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Original Paper

Mobile App to Help People With Chronic Illness Reflect on Their Strengths: Formative Evaluation and Usability Testing

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Abstract

Background: Supporting patient engagement and empowerment is increasingly seen as essential in providing person-centered health care to people with chronic illness. Mobile apps helping patients reflect on their concerns as preparation for consultations with their health care providers can have beneficial effects on the consultation quality. However, apps focusing on empowerment and personal strengths are still scarce.

Objective: This study aimed to (1) develop a mobile app to support patients with rheumatic diseases in reflecting on their strengths in preparation for consultations with health care providers and (2) explore patients' perceived usability of the app in a nonclinical test setting.

Methods: A prototype app was developed based on input from patients and health care providers, as reported in previous studies. The app was designed for use in self-management support settings aiming to promote awareness of strengths and to focus attention on strengths in the patient-health care provider dialogue. The features included in the prototype were as follows: (1) introduction to the topic of strengths, (2) list of examples of strengths to promote reflection and registration of own strengths, (3) summary of registered strengths, (4) value-based goal setting, (5) linking of strengths to goals, (6) summary of all registrations, and (7) options to share summary digitally or as a print version. In this study, the app was refined through a formative evaluation with patients and health care providers recruited from a specialized rheumatology hospital unit. Patients' perceptions of the app's usability were explored in a test setting with self-report measurements and semistructured interviews. The interviews were audiotaped, transcribed, and analyzed with directed content analysis. Data from questionnaires were analyzed with descriptive statistics.

Results: Developmental and formative evaluation included 18 patients and 7 health care providers. The evaluation resulted in minor adjustments to the prototype but no major changes in features. The usability testing included 12 patients. All participants found the usability acceptable; the median score on the System Usability Scale was 86.3 (range 70-100). All reported that it was meaningful and relevant to use the app. Out of 12 participants, 9 (75%) reported becoming more aware of their own strengths by using the app; 1 (8%) disagreed and 2 (17%) provided a neutral response. The results on the goal-related feature were mixed, with half of the patients finding it useful to link strengths to concrete goals. A statistically significant positive change from pre- to postintervention was identified on measures of self-efficacy and negative emotions.

Conclusions: In this formative evaluation of a mobile app to promote patients' reflections on their strengths, patients perceived the app as meaningful and supporting awareness. The results suggest the usefulness of building in functionality to support use of

strengths and goal attainment. Further studies on efficacy and usability in a clinical setting, including health care providers, are needed.

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KEYWORDS

mobile app; self-management; strengths; chronic illness; rheumatology; usability; formative evaluation

Introduction

Person-centered health care involves a holistic approach with a focus on patient empowerment and engagement [1,2]. It includes helping people with chronic illness to recognize and cultivate their existing strengths and develop new ones [1,3,4]. Strengths have been described as the repertoire of potential attributes that mobilize positive health behavior and promote health and well-being [5]. Strengths are usually contextual and interwoven with goals, interests, values, and situational factors [6]. People with chronic illness report various strengths, such as knowledge, courage, perseverance, kindness, positive emotions, use of coping strategies, and social support [7-9].

Helping patients to identify and engage with their personal strengths is increasingly common in the domain of psychotherapy (ie, positive psychology), as well as in educational and organizational contexts. Research indicates that focusing on strengths can promote outcomes such as motivation, positive affect, and work performance [6,10,11]. Strengths interventions are in line with the broaden-and-build theory stating the important role of positive emotions in promoting a positive spiral of action toward well-being [12]. Including a strengths-based assessment in health care is suggested to provide a more holistic view of patients [1,13]. Assessing strengths can help the health care provider understand each patient's reservoir of resources that can be utilized in the management of challenges and to promote well-being [13]. Several scales are available for assessment of strengths and resources [13-16]. However, research on strengths assessments in clinical practice is sparse [17,18]. A recent review on strengths interventions published between 2011 and 2016 included 18 studies, of which only three used clinical samples; most studies were done on samples of students or employed adults. Three types of strengths interventions were identified: (1) interventions that helped participants identify their strengths (eg, by reflecting on their best self) without providing instructions on how to use or develop those strengths, (2) interventions that supported identification and use of strengths (eg, using strengths in a new way), and (3) interventions addressing the impact of patients' use of strengths on others, regulation of use of strengths, or use of strengths in different contexts. Most studies found positive effects on well-being, and the type of intervention was not found to moderate the effect [17].

Interventions aiming to prepare patients for consultations can lead to more active patient engagement during clinical encounters [19]. For example, digital pre-encounter communication interventions that help patients prepare for a conversation about their symptoms and problems have shown positive effects on communication and consultation quality [20-22]. Following a strengths assessment, the health care

provider and the patient can explore together how the patient's strengths have helped previously and how they might help in the current situation [13]. However, interactive digital interventions that support patients in exploring and reporting their strengths in a clinical setting are generally still few [18].

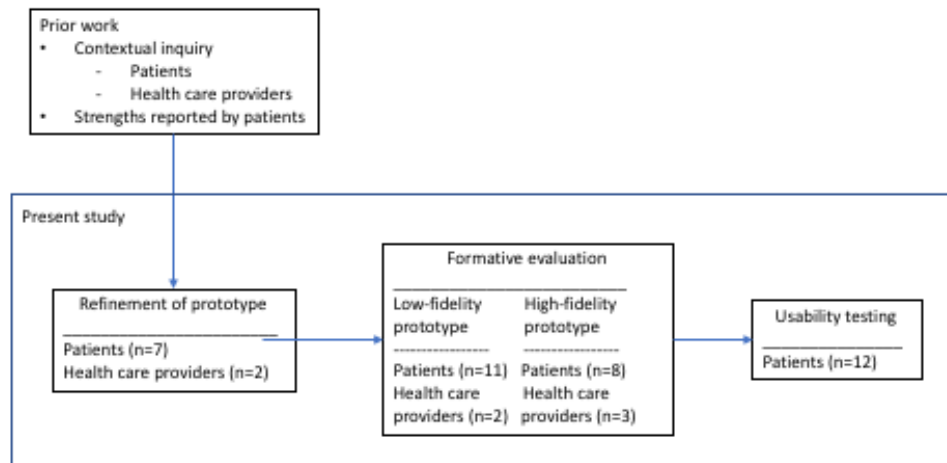
Two prior studies have explored insights from patients and health care providers regarding the use of a mobile app aiming to support reflection and dialogue about patients' personal strengths [23,24]. People with different chronic illnesses were generally positive toward using technology to help identify and discuss their personal strengths in clinical consultations. Patients suggested the app should include examples of strengths reported by other patients with chronic conditions and an option to extend the list with personal items using intuitive and engaging user-interface design [23]. Health care providers working in a rheumatology setting described how they supported their patients in mobilizing their strengths and emphasized the importance of communication skills, exploration of values, and goals to mobilize strengths, as well as patient education [24]. The health care providers were also generally positive toward the idea of an app to support the patients' reflections on strengths as a preparation for consultations to promote self-management [24].

The aim of this study was to (1) develop a mobile app to support reflection and dialogue about personal strengths among patients receiving self-management support and (2) explore how patients perceived the app's usability, as well as its potential effects on emotions and self-efficacy, in a nonclinical test setting.

Methods

Overview

This study used a person-centered approach for design and development of the app, with mixed methods for evaluation [25]. The study was approved by the Privacy and Security Protection Committee of a major hospital in Northern Europe. Participants were recruited from two units of a rheumatology specialist department—one of which arranged outpatient self-management programs, whereas the other had an inpatient rehabilitation unit—and from a patient-research partner advisory board. Inclusion criteria for patients were being 18 years of age or older, being fluent in Norwegian, and having a rheumatic disease. The only inclusion criterion for health care providers was to have experience with health care for people with rheumatic diseases; they were recruited from the inpatient rehabilitation unit. All participants provided written informed consent and patient participants received a gift certificate as compensation for time spent and travel expenses. Information about patients who were invited to participate but declined was not registered. [Figure 1](#) gives an overview of the development and evaluation process.

Figure 1. Overview of the development and evaluation process.

Development

Refinement of the Prototype

Design of the prototype was guided by suggestions from people with chronic illness who had participated in designing a preliminary low-fidelity (ie, paper) prototype [23] as well as feedback on this prototype from health care providers [24]. The preliminary prototype offered the following main features: (1) a preliminary list of strengths with *yes* and *no* response options, (2) registration of a health-related goal, (3) marking of 3-5 most relevant strengths, (4) linking strengths and goals, and (5) an easy way of sharing results with a health care provider.

In a prior study, people with chronic illnesses were asked about their strengths [7]. This resulted in a preliminary list of strengths items that was used in a study exploring patients' requirements for a strengths-based preconsultation app [23]. The list of strengths items from this previous work was further refined (eg, number of items reduced and wording clarified) in this study during discussions between authors and based on feedback during formative evaluation. The items on the list were meant to serve as examples of strengths to support reflection rather than to be a formal assessment.

The development process involved a multidisciplinary team from a hospital research center comprising behavioral scientists, an information technology scientist and developers, a designer, specialists in the development of content and functionality in eHealth apps, and user representatives—two women with rheumatic disease. The intention was to make an app available without cost to other users once its efficacy had been demonstrated and guidelines constructed to facilitate implementation of the app into existing health care contexts. The hospital's Privacy and Security Protection Committee was consulted for approval of privacy and security requirements of the app.

To refine the features of the prototype, patient representatives with rheumatic diseases were invited to participate in a workshop. They were members of the patient advisory board at the hospital where recruitment took place. The workshop was led by a team member who is a specialist in eHealth app development. The workshop included a short introduction,

individual reflection, and discussion. Participants were asked to identify strengths from a predefined list, write about their values and goals, and to reflect on how the strengths could be linked to their goals and values. Input from the workshop was audiotaped and summarized by two team members (OBK and MW). Feedback on main features of the prototype and context of use was gathered in one workshop with health care providers from the inpatient unit. The workshop was audiotaped and main results summarized by two team members (OBK and MW). As a service design method [26], a simple journey map was made to help visualize where using the app might be appropriate in the context of a rehabilitation program.

