weight, blood pressure, and CO) from the study.

In March 2020, the US Food and Drug Administration offered recommendations for ongoing and planned clinical trials [20], including "alternatives to in-person safety assessment (eg, phone contact, virtual visits, alternative locations for assessment), direct-to-patient investigational product delivery, the collection of efficacy endpoint data, replacing on-site monitoring with decentralized or remote monitoring, and additional safety monitoring of trial participants if the trial is halted or treatment is discontinued." Consistent with these recommendations, we used the final in-person visit to provide participants in our clinical trial with the materials and resources to continue visits remotely. Importantly, the implications of these modifications remain unclear. Thus, we examined quantitative (rates of remote visit completion and rates of saliva specimen collection) and qualitative aspects of the transition to remote visits. To our knowledge, this study is among the first to explore participants' experiences and the impact of such transitions in a smoking cessation trial during the COVID-19 pandemic.

The findings for visit completion were generally encouraging; we observed robust and sustained rates of completion for scheduled clinic visits after the migration to a remote platform of telephone and/or Zoom calls (83.6%) as a result of the COVID-19 pandemic. Importantly, the completion rate was not significantly lower than that of a historical comparison group, namely the pre–COVID-19 cohort comprising participants from the calendar years 2018 and 2019 who only experienced in-person visits (89.8%). Although the comparison is quasi-experimental, the two cohorts were comparable on all baseline participant and smoking characteristics, ruling out a variety of potential confounds. However, there is one critical confound between groups: participants in the COVID-19 cohort were also faced with the unique circumstances of the pandemic.

It is important to note that we were not powered to detect small group differences in visit completion rates. Conversely, the transition from in-person to remote visits was made quite rapidly and may represent a "worst case scenario." We would anticipate that remote visit completion rates would be even better if participants were preinformed of the remote visits and as a result of further refinement and standardization of our procedures. Regarding remote visits more generally, it is important to note that none of the current participants anticipated the possibility of remote visits upfront. Visit completion rates may be even higher in trials that are specifically designed to be remote [21].

The second goal of this research was to understand the opinions and experiences of clinical trial participants who were required to change from in-person to remote visits after completing at least one in-person clinic visit. Interviews with 15 such participants suggested a mix of benefits and challenges for remote visits. Benefits included not having to travel to on-site appointments, avoiding potential exposure to COVID-19, and the general convenience of staying at home. Challenges of remote visits involved the less personal nature of interactions with project staff, technology challenges, and less accountability.

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Taken together, these data provide suggestions for more satisfying participant experiences in future intervention trials. For example, planning sufficient time and pre-educational sessions to deliver technology support may be necessary for successful remote visits via telephone or video. In addition, sending reminder calls or SMS text messages in advance of scheduled video or teleconferences seems to enhance participants' accountability. Several participants in our study also commented on less privacy and more distractions at home, while others felt that privacy was greater at home. Few participants (2/15, 13%) who were required to transition to remote visits reported familiarity with virtual visits or telehealth at the time of migration to a remote platform. However, following their experience in this study, a large percentage (13/15, 87%) reported a willingness to participate with telehealth visits either via telephone or video in the future. After the experience of both in-person and remote visits, most participants recommended a mix of visit types or choosing from both options going forward. Studies comparing use of video counseling to telephone counseling have focused on specific groups of smokers (eg, women with HIV, Korean American women, rural residents in Kansas, rural residents in Australia) [6-8], limiting generalizability. Nonetheless, it seems both reasonable and practical to use video and telephone platforms to deliver counseling support to smokers interested in quitting.

Participants in our clinical trial were already familiar with electronic data capture (REDCap) for completing many study measures; therefore, the transition to remote visits may have had less of an impact on that component. We did lose the ability to assess exhaled breath CO; however, we successfully retained our primary bioverification measure (salivary cotinine), as 93% of all remote visits were accompanied by the participant sending back their saliva sample.

Adherence, measured as time spent in treatment, for face-to-face versus a mix of face-to-face and web visits was studied among 292 persons enrolled in a 10-session smoking cessation trial conducted in the Netherlands [5]. Adherence was similar in the 2 groups; however, the blended group demonstrated more treatment time spent during face-to-face visits compared to web visits; the only factor that predicted increased adherence was older age (R^2=0.047). These authors concluded that in-person visits compensated for weaknesses of the web visits, which was also noted in qualitative research among smokers in this trial [22]. Our study assessed adherence based on completion of scheduled visits and did not track duration of visits. Finally, we observed that 93% of the remote visits in the COVID-19 cohort were accompanied by returned saliva specimens, suggesting that saliva specimen collection for bioverification of cessation or assessing study drug levels is feasible.