Formative Evaluation

Overview

The formative evaluation included testing of low- and high-fidelity versions of the prototypes. Patients participated in an individual testing session. They were guided by a moderator and asked to think aloud during the process to elicit feedback [26]. Testing sessions with patients were video recorded and sessions with health care providers audiotaped. All patients were asked to complete a background information survey, including questions on age and gender.

Data on usability were extracted from observation notes and video and summarized by two team members (OBK and MW) into the following categories: *functionality*, *content issues*, *navigation*, and *nice to have*. This summary was then discussed within the project group and used as feedback for iteratively adjusting the prototype between testing rounds.

Low-Fidelity Prototype Testing

For this phase, participants were recruited from three settings within the hospital. Patients recruited from the self-management programs and the inpatient unit were informed of the study by their health care providers. Those who expressed interest were contacted by a research team member by telephone and provided with more information about the study. Members of the patient advisory board were sent an email with study information and an invitation to participate. The project's user representatives also participated in this phase of testing.

The first low-fidelity prototype was developed using a combination of paper sketches and app screenshots that simulated the app's features and flow. Prototyping was done using the POP app by Marvel [27]. It included the following features and functionality: (1) information in text and audio, (2) strengths reflection: list of strengths presented with response options *yes* and *no*, (3) possibility to add notes to strengths, (4) overview of marked strengths, presented within four categories, (5) value-based goal setting, to be entered into a text box, (6) linking of strengths to goals, and (7) sharing, indicated with a printout symbol (see [Multimedia Appendix 1](#)).

The testing procedure was piloted with coworkers to ensure feasibility of the procedure before it was used with patients. The testing sessions were held at the research center. The prototype included multiple pieces of paper that were handled according to what the participant "clicked" on to simulate activities on a touch screen. Participants were encouraged to write on the paper to contextualize their interaction with the prototype, for example, if or how they wanted to express or visualize their strengths or adjust the interface. In addition to the participant, there were three facilitators in the room. One person moderated the process, one administered the paper parts of the prototype according to participants' choices on the screen, and one observed and assisted. The team of facilitators had interdisciplinary backgrounds: researcher, system developer, and content manager. Health care providers participated in a group session where the prototype was shown and discussed, using a journey map to aid discussion on context for use.

High-Fidelity Prototype Testing

Based on feedback from the low-fidelity prototype testing, a high-fidelity prototype was programmed using the software program Unity (Unity Technologies) [28]. For this phase, participants were recruited from the inpatient rehabilitation unit only. Patients were informed about the study by a health care provider and for those willing to participate, a testing session was scheduled at the unit. The high-fidelity testing procedure was similar to the low-fidelity prototype testing but with one fewer facilitator in the room. Health care providers at the same unit were also invited to test the prototype and provide feedback; they each tested the prototype with either one or two providers per session. The sessions with health care providers were audiotaped and included a moderator but no facilitators. Lastly, the interface was explored by an external interaction designer who was provided with the intended context of use and then performed an informal heuristic evaluation of the app on his own. He provided feedback on user-friendliness issues and suggestions for improvements in a meeting with team members.

Testing Usability of the Final Version of the Mobile App

Participants were recruited from self-management programs for people with a rheumatic disease. The program facilitator presented the researcher, research assistant, and/or patient representatives to the group. The study was presented and those who were interested provided their contact information. Subsequently, they were called and given more detailed information about the study, and a date for participation was agreed on. The usability testing took place at the research center.

After the participants had filled out self-report questionnaires, the researcher presented a scenario and the usability tasks. Participants were asked to imagine being invited by their health care provider to use the app to reflect on strengths and goals, before a consultation. The description of the scenario was available in written format during the testing session. During the testing, the participant was alone in the room. The participant was informed that the testing would take approximately 30 minutes and that the researcher would check in after about 20 minutes to see if they needed more time. After the usability testing, the researcher printed out a copy of the strengths report for use in a posttest interview.

Self-Report Measurements

Overview

Prior to the usability test, participants filled out a questionnaire on background information and a study-specific item on strengths. To explore potential usefulness, participants were also asked to fill out outcome measures on emotions and self-efficacy before and after testing the app. Lastly, after the usability test, participants were asked to fill out a study-specific outcome measure on perceived usefulness and a usability scale. Statistics were analyzed using SPSS Statistics for Windows, version 25.0 (IBM Corp). The related-samples Wilcoxon signed-rank test was used to compare the median of differences between pre- and posttest scores.

Usability

Participants also completed an 11-item study-specific questionnaire about the functionality and perceived usefulness of the app. Response options ranged from 1 (*strongly agree*) to 5 (*strongly disagree*). See the Results section for an overview of items. Usability of the app was measured with the System Usability Scale [29], a 10-item measure with five response options ranging from *strongly agree* to *strongly disagree*. Scores were converted so that all values were between 0 and 4, with 4 as the most positive response. See the Results section for an overview of these items. The converted scores were summed up and multiplied by 2.5, leading to a value range of 0-100, with 100 being the most positive response. In case of a single missing response, the item was scored with a neutral value (score=2).

Emotions and Self-Efficacy

Self-efficacy and emotions were measured to explore whether the testing session would lead to any preliminary indications of changes. Positive and negative affect was measured with the Positive and Negative Affect Schedule [30]. This measure includes subscales for positive (eg, interested and enthusiastic) and negative affect (eg, guilty and scared), with 10 items in each. The participant was asked to indicate to what extent he or she was currently feeling a specific emotion, with the response alternatives *very slightly or not at all*, *a little*, *moderately*, *quite a bit*, and *extremely*. Subscale scores ranged from 10 to 50, with higher positive affect scores representing higher levels of positive affect and lower negative affect scores representing lower levels of negative affect. In case of a single missing item on the preintervention measurement, the item was given the same score as the reported postintervention item.

A revised version of the Arthritis Self-Efficacy Scale was used to measure self-efficacy to cope with pain (five items) and others symptoms (six items) [31,32]. In this scale, the respondent is asked about level of certainty in being able to undertake specific tasks (eg, decrease pain, continue daily activities, control fatigue, and do something to feel better). Five response options are provided from *very uncertain* to *very certain*. A score for the *pain* subscale (range 0-20) and the *other symptoms* subscale (range 0-24) was calculated, with higher scores representing higher levels of self-efficacy. In case of a single missing item on the preintervention measurement, the item was given the same score as the reported postintervention item.

Posttest Interview

After the participants had filled out the posttest outcome measures, they were interviewed by the first author (OBK). During the interview, the printout of the strengths overview and the app were available and referred to. The interview was semistructured (see [Textbox 1](#)), audiotaped, and transcribed. The data were analyzed using content analysis [33] directed by predefined categories following the interview guide as follows: (1) the app as a reflection support, (2) the app as a dialogue support in health care, and (3) user-friendliness and suggestions for improvement. The interviews were intended to supplement the questionnaire data on the experience of using the app.

Textbox 1. Examples of questions from the interview guide.

How did you experience being asked about your strengths through the app?

How was it to describe your strengths with the app versus without it (as you did on paper before the usability testing)?

What are your thoughts about using the app as preparation before a consultation/conversation with your health care provider? Do you have a health care provider in mind? If so, what profession/setting?

Do you think it would be helpful to use the app, without sharing the report? Please elaborate.

What are your thoughts about the usefulness of the app in relation to a group-based self-management program, such as the one you recently attended?

How easy was it to navigate in the app? Do you have suggestions for improvement?

Results

Design and Development: Refinement of Main Features

Workshop With Patients

A total of 7 patients participated: 4 out of 7 (57%) were women. The age range was 31-63 years (median 56 years). The patient representatives in the project participated in the workshop and are included in the sample description. Patients highlighted the need to acknowledge the fluctuating nature of the illness and the variation in perceived strengths. Patients wanted to be able to reflect on previous use of strengths. Acknowledging challenges in addition to strengths was considered important. There was some confusion about how to make a link between strengths, values, and goals. Some found goal setting and value reflection easy and motivating, while others found it challenging to find realistic and inspiring goals.

Workshops With Health Care Providers

Two health care providers participated in a workshop where the idea of the app was discussed with a focus on potential context of use; this was supported by a journey map developed in preparation for the workshop. They described the importance of taking into consideration the patient's readiness for change. The app was viewed as potentially useful (1) when exploring strengths of patients in general (eg, what is currently working well) and, more specifically, (2) when working with goal setting and self-efficacy toward goals. The health care providers suggested adding the possibility to register obstacles to reaching goals, as well as overview of and feedback on progress.

Formative Evaluation

Low Fidelity

In the first of three rounds, the prototype was tested by 3 patients (2/3, 67% women; age range 42-63 years, median 57 years), including the patient representatives in the project. In total, 5 women participated (age range 28-64 years, median 50 years) in the second round and 3 women (age range 30-77 years, median 43 years) in the third round. A total of 2 participants had also participated in the previous workshop. Finally, the patient representatives in the project tested the prototype again.

In general, participants appreciated the list of strengths items and all were able to find several or many relevant items. A few changes were made based on feedback during this evaluation phase. Since some patients reported that it was difficult to assign strengths to an *either/or* category, the response alternative *partially* was added. Also, some patients reported appreciating being able to view the list of strengths registered with a *no*. They perceived this as feedback on self-management strategies they could potentially work on or do more of. Other adjustments included simplifying the structure of the overview, including more information and guidance (eg, by adding instructions and examples of goals and pop-up information with encouragement and guidance), and the option to share a selection of strengths with the provider instead of the complete overview.

A few changes that were made and tested did not work well and were, therefore, not implemented in the high-fidelity prototype (eg, the option to choose to start with goal setting rather than selecting strengths and the option to mark strengths items the user wanted to use more actively in the future). In addition, participants made several suggestions for added functionality that were not implemented due to limited resources. Examples include functionality related to goals (eg, progress bar and reminders), reminders of their strengths, registration of strengths

uses, tailored information on how to use their strengths, registration of challenges, and a forum for sharing between users.

Two health care providers gave their feedback on the prototype in one shared session. They were generally positive toward the functionality. They emphasized the importance of the possibility of adding one's own formulations and using the notes function to write about how the strengths could help them toward a goal. They reported that the items, categories of strengths, and response alternatives seemed appropriate.

I absolutely think this is a way to activate the patient in the process, a good tool. [Health care provider]

The guidance and examples of goals were appreciated, but several participants commented that the instructions on writing a goal needed clarification. They suggested that the app could be introduced by the patient's primary nurse in the context of conversations about goal setting and achievement.

High Fidelity

The high-fidelity prototype was a mobile app called *Styrkefunn* in Norwegian (meaning *strengths discovery*). To introduce the app and the concept of strengths, a short animated video was made and included in the app. The video included a metaphor of being out at sea, representing illness, and needing to take a second look at the options, representing strengths, available to keep the boat going forward in the right direction. A few adjustments were made on the app based on feedback from low-fidelity prototype testing; for example, options were added to allow users to mark strengths as *not relevant* (ie, to skip them), to add subgoals, and to link strengths to both levels of goals. The decision to not prioritize a digital sharing functionality (eg, by direct integration to electronic health records) was taken, due to issues related to privacy protection regulations and project resources. For the purpose of the usability testing, this functionality was implemented by enabling a feature that allowed for making a printout of the overview of all registrations made in the app. The list of strengths was refined based on feedback from participants (eg, some items were merged or divided and the language edited). The high-fidelity prototype included 42 strengths items categorized

into four domains: (1) qualities (eg, I am persistent and I am creative), (2) strategies (eg, I seek the knowledge I need, I have a healthy lifestyle, and I take care of myself), (3) external resources (eg, I have someone who understands me and I have health care providers whom I trust), and (4) joy and meaning (eg, I prioritize that which is important to me and I have activities that I look forward to) (see [Multimedia Appendix 2](#) for the refined list).

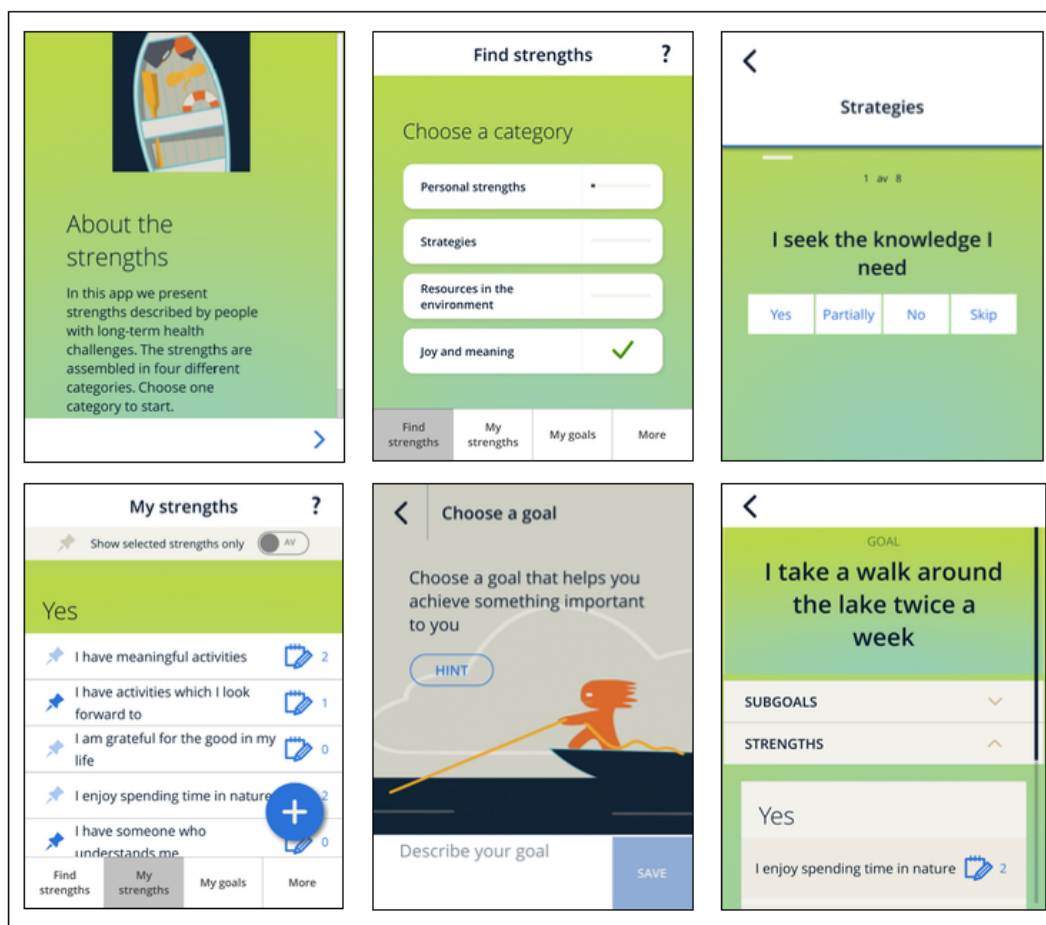
The high-fidelity prototype was tested in two rounds, with 3 patients participating in each (5/6, 83% women; age range 34-50 years, median 45 years). Additionally, the 2 patient representatives within the project and 3 health care providers from the inpatient unit participated; 1 health care provider had participated previously. The feedback from the patients indicated that the strengths reflection worked well, both the items and the response alternatives. All appreciated the introductory video. Several user-friendliness issues were experienced, indicating a need for better navigation and guidance in the goal part of the app. The three health care providers were positive toward the app; they reported liking the introductory video and the list of strengths items.

I think this can be a very nice tool to use ... If we ask the patients about their resources, then they are unsure about how to start answering, I don't think they understand the question ... but if you get the suggestions, then it is easier ... [Health care provider]

The health care providers suggested that the goal part needed more instructions and ideally the app should be designed to support self-management beyond the reflection and consultation.

Finally, patients, health care providers, and the interaction designer experienced some usability issues related to navigation (eg, pop-up guidance was found confusing and it was unclear where to access strengths and subgoals from the goal page). The designer also pointed out synchronicity issues in layout. The issues were categorized as mainly cosmetic and minor and were addressed by the project team, but more functionality was not added due to limitations in project resources. [Figure 2](#) shows screenshots of the app's interface after refinement from formative evaluation.

Figure 2. Screenshots of the app.



Usability Testing of the Digital App

Participants

Participants (N=12) were mainly female (11/12, 92%) and had different (ie, one or more) rheumatologic diagnoses (eg,

psoriasis arthritis, fibromyalgia, spondyloarthritis, and rheumatoid arthritis). Median age was 50.0 years (range 30-76). Out of 11 participants, 9 (75%) reported a high degree of experience with a mobile device and 3 (25%) reported having some experience. See [Table 1](#) for additional descriptive information.

Table 1. Participants' demographics and duration of pain.

| Variable | Participants (N=12), n (%) ^a |
|---|---|
| Married or cohabiting | 9 (75) |
| Employment | |
| Full-time work | 3 (25) |
| Part-time work | 2 (17) |
| Sick leave | 2 (17) |
| Disability benefits | 5 (42) |
| Education | |
| Elementary or upper secondary school | 4 (33) |
| Education beyond upper secondary school | 8 (67) |
| Pain duration (years) | |
| <1 | 0 (0) |
| 1-2 | 4 (33) |
| 2-4 | 1 (8) |
| 4-6 | 0 (0) |
| 6-10 | 3 (25) |
| >10 | 4 (33) |

^aDue to rounding, percentages may not add up to 100%.

Usability

On the study-specific question about strengths, prior to using the app, participants listed between 3 and 10 strengths (eg, family and friends, being able to work part time, creativity, positive mindset, being mentally strong, being goal oriented, regular exercise, healthy diet, insight into what nurtures and what does not, valuable work, pets, and support from health care providers). When using the app, all participants registered strengths. The number of strengths registered in the *yes* category ranged from 6 to 35 (median 25), the number of strengths in the *partially* category ranged from 6 to 26 (median 17), and the number of strengths categorized as *no* ranged from 0 to 7 (median 1). Out of 12 participants, 11 (92%) registered a goal and 7 (58%) also registered a subgoal; 8 participants (67%) linked their strengths to a goal.

All participants reported finding it meaningful and relevant to use the app. Out of 12 participants, 9 (75%) reported becoming more aware of their strengths by using the app and 10 (83%) found it useful to see the overview of strengths. The results on

the perceived usefulness of registering goals were mixed: 5 out of 12 participants (42%) found it useful, whereas 4 (33%) were neutral in their opinion, and 2 (17%) did not find it useful. Out of 12 participants, 6 (50%) found it useful to link strengths to a goal but 5 (42%) provided a neutral response. See [Table 2](#) for more detailed results from the study-specific questionnaire.

The median score on the System Usability Scale was 86.3. One missing score was replaced with a neutral score. The scores ranged from 70 to 100 (ie, all participants found the usability acceptable). Results from half of the participants met criteria for excellent usability (ie, score >85.5) [34]. The statements in the usability questionnaire alternated between expressing positive and negative opinions. Disagreement with a negatively formulated statement was scored as a positive response. One item—*I think that I would like to use this system frequently*—received two negative responses and five neutral responses. Another item—*I found the system unnecessarily complex*—received one negative response. Other items received neutral responses and mostly positive responses (see [Table 3](#) for details).