Limitations of this study include the modest size of the cohort that transitioned to remote clinic visits, limited power to examine differences in rates of completion by individual visits or among specific subgroups of participants, and the inability to assess nonrespondent bias. Also, the duration of the interviews with participants who completed remote clinical visits was generally shorter than what is typical for qualitative studies; however, this was reflective of the focused nature of the interview guide and a desire to not burden respondents to an extent that would negatively affect the completion of long-term follow-up visits for participants still in the trial. These modest limitations are offset by the unique strengths of our mixed methods approach, which supported an examination of opinions and experiences of participants enrolled in an ongoing clinical trial of smoking cessation who were required to change from in-person clinic visits to remote visits and the quasi-experimental design comparing rates of visit completion to a comparable group of participants followed over a similar time period in calendar years 2018 and 2019.

The experience of the COVID-19 pandemic has forced many investigators to more rapidly use and incorporate mobile health and technology applications into their ongoing clinical trials. This study suggests that participants in our smoking cessation trial were successfully transitioned from in-person to remote clinic visits based on high rates of visit and biospecimen completion and general satisfaction with the experience.

These unique analyses provide valuable information on the experiences and perspectives of participants enrolled in a clinical trial of smoking cessation who were transitioned from in-person to remote clinic visits due to the COVID-19 pandemic. This synthesis of qualitative and quantitative data support a successful transition process from in-person to remote visits for this smoking cessation clinical trial, as Dahne and colleagues [1] suggested. As such, this study also provides some initial direction for the design of future clinical trials, given the robust rates of completion for remote visits.

In summary, our findings indicate strong acceptability among participants in this clinical trial for completing clinic visits remotely after starting initially with in-person visits and suggest the potential importance of considering individual preferences with regard to potentially transitioning to remote visits. These study findings are consistent with promising results of studies in which technology was used to support remote delivery of smoking cessation treatment [3,6-8,23]. However, this study extends the possibilities to use of mobile and virtual modes for successful smoking cessation trial implementation, including assessment and data collection in the context of a pandemic. Furthermore, the mixed methods approach provides a more in-depth understanding of the potential impact on visit completion rates and experiences regarding the transition process among study participants who were not anticipating such changes. However, the optimal mix of in-person and remote visits remains undetermined, as does our understanding of how these changes may impact study outcomes. Finally, the successful transition of these clinical trial participants from in-person to remote visits was likely supported by several factors, including the development of rapport through in-person visits, provision of detailed instructions, the availability of both telephone or video platforms and the availability of support to trouble shoot technical issues, as well as strong motivation by participants to quit smoking.

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Authors' Contributions

All authors have read and agree to the published version of the manuscript. MCM, LWH, and NJS conceived the study; MCM, EP, and NJS contributed to the methodology; MCM, LWH, CD, and NJS contributed to the data collection; MCM, EP, and NJS performed the formal analysis; MCM prepared the original draft; MCM, LWH, NJS, EP, and CD reviewed and edited the manuscript; LWH, MCM contributed to funding.

Conflicts of Interest

MCM has received study medications from Pfizer in support of randomized clinical trials and has previously served as a consultant to and speaker for Pfizer on the topic of smoking cessation; he also serves as medical director of the New York State Smokers Quit Line.

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Abbreviations

CO: carbon monoxide
FTCD: Fagerstrom Test of Cigarette Dependence
IRB: Institutional Review Board
MEMS: Medication Event Monitoring System
REDCap: Research Electronic Data Capture

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Corrigenda and Addenda

Correction: System Architecture for "Support Through Mobile Messaging and Digital Health Technology for Diabetes" (SuMMiT-D): Design and Performance in Pilot and Randomized Controlled Feasibility Studies

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In “System Architecture for “Support Through Mobile Messaging and Digital Health Technology for Diabetes” (SuMMiT-D): Design and Performance in Pilot and Randomized Controlled Feasibility Studies” (JMIR Form Res 2021;5(3):e18460) two errors were noted after publication.

In the originally published version, under the section “Random Selection Management,” an inline graphic was not inserted in the text in the following sentence:

> *In addition, all the messages in the same BCT group (ie, Inline graphic 10) would have doubled the chance (ie, increase 100% probability) to be selected and sent to this participant in the future.*

The graphic has been added to this sentence in the corrected version.

Two extraneous inline graphics were also inadvertently published in the Results section due to a system error. These have been removed from the corrected version.

The correction will appear in the online version of the paper on the JMIR Publications website on April 9, 2021, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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