Table 2. Perceived usefulness of the app among patients (N=12).

| Usefulness statement | Response, n | | | |
|--|-------------------------------|---------|-------------------------|---------|
| | Disagree or strongly disagree | Neutral | Agree or strongly agree | Missing |
| It was meaningful and relevant to use the app | 0 | 0 | 12 | 0 |
| I became more aware of my own strengths by using the app | 1 | 2 | 9 | 0 |
| It was useful for me to see an overview of my own strengths | 0 | 2 | 10 | 0 |
| It was useful for me to be able to register a goal | 2 | 4 | 5 | 1 |
| It was useful for me to be able to link the strengths to concrete goals | 0 | 5 | 6 | 1 |
| I liked the possibility to register my own notes | 0 | 4 | 7 | 1 |
| For me it would be relevant to share the overview of my strengths with my health care provider | 0 | 4 | 8 | 0 |
| It was boring to use the app | 9 | 1 | 2 | 0 |
| It was demanding for me to use the app | 11 | 0 | 1 | 0 |
| I would like to have the app on my own mobile device | 2 | 3 | 7 | 0 |
| I would recommend the app to others in my situation | 0 | 3 | 9 | 0 |

Table 3. Questions and results from the System Usability Scale (N=12).

| Usability statement | Response, n | | | |
|---|-----------------------|---------|-----------------------|---------|
| | Negative ^a | Neutral | Positive ^b | Missing |
| I think that I would like to use this system frequently | 2 | 5 | 4 | 1 |
| I found the system unnecessarily complex | 1 | 1 | 10 | 0 |
| I thought the system was easy to use | 0 | 1 | 11 | 0 |
| I think that I would need the support of a technical person to be able to use this system | 0 | 0 | 12 | 0 |
| I found the various functions in this system were well integrated | 0 | 1 | 11 | 0 |
| I thought there was too much inconsistency in this system | 0 | 1 | 11 | 0 |
| I would imagine that most people would learn to use this system very quickly | 0 | 1 | 11 | 0 |
| I found the system cumbersome to use | 0 | 0 | 12 | 0 |
| I felt confident using the system | 0 | 2 | 10 | 0 |
| I needed to learn a lot of things before I could get going with this system | 0 | 0 | 12 | 0 |

^aAgree or strongly agree for negatively formulated items; disagree or strongly disagree for positively formulated items.

^bAgree or strongly agree for positively formulated items; disagree or strongly disagree for negatively formulated items.

Self-Efficacy

A statistically significant positive change from preintervention to postintervention was identified on both the *pain* and the *other symptoms* subscales. The median preintervention score for the *pain* subscale was 12.0 (range 5-16) and the median postintervention score was 14.0 (range 6-17), resulting in a median difference of 2.0 ($P=.01$). The median preintervention score for the *other symptoms* subscale was 16.0 (range 8-22) and the median postintervention score was 17.0 (range 10-22), resulting in a median difference of 1.0 ($P=.03$). One participant did not fill out this questionnaire and one missing item was replaced.

Emotions

There was no improvement postintervention on the positive emotion subscale ($P=.77$) (median preintervention score 34.0, range 31-46; median postintervention score 35.0, range 28-45). A statistically improved postintervention score was identified on the negative emotion subscale ($P=.02$) (median preintervention score 12.0, range 10-23; median postintervention score 11.0, range 10-16). One participant did not fill out this questionnaire and three missing items were replaced.

Qualitative Results

The App as a Reflection Support

Out of 12 participants, 8 (67%) described positive experiences related to reflection on strengths after using the app. They described feeling more aware and reminded of their strengths

and how that felt good. They described how the app, in particular the strengths items, made it easier to reflect on strengths than when they reflected without the app, as they were asked to do in the pretest questionnaire. The overview of strengths and goals at the end was appreciated and a few mentioned liking the option to print it out to keep visible as a reminder and for a continued awareness process.

You go in, and then you talk about everything that's wrong, and then you get some medicines. And then you hope it will work out OK, sort of. While on the other hand, thinking about these strengths, just becoming a bit aware of how good your situation really is, even if your body isn't a hundred per cent. Getting a bigger picture of things, I think this is really useful. [Participant #1]

Out of 12 participants, 5 (42%) described already being generally aware of their strengths. Some of them had experience of a strengths-based approach in their work or education in leadership or health care, and 3 (25%) described the reflection on strengths as a neutral experience, attributing this to the fact that it was not new to them.

I think I'm very aware of my strengths. I've worked a bit with this before, so ... and I am also very positive by nature. So for me, I think I have such a clear picture of this at the moment, that I felt that with the short time I used the tool, it was maybe not so useful for me. [Participant #11]

The three response alternatives for grading of strengths were generally well received. Some reported finding the items they had marked as *partially* as the most important ones to discuss with the provider and also as something to work on themselves. Some described liking the inclusion of the *no* items on the overview, as this was found to reflect areas for improvement. One participant described that it was difficult to choose response alternatives since strengths varied over time, and another described finding it difficult grading the strengths without having a specific context in mind. Two participants found the strengths items somewhat vague or general. One described missing an item on well-being where she could specify how she created moments of well-being during the day. A couple suggested adding items on negative traits so that you could also reflect on what negative traits were not a description of you.

The participants had different experiences related to the goal setting part of the app. About half of the participants appreciated this functionality and said that they had written a goal of their own without difficulty.

That was maybe the one that I had most benefit from. Yes, because I have a very clear goal. All along I've had in my mind that I would go back to work. This is very important to me. But when I had to set up subgoals, I became much more aware that, okay, there was actually a strong connection here. These are things that you must be able to get done so that you will manage to reach that goal, in a way. So that process of becoming aware, and, and so which of my strengths I can use to achieve that. That is what I gained the most from. [Participant #7]

Others described setting a goal as difficult and, similarly, some described linking strengths to goals as challenging. A few expected a clearer link or transition from registering strengths to setting goals. Some perceived the written guidance available in the app as helpful and adequate for goal setting, but not all had seen this information and some stated they needed more guidance to be able to set a goal in a constructive way. A few had goals they felt unsuccessful at reaching, causing them to feel bad about themselves. Some said they needed a clearer picture of the setting and what type of health care personnel would be providing follow-up to know what kind of goal to set. Some participants described expecting the app to make goal suggestions based on their registration of strengths (eg, suggest a goal related to building or using more strengths for items marked as *partially*).

The App as a Dialogue Support in Health Care

The majority of the participants were generally positive toward sharing the overview of strengths and goals with their health care providers. However, several participants reported concerns about the use of the overview in a dialogue with a health care provider. Some wondered if the health care providers were able to use the overview in a useful way and if they had the time available to do so in settings where learning and mastery were not prioritized topics. A couple of participants expressed a concern that giving the health care provider an overview of the patient's strengths might lead to less attention being paid to the need for help. A few suggested that the strengths registered as *not relevant* or *partly relevant* were those that might be most relevant to discuss with the health care provider. When asked about which of their health care providers might be relevant for the dialogue on strengths, many of the participants said that it would not be their general practitioner or rheumatology specialist, mostly due to time limitations, but also because of not meeting the same physician at follow-ups. Several other health care professionals were suggested as being more suitable for a conversation that included the strengths summary (eg, psychomotor therapists, psychologists, social workers, nurses, and psychiatric nurses). Almost all said they believed the app could be useful in a self-management program setting, either as a reflection to prepare them for the program, as a reflection exercise to prepare for group discussions, or as a follow-up and reminder after the program if more self-management support functionality was included.

Several described how the topic of strengths was neglected due to a focus on treatment and time limitations, and how they had to search for the health care provider that could help them work toward better self-management of the illness beyond medical treatment. Conversely, a few others described having received health care that addressed their support needs in a positive way.

No, there is just no focus on that. There just isn't. It's all about swollen joints and where you have pain. Inflammation and medication. That's what it's about. It even took many years. After all, I've been ill for a long time. So it took many years before I heard about the offer of courses and training in life skills. And ... yes, things like that. [Participant #3]

User-Friendliness and Suggestions for Improvement

The majority of the participants found the app generally easy to use. Still, half of the participants reported some minor usability issues (eg, being unsure if something was saved before continuing to the next page or how to move back a step, finding the buttons too sensitive or quick, and missing a better overview of the functionality from the start). A few did not notice the possibility or understand how to add subgoals to the main goals or to link their strengths to a goal (eg, did not see where to press to find the text field for subgoals). Many of the participants mentioned liking the animated instruction video but a few also suggested adding more information, specifically about the health care provider receiving the overview and what to expect from the follow-up dialogue. Participants provided several suggestions for added functionality, and some had expected an app with more functionality relating to self-management support. The most common suggestions involved the following:

1. The app should give advice and suggestions based on the strengths registration about how to improve and/or build strengths and a feature to help users leverage their strengths (eg, providing a progress overview of strengths use or help with setting a strength-related goal).
2. Refining the goal-setting and goal follow-up features within the app (eg, more guidance in setting goals, reminders, view of progress, and encouragement).

A few also mentioned the possibility to add a feature aiming to help the user prepare for a consultation (eg, what to request help for and how).

Discussion

Principal Findings

In this study, we developed a mobile app to support reflection on personal strengths for patients in need of self-management support due to a chronic illness and then tested its usability. In general, the patients reported that the app supported reflection on their strengths and was easy to use. The results on the goal-setting part of the app were mixed, as many of the patients did not find it helpful to register a goal and/or reflect on which of their strengths would help them toward achieving the goal. Even though the main prototype features were based on prior work and were not changed in any major ways during the formative evaluation, both patients and health care providers gave feedback that resulted in adjustments of the design of the prototype. Minor functionality changes were made (eg, to enable patients to mark strengths as partially possessed and to skip items considered irrelevant, added guidance on goal setting, and improved navigation). The need for only small adjustments might be due to considerable prior work during the inquiry phase [23,24]; however, testing in clinical practice might have resulted in more adjustments being made (eg, on the goal-setting part).

During the formative process, patients reported finding it important to include in their overview of strengths not only the strengths they identified with, but also the ones they identified with partially or not at all. Patients described how these items, particularly items marked *partially*, were areas they wanted to

work on and focus on in a following consultation. This is in line with a view of strengths as malleable qualities that can be cultivated, as opposed to fixed traits [6]. The inclusion of self-management behaviors on the list of strengths, and not solely character strengths or individual qualities, can also contribute to explaining the importance of not only identifying strengths currently present, but also including strengths that have been used previously or that the user wants to develop. Skills and behavior are commonly included in definitions of strengths [18,35]. Overall, the list of strengths was positively received by both patients and health care providers; its inclusion of 42 items was not perceived as overwhelming. Participants, both patients and health care providers, generally agreed that the reflection on strengths was important in itself, and that it promoted positive emotions, although some patients did point out the possibility of some negative effects on the interaction with clinicians. The positive perceptions by patients and health care providers are similar to results reported from related work done at community centers in the United States, to develop an app for patients from disadvantaged backgrounds. However, in that setting, additional video prompts were needed to help patients see and report their strengths [18].

Both patients and health care providers had many suggestions for improving the app by adding functionality that would extend its usefulness beyond the reflection and the subsequent consultation (ie, providing support and guidance on using strengths, cultivating strengths, and goal achievement). Therefore, a potential next iteration of the app could include more educational content and exercises. Since no general theoretical model for strengths-based assessments or interventions is available to date [35], the added material should be anchored in evidence-based behavioral change theory supporting a strengths-based approach, such as acceptance and commitment therapy [36] or goal-setting theory [37]. Many, but not all, participants agreed on the importance of viewing the strengths in relation to a goal. However, the results indicate clearly that the goal part of the app needs to be expanded to include more guidance on goal setting and additional functionality to support goal achievement over time.

The results indicated changes in a positive direction in self-efficacy and negative emotions. This is promising, but due to the small sample and study design, these results need to be interpreted with caution; more research is needed to explore whether the app can promote clinically significant changes. Interestingly, the results did not show changes in positive emotions and were, therefore, not in line with models and evidence suggesting positive emotions as a mediating factor between positive activities and well-being [12,17].

Helping patients to recognize and cultivate their strengths relevant for their individual values is essential for person-centered health care [1]. However, a cautious approach toward interventions promoting standardized ways or tasks to cultivate strengths is warranted, since different kinds of interaction and support will be needed depending on the person and context [1]. Health care providers' beliefs in the importance of providing person-centered care, their contextual possibilities, and communication skills are crucial [1,38]. A strengths-based app as presented here might potentially be a helpful supplement

for health care providers in engaging their patients. More research on the efficacy of this app is needed before making it available and recommending it to users. Exploring the use of the app in the context of self-management programs might be a feasible next step. Even though one specific patient group was involved in this study, the app itself was made without any reference to a specific diagnosis and might, therefore, be suitable for people with different chronic illnesses. It might also be of interest to test the use of the app in the context of the patient's home and involving a relative or a friend, as apps designed to improve communication between patients and health care providers can also prompt patients to share their experiences with relatives [39]. Framing the task of identifying strengths as reflecting on positive memories of self or visualizing best possible selves seems to be promising [40] and might be important to consider when asking patients to identify strengths as a way to cultivate a strengths-based growth mindset.

Limitations

Limitations of the study include the small sample size with few participants in each iteration, a sample with a majority of women with one specific chronic disease (ie, rheumatic diagnosis), and the recruitment from a specialized hospital unit and patient advisory group. A small number of participants is not uncommon in formative evaluation studies but a larger number would have been preferable to promote variance in feedback. A majority of the patients invited to participate were women; thus, adjustment in recruitment methods might have been necessary to include a more balanced sample. Men and patients recruited from primary care might have experienced the app differently, since they might be expected to have less experience with extended self-management support and programs. During

the testing sessions, the participants met with researchers and team members involved in the development of the app. This might have resulted in a bias toward positive results, something that might have been addressed by involving an independent person during the testing. The inclusion of two patient representatives throughout the project was a strength, as they grew confident in giving their honest opinions over time and had the advantage of consulting each other. The development platform for the study was Unity, a platform most suitable for creating games. This turned out to be a suboptimal choice for this project, as the platform was new to the developer team and the development took more resources and time than anticipated; also, no game-like features ended up being included in the app. During the formative evaluation task, task success was evaluated by observation; in the usability test of the app, evaluation took the form of a postintervention interview and assessment of what had been registered in the app. A more systematic use of a usability model might have led to more detailed measures of usability (eg, time on task or error rate) [41]. Research is needed on the usability of the app in a clinical setting and on how its usefulness is perceived by health care providers.

Conclusions

In this formative evaluation of a mobile app to promote patients' reflection on their strengths, patients perceived the app as meaningful and supporting awareness. The results provide preliminary evidence for beneficial effects on negative emotions and self-efficacy. The results suggest building in functionality to support strengths use and goal attainment; the results show the utility of a careful process of app refinement with multiple stakeholders. Further studies on efficacy and usability in a clinical setting, including health care providers, are needed.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshots from the low-fidelity prototype (in Norwegian).

[[DOCX File , 867 KB - formative_v4i3e16831_app1.docx](#)]

Multimedia Appendix 2

Refined list of strengths used in the Styrkefunn app (in Norwegian and English).

[[DOCX File , 17 KB - formative_v4i3e16831_app2.docx](#)]

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Original Paper

Patients' Attitudes Toward an Online Patient Portal for Communicating Laboratory Test Results: Real-World Study Using the eHealth Impact Questionnaire

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Abstract

Background: Communicating laboratory test results online has several advantages for patients, such as improving clinical efficiency and accessibility, thereby helping patients to take an active role in managing their health.

Objective: This study aimed to investigate the experiences and self-efficacy of patients using an online patient portal that communicates laboratory test results.

Methods: We used the online-administered eHealth Impact Questionnaire to explore patients' attitudes toward the portal. Patients visiting the portal were asked to complete the questionnaire. The subscale Information and Presentation assessed the usability of the patient portal and the subscale Motivation and Confidence to Act assessed self-efficacy to determine whether patients were motivated to act on the presented information. We used a cutoff score of 65 or greater to determine whether the portal was rated positively.

Results: The questionnaire was completed by 354 of 13,907 patients who viewed their laboratory results in the patient portal, with a response rate of 2.55%. The mean Information and Presentation score was 67.70 (SD 13.12) and the mean Motivation and Confidence to Act score was 63.59 (SD 16.22). We found a positive, significant correlation between the 2 subscales ($r_{345}=.77$, $P<.001$).

Conclusions: Patients participating in the study rated the usability of the portal positively. However, the portal only slightly helped patients to take an active role in managing their own health. The low response rate precludes generalization of the results. Future research should examine avenues to further increase patients' self-efficacy and study whether portal acceptability differs in subgroups. Patient portals conveying laboratory test results in understandable language seem usable and potentially provide a viable way to help patients take a more active role in managing their own health.

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KEYWORDS

patient portals; eHealth Impact Questionnaire; eHIQ; laboratory test results; attitude to health; self efficacy; telemedicine; usability

Introduction

Background

Patient involvement in decision making and delivery of health care is important to patients, health care providers, and policy makers. When patients are activated to be more engaged in health and disease issues, their behavior changes toward more self-management [1]. Therefore, patient involvement is stimulated as an essential element of patient-centered care and as a means to improve the quality and efficiency of care [2,3]. With modern digital possibilities, such as electronic patient portals, patients' activation and information can be organized more easily. The internet is increasingly being used by care consumers to look for answers about health concerns and has the potential to change health care behavior [4,5]. Although personal health records and patient portals are promising tools, evidence of their effects on patient centeredness of care, efficiency of care, and health outcomes is inconsistent [6-8]. Furthermore, adoption rates of electronic health (eHealth) vary greatly and are often less than 50% [9-13].

Several health care organizations in the Netherlands, such as Saltro diagnostic center, have invested in the development of a high-quality patient portal that is blended into usual care. Solutions that are blended into usual care generally have higher adoption rates [14]. Saltro's portal provides access to laboratory test results, including explanatory information and visualization, for the individual patient [15]. The aim is to facilitate patients to play an active role in their diagnostic process and disease management. Patient health engagement is indispensable to improve diagnostic accuracy [16]. When patients take an active role in this process, for instance by asking questions and voicing their opinions, it improves the diagnostic process [17]. Consistent with the trend of patients being more proactive and involved in their own health care [18], becoming a more knowledgeable consumer may reduce the risk of diagnostic error [19].

The full potential of patient portals will only be reached if patients understand the results that are communicated, in this case, the information that becomes available from laboratory tests. How the content is presented in a portal and how the patient interprets this affects the overall usefulness of the information [20]. The information in a patient portal can, for example, cause insecurity for the patient—as patients can become emotionally destabilized by the confusion or impact of the test results—which can negatively affect patient health engagement [21]. This risk is more prominent when patients find the results difficult to interpret [22]. Problems have previously been reported with the complexity of the provided information, making it mainly useful for patients with high health literacy [23]. Research has also shown that misinterpreting the risk of blood test outcomes is common, with patients underestimating the severity [24]. These findings raise concerns for patient safety. How results are communicated through patient portals is thus important and needs to be done in a manner that minimizes the risk of misunderstanding. Therefore, testing how patients perceive online portals and test

results is recommended, for example, by using the eHealth Impact Questionnaire (eHIQ) [25].

Objective

Previous research with the Saltro patient portal showed that the presented test results were valuable and important to the majority of the participants (ie, members of a health care consumer panel) [15]. To further scientific knowledge, research is needed to examine how patients perceive the online portal. Therefore, we set up a questionnaire study to explore patients' attitudes toward a patient portal that was specifically designed to communicate laboratory test results with explanatory texts and supporting visuals. The first aim of this study was to provide insight into the usability of patient portals (including ease of use, perceived trustworthiness, and appropriateness of information). Examining user experience is important, because perceived trustworthiness has been linked to use and engagement with online health information [26,27]. The second aim of this study was to provide insight into how the Saltro laboratory test results portal affects patients' motivation and confidence to manage their health. This relates to self-efficacy, defined as a person's confidence in his or her ability to perform specific behaviors that are considered beneficial [28]. Self-efficacy is considered important for motivation and intention to act on information [29]. The third aim of this study was to analyze whether there is a positive association between the perceived usability of the patient portal and self-efficacy, consistent with the literature [30,31]. Overall, this study aimed to assess the experiences and self-efficacy of patients using a patient portal and the association between the 2 constructs.

Methods

Design and Participants

We conducted a real-world study between September 2018 and February 2019 to explore patient attitudes toward a patient portal. The participants were patients who received a diagnostic request form from their general practitioner (GP) for a blood test at Saltro, a primary care diagnostic center and laboratory in the Netherlands. Each month approximately 65,000 patients receive a diagnostic request form for a blood test at Saltro. These patients have access to the patient portal, although not all patients use the patient portal. Patients who viewed their test results in the patient portal were approached online to participate in this study by completing an online questionnaire. There were no specific inclusion or exclusion criteria. This study did not require approval from an ethics committee, because no personal information was collected, and the data could therefore not be traced back to the individual.

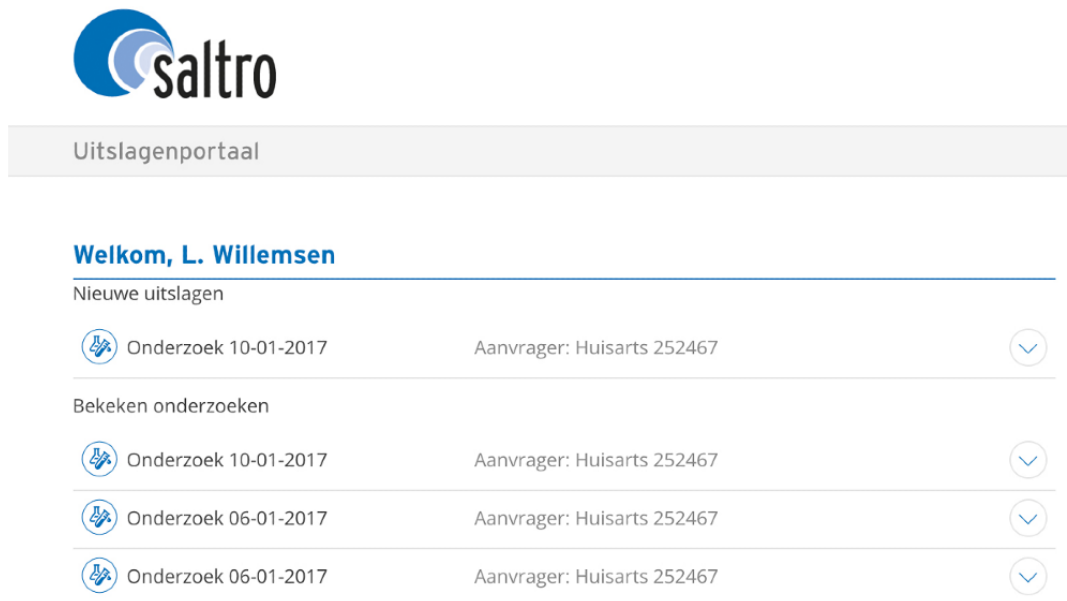
Patient Portal

In 2015, Saltro launched a test result Web-based portal that gives patients access to their laboratory test results, including understandable explanatory information personalized to the individual patient (based on sex and age). The portal was created together with health care professionals and patients. All medical content was written by a multidisciplinary team consisting of a GP, a communication specialist, and a clinical chemist. The texts were written to be understandable for the majority of

people and have been reviewed by patients and adjusted based on their advice. The level of health literacy of the result information has been estimated at communication level 1B on the scales of the Common European Framework of Reference for Languages [32]. A previous evaluation study showed that over 85% of patients found the accompanying text with the laboratory results comprehensible [33]. Daily, approximately 300 unique individuals look up their laboratory results in the portal. Patients also have the option to share their results with others.

After having blood drawn, patients can look up the test results by logging in to the GP website with a username and password. The login procedure is in line with Dutch security legislation and guidelines (ie, the Dutch Personal Data Protection Act) and the General Data Protection Regulation guidelines. There are no age restrictions to logging in. After logging in, the patient sees an overview of all new and old laboratory tests ordered by date (see [Figure 1](#)). This makes it possible to compare new test results with previous results.

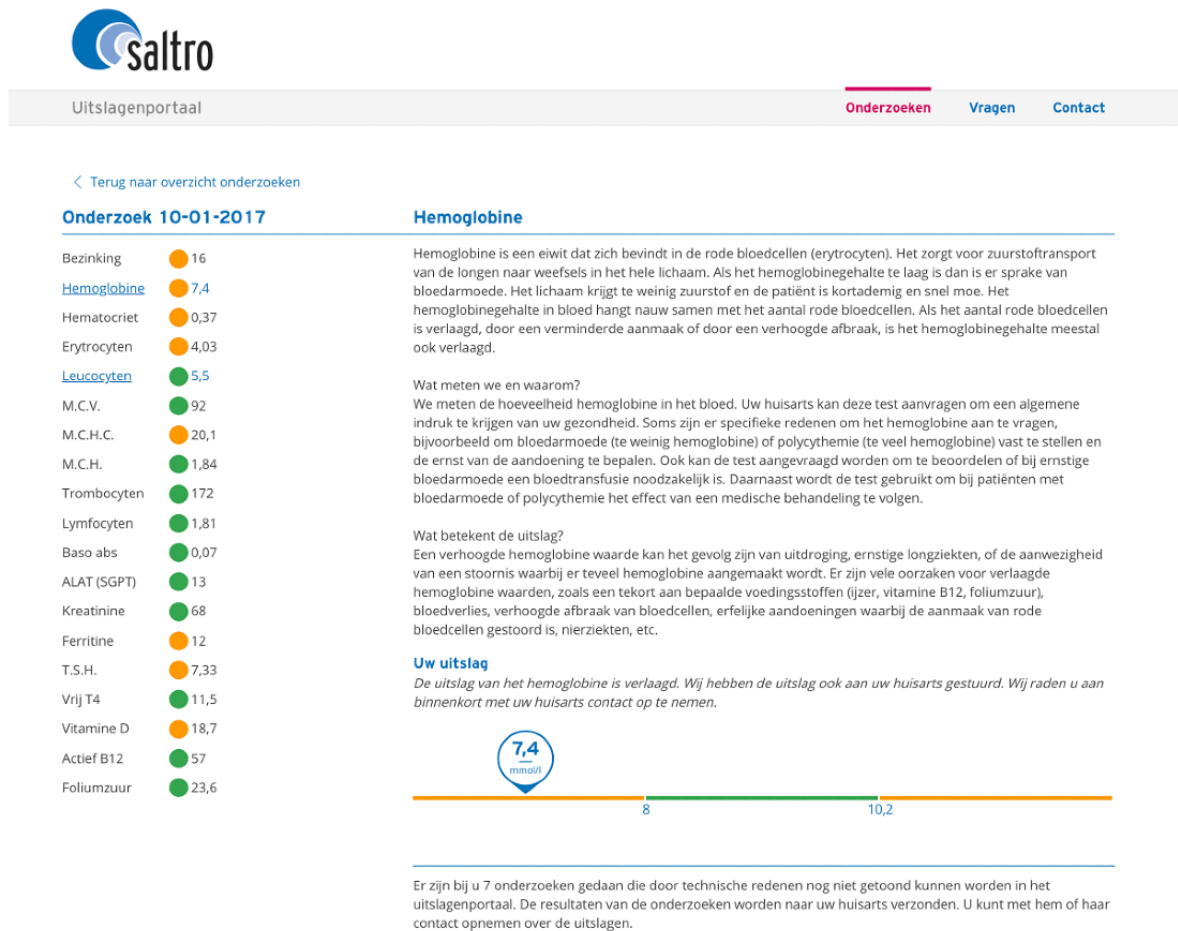
Figure 1. Patient portal overview showing the laboratory tests that were ordered, with the result of the most recent test displayed at the top.



After clicking on a specific date, the patient is shown the results of the laboratory test that was performed on that date (see [Figure 2](#)). For each laboratory test, the patient sees the individual results together with traffic light-colored bullets indicating normal or abnormal results. Clicking on an individual test result shows an explanation of the laboratory test results in a simple and understandable manner. The texts contain an explanation about the test, what was measured, and why a physician might order this test. If a test result is abnormal, then possible diagnoses are mentioned, and patients are advised to discuss the result with the GP. Next, the individual test results are discussed together, and an explanation of what the results could mean for the patient is given.

In addition to the text, a visual is presented underneath the explanatory text (see [Figure 2](#)). The visual presents the

individual numeric value of the laboratory test result and how it relates to the reference value(s). Colors are added to emphasize this range. The reference values differ per laboratory test, and sometimes also by sex and age. A green dot or line means that the result is normal for the patient, and there is no deviation. An orange dot or line means the laboratory result is divergent or abnormal. As the individual numeric value of the laboratory test is presented above the line, patients can see whether their value is normal or deviates from the reference value. The majority of patients find this information valuable and important [15]. Patients are referred to their GP if they have questions. If the dot or line is red, it means the laboratory result is severely deviating (compared with the reference value). In that case, Saltro directly contacts the GP to get in contact with the patient for suitable treatment. [Textbox 1](#) shows an example of a patient journey.

Figure 2. Display of the results of a specific laboratory test in the patient portal.**Textbox 1.** Example of a patient journey.

A person develops complaints about his health and goes to the general practitioner (GP). The GP examines the person and requests blood tests. The person goes to the phlebotomist from Saltro, who collects blood, which is analyzed in the laboratory. The same evening the person can look up the results in the portal. He can see which tests are normal and not likely to be the cause of health complaints. He can see what is tested and will know what is functioning accurately in his body, which will be reassuring. He can also see and choose to read the divergent laboratory results first. He can compare the value with reference values to see how deviating the value is. He does not have to search on the internet; he reads quickly what this test means and can contact the GP to discuss worries and questions, and to make decisions together regarding further steps and treatment.

Outcome Measure

The primary outcome of this study was the second part of the validated Dutch version of the eHIQ [25,34]. The eHIQ is a self-reported questionnaire of which Part 2 measures patients' attitudes toward a *specific* health-related website, in this case, the patient portal. We chose the eHIQ for the following reasons. First, the eHIQ assesses the patient's perspective of the website. Second, the questionnaire is translated and validated in Dutch. Third, information from the eHIQ can be used to compare the effects of the websites for benchmarking; with this study we set a first standard. Fourth, the information can be used to improve a website further, in this case, the patient portal. Each of the 26 items is scored on a 5-point Likert scale ranging from "strongly disagree (1)" to "strongly agree (5)." The questionnaire has 3 subscales: (1) Information and Presentation, (2) Motivation and Confidence to Act, and (3) Identification. The Information and Presentation subscale has 13 items and measures whether

people find the website easy to use; this includes items on understanding, trustworthiness, and whether images used were appropriate. This subscale relates to usability. The Motivation and Confidence to Act subscale consists of 10 items and assesses whether an individual felt reassured after reading the information on the website and was motivated to manage their health. This subscale relates to self-efficacy. The final subscale, Identification, consists of 3 items and measures whether individuals identify with others who use the website. An example item is "I feel I have a sense of solidarity with other people using the website." As users of the patient portal do not interact with other users, we considered this subscale to be irrelevant for this study and therefore did not discuss it further. We transformed the total scores for each subscale to a scale of 0 to 100, with higher scores representing a more positive attitude. No official cutoff score is available to determine whether a website or portal is rated as positive or negative. In consultation with the authors who translated and validated the

eHIQ in a Dutch population of eHealth users, we determined that a score of 65 or greater is considered positive. The eHIQ has good construct validity, internal consistency, and test-retest reliability [25,34]. Cronbach alpha in this study was considered good (.88 to .90).

Procedure

Patients who received a laboratory request form for a blood test at Saltro and who used the patient portal in the period between September 2018 and February 2019 were digitally approached to complete the eHIQ-Part 2. After patients viewed their results in the portal, a pop-up window appeared asking them whether they wanted to fill in a questionnaire. Below this question, the questionnaire was shown to patients and patients could complete it in the portal. Individuals who were unwilling to complete the questionnaire (based on the first question) had to click the pop-up away. These individuals, however, were asked to complete the questionnaire again when they logged in at a later point to view other test results. Patients could complete the questionnaire only once.

Completed questionnaires were automatically sent to us by email. The answers to the questionnaire were coupled to the last test result, indicating whether it was normal or deviant, and the number of laboratory requests for that participant. No personal information of the participant, type of blood test, and the interpretation of the laboratory results were visible to us.

Statistical Analyses

To gain insight into the patient's perceived usability of the patient portal and their self-efficacy of using a patient portal, we performed descriptive statistics. We calculated the mean scores of the 2 eHIQ subscales and used a cutoff score of 65 or greater to determine how the portal was rated. When the mean of the subscale was 65 or higher, we evaluated the subscale positively. Also, we examined the highest- and lowest-scoring items for each subscale to get a better understanding of which aspects of the patient portal were appreciated and which could be improved further. For items with the same mean score, we chose the items with the highest precision. To examine whether the perceived usability of the patient portal (first subscale, Information and Presentation) was positively associated with self-efficacy (second subscale, Motivation and Confidence to Act), we performed a Pearson correlation. Data were normally

distributed and we identified no significant outliers. We performed all analyses using IBM SPSS Statistics version 24 (IBM Corporation).

Results

A total of 13,907 patients viewed their laboratory results on the patient portal and were invited to complete the eHIQ. The questionnaire was completed by 354 patients (2.55%). These participants completed all items of the eHIQ. The mean score of the subscale Information and Presentation was 67.70 (13.12) on a scale ranging from 0 to 100. This subscale of eHIQ thus scored above the set cutoff score of 65 and was evaluated positively. The mean score of the subscale Motivation and Confidence to Act was 63.59 (SD 16.22) on a scale of 0 to 100. This score was just below the set cutoff score and was therefore not considered positively evaluated. Table 1 presents the mean scores of the 2 subscales and the individual items.

We identified the 3 highest- and lowest-scoring items of the 2 subscales. The highest-scoring items on Information and Presentation were trust in the provided information (mean 4.06, SD 0.69), ease of understanding the information (mean 4.06, SD 0.81), and use of understandable language in the portal (mean 4.04, SD 0.80). The lowest-scoring items were about whether the images were distressing (mean 3.44, SD 0.79), tips were useful (mean 3.27, SD 0.94), and website imagery was appropriate (mean 3.27, SD 0.71). The highest-scoring items on Motivation and Confidence to Act were on better understanding personal health by using the website (mean 3.86, SD 0.74), being encouraged to take health-beneficial actions (mean 3.85, SD 0.93), and confidence to take action (mean 3.56, SD 0.84). The lowest-scoring items were on whether the website would be consulted to make a decision about health (mean 3.38, 0.95), gives confidence to discuss health with other people (mean 3.37, SD 0.94), and gives confidence to explain health concerns to others (mean 3.36, SD 0.91).

To examine whether the perceived usability of the patient portal was positively associated with self-efficacy, we calculated a Pearson correlation. There was a large, positive, significant correlation between the subscale Information and Presentation and Motivation and Confidence to Act ($r_{345}=.77, PP<.001$). This finding was in line with our expectations.

Table 1. Mean scores of the 2 subscales of the eHealth Impact Questionnaire (eHIQ)-Part 2 and the individual itemsa.

| Subscale and item | Score, mean (SD) |
|--|------------------|
| Information and Presentation | 67.70 (13.12) |
| I trust the information on the website | 4.06 (0.69) |
| I can easily understand the information on the website | 4.06 (0.81) |
| The language on the website made it easy to understand | 4.04 (0.80) |
| The information on the website left me feeling confused ^b | 3.95 (0.98) |
| I value the advice given on the website | 3.79 (0.78) |
| The website is easy to use | 3.82 (0.89) |
| The website provides a wide range of information | 3.73 (0.83) |
| The website has a positive outlook | 3.64 (0.88) |
| The people who have contributed to the website understand what is important to me | 3.63 (0.79) |
| On the whole, I find the website reassuring | 3.51 (0.82) |
| I found the images on the website distressing ^b | 3.44 (0.79) |
| The website includes useful tips on how to make life better | 3.27 (0.94) |
| Photographs and other images were used appropriately on the website | 3.27 (0.71) |
| Motivation and Confidence to Act | 63.59 (16.22) |
| The website helps me to have a better understanding of my personal health | 3.86 (0.74) |
| The website encourages me to take actions that could be beneficial to my health | 3.85 (0.93) |
| The website gives me confidence that I am able to manage my health | 3.56 (0.84) |
| The website encourages me to play a more active role in my health care | 3.56 (0.88) |
| I have learned something new from the website | 3.55 (0.97) |
| I feel more inclined to look after myself after visiting the website | 3.53 (0.87) |
| The website prepares me for what might happen to my health | 3.42 (0.91) |
| I would consult the website if I had to make a decision about my health | 3.38 (0.95) |
| The website makes me more confident to discuss my health with the people around me (for example, my family, or people at work) | 3.37 (0.94) |
| The website gives me the confidence to explain my health concerns to others | 3.36 (0.91) |

^aAlthough the Dutch version of the eHIQ was used in this study, for the purpose of this paper the items from the standard English-language version of the eHIQ are shown.

^bThis item was reverse scored.

Discussion

Principal Findings

This study aimed to investigate patients' attitudes toward a patient portal specifically designed to communicate laboratory test results, thereby helping patients to take an active role in managing their own health. Findings showed that the usability of the patient portal, assessed by the subscale Information and Presentation of the eHIQ, was rated positively. This suggests that study participants found the patient portal easy to use, considered it trustworthy and appropriate, and found the provided information easy to understand. The self-efficacy of patients using the patient portal, indicative of patients' motivation and confidence to act on the presented information, also received a relatively high score, but this score was just below the set cutoff score that we used to determine whether patients' attitudes toward the portal were positive. In addition,

as expected, we found a positive association between the portal's usability and patients' self-efficacy [30,31]. Altogether, the findings show that patients were generally positive toward the portal, but it is important to identify opportunities to further optimize patients' self-efficacy, as this affects a person's intention to act on the information.

Comparison With Prior Work

The usability of the patient portal, which includes patient understanding, was rated positively. This is important because, if all patients are to receive their test results automatically online, the portal needs to be easy to use and provide information that is understandable for all. The high score on usability is in line with previous research examining patient portals with laboratory test results [35-37]. The lowest-scoring items on usability were on provided tips and imagery, which we considered less relevant for this patient portal, as the portal does not include tips or imagery. Therefore, the actual usability of this particular patient

portal might have been higher than this study found it to be. As no sociodemographic information was available, we could not determine whether the results differed by subgroup (eg, age, sex, level of health literacy). Future studies should examine whether the patient portal with laboratory test results is usable for all.

As mentioned above, the self-efficacy of patients using the portal—measured with the Motivation and Confidence subscale—was slightly lower than the set cutoff score. Considering that this was, to our knowledge, the first study of a patient portal to use the eHIQ, no official cutoff was available, and this limits our ability to compare this study's self-efficacy score with other studies' results. Moreover, to the best of our knowledge, no studies have examined patients' self-efficacy with questionnaires other than the eHIQ after being presented with online laboratory test results. Both usability and self-efficacy affect an individual's intention to follow up the test result [29,38]. Therefore, it is important that these factors be evaluated and improved where needed. We discuss some potential avenues for improvement below.

One potential area to improve is the use of reference values when communicating laboratory test results. Currently, a visual presents how the numeric value of the laboratory test result relates to a reference value that takes sex and age into account (when relevant). This standard reference value might, however, be less relevant for individuals with a chronic condition (eg, diabetes). Research has now shown that using reference values that are clinically appropriate (ie, personalized) can help to improve patients' understanding and decrease negative responses to the results [39]. Replacing standard reference values with clinically relevant values will not be relevant for all laboratory tests (eg, not for sexually transmitted infection tests), but might be useful for other tests (eg, glucose, kidney function), and future studies should investigate this possibility.

A second potential area to improve is the understanding and effective use of laboratory test results by providing additional information [40]. One study showed that 50% of patients using a portal accessed additional, external information related to the diagnostics test results [36]. Adding additional information, however, might also increase the complexity of the presented information and this, in turn, might decrease understanding and limit a patient's ability to extract the relevant information [41]. This highlights the need to find the right balance between providing enough information and information overload. Adding links to additional information might provide a solution, by making more in-depth information easily available to those interested, while not running the risk of overwhelming patients with large volumes of text.

A third potential area to improve relates to patient portal use being predicted by perceived usefulness and perceived ease of use [38]. This emphasizes the necessity to involve end users when designing patient portals to ensure that the portal is perceived as useful and easy to use [42]. The Saltro patient portal was developed in close collaboration with both patients

and health care providers, thereby attempting to address the end users' needs and assure usability. Nevertheless, it is important to continually evaluate these aspects to ensure that they are adequately met and to identify areas for future improvements.

Limitations and Strengths

Even though communicating laboratory test results online can have some advantages, such as improving clinical efficiency and improving accessibility of results, there is a limited number of studies on the use of such systems [41,43]. This study, therefore, adds to the limited existing literature base. Some limitations, however, also need to be discussed. First, the response rate was low and, consequently, there is risk of self-selection bias. A low response rate, however, does not automatically equal low study quality, as a low response rate is only problematic when it affects the sample's representativeness [44]. Still, 97.45% (13,553/13,907) of the patients did not complete the study questionnaire. This high rate of noncompletion precludes generalizing whether the patient portal display and explanation of results are acceptable and informative for all patients.

Second, as mentioned above, no sociodemographic information was available from participants. This restricted us from doing subgroup analyses to see whether attitudes regarding the portal were dependent on these characteristics. Limited research is available on whether portal use and acceptance differ between groups. One study did find that portal use was influenced by age, presence of a chronic illness, and eHealth literacy level [39]. Further research into potential group differences is necessary, and such information can be used to fine-tune the portal to make it acceptable for every user.

Third, in some cases, it is important that patients act on the test results presented in the portal. Even though self-efficacy can be a valuable predictor of action [45], it is still a proxy of action and it would be interesting to study the effect on actual behavioral activation.

A strength of this study is that patients completed the questionnaire immediately after they accessed the portal and viewed their results, thereby limiting recall bias and giving an accurate picture of patients' attitudes toward the portal.

Conclusions

Study participants evaluated the usability of Saltro's online patient portal communicating laboratory test results positively. Nevertheless, it should be noted that the low response rate precludes generalization of the results. Patients' motivation and confidence to act on the presented information also scored relatively high, but future research should examine ways to further optimize patients' self-efficacy to increase an individual's intention to act on the information. In addition, it is important to determine potential group differences in portal use and acceptance. Overall, study participants had a positive attitude toward the patient portal and the portal potentially can help patients take a more active role in managing their own health.

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Conflicts of Interest

ETK, RTS, AG, and AV are employees of Saltro, where the portal has been developed and implemented.

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Abbreviations

eHealth: electronic health

eHIQ: eHealth Impact Questionnaire

GP: general practitioner

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Original Paper

Understanding Students' Mental Well-Being Challenges on a University Campus: Interview Study

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Abstract

Background: Research shows that emerging adults face numerous stressors as they transition from adolescence to adulthood. This paper investigates university students' lived experiences of maintaining mental well-being during major life events and challenges associated with this transitional period. As we continue to design health technology to support students' mental health needs, it is imperative to understand the fundamental needs and issues particular to this phase of their life to effectively engage and lower the barriers to seeking help.

Objective: This study first aimed to understand how university students currently seek and receive support to maintain their mental well-being while going through frequent life events during this period of emerging adulthood. The study then aimed to provide design requirements for how social and technical systems should support the students' mental well-being maintenance practice.

Methods: Semistructured interviews with 19 students, including graduate and undergraduate students, were conducted at a large university in the Midwest in the United States.

Results: This study's findings identified three key needs: students (1) need to receive help that aligns with the perceived severity of the problem caused by a life event, (2) have to continuously rebuild relationships with support givers because of frequent life events, and (3) negotiate tensions between the need to disclose and the stigma associated with disclosure. The study also identified three key factors related to maintaining mental well-being: time, audience, and disclosure.

Conclusions: On the basis of this study's empirical findings, we discuss how and when help should be delivered through technology to better address university students' needs for maintaining their mental well-being, and we argue for reconceptualizing seeking and receiving help as a colearning process.

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KEYWORDS

emerging adults; university students; life events; mental wellbeing; mental wellness; mental health; social support

Introduction

Background

Emerging adulthood, a transitional period between adolescence and adulthood, is characterized by various challenges individuals struggle with while taking on adult roles and responsibilities

[1]. The literature defines emerging adults as those aged from 18 to 29 years [1]. Some key characteristics of emerging adulthood are instability, identity exploration, self-focus, and feeling in-between (ie, not quite an adult and not quite an adolescent) [1]. These characteristics are particularly prevalent in students on college campuses as they face increased academic pressures in addition to sudden shifts in their social, geographic,

and economic life contexts [2]. According to a recent national survey of college students in the United States [3], over the last year, 85% of the students felt overwhelmed by their given tasks, and 49.8% of the students reported feeling hopeless.

During this transitional phase of emerging adulthood, university students experience various life events at different scales, ranging from entering college, leaving home and moving to a new city, and making new networks, to taking finals and looking for a job [4]. These life events become potential stressors as students are expected to increase their personal responsibility and independence and make constant adjustments, including personal, emotional, and social adjustments [5]. Research shows that support from peers, family, and health care resources aids their life satisfaction, self-esteem, perceived social acceptance, and well-being [6,7].

With advances in technology, researchers have approached the problem of supporting students' mental health through a variety of technological interventions and tools. Novel tools and mobile apps have been developed to support clinical interventions, risk predictions, and self-monitoring of illness triggers and symptoms, such as home clinical therapy mobile app [8], self-monitoring tools that help track and reduce stress [9], and social media platforms to provide social support and monitor mental health risks [10] and suicidal ideation [11]. These tools help to monitor and forecast mental illness and allow clinical therapies and treatments to be more accessible. However, such clinical approaches to technological interventions could leave out those who do not consider their problems to be mental illness or disorder problems but a "normal" part of maintaining mental well-being [12].

We build upon recent work in human-computer interaction (HCI) and Health Informatics [13-17], which approaches university students' struggles and challenges as a mental well-being problem rather than as a clinical, mental illness problem. This approach helps address the problems that students need to engage but often ignore because they consider those problems not to be mental health concerns but "normal" problems that occur during emerging adulthood [12]. Focusing on mental well-being helps us understand students' everyday lived experiences of muddling through major life events during their emerging adulthood.

With this perspective, this study first aimed to understand how university students currently seek and receive support to maintain their mental well-being while going through frequent life events during their emerging adulthood. The study then aimed to provide design requirements for how social and technical systems should support the students' mental well-being maintenance practice. In this paper, we report findings from semistructured interviews with 19 students on a university campus. We identified three key needs: (1) the need to receive help that matches the perceived severity of a problem caused by life events, (2) the need to constantly draw on new support givers because of frequent life events, and (3) the need to negotiate the tension between the benefits of self-disclosure and the stigma associated with such disclosure. On the basis of this study's findings and analysis, we make the following contributions:

- We extend our knowledge about university students' understandings and perceptions of mental health and coping strategies.
- We discuss how students strive to maintain their mental well-being and perceive the boundary between what counts as mental "illness" vs "wellness" in assessing whether to get help.
- We present design implications for sociotechnical systems to support the needs of students to better maneuver through this important transitional life phase.

Related Work

The American Psychological Association defines emerging adulthood as the "in-between age," referring to the phase of development between adolescence and adulthood [18]. Regardless of socioeconomic prospects, those between the ages of 18 and 29 years commonly struggle with "feeling in between" [19]. Emerging adults, particularly those who attend universities, go through a great amount of stress. According to the US Department of Education (2011), student enrollment in college increased to 38% since 1999, reaching its peak. However, the majority of those who drop out of college do so in their first year [20], indicating that the transition process is crucial to students' success. In addition to dealing with academic pressure, they are expected to make a series of adjustments, ranging from academic assimilation to personal (eg, changed interests), emotional (eg, home sickness), and social (eg, finding new friends) adjustments [5].

What makes emerging adulthood more uniquely challenging than other periods is the intensity of multiple life events mounting up together in a short period. The danger of multiple life events occurring in a short period has been noted in life events research—critical life events (eg, moving, starting a new job, leaving family, and paying new rent or mortgage) and their accumulation can predict long-term medical and psychiatric illness problems [21,22]. The major life events of emerging adults often begin with entering college and leaving home and their old, existing networks. To help such students with the struggles brought by the transitional phase of emerging adulthood, the American College Health Association has identified coping with stress as a high priority issue in the Healthy Campus initiative [23]. This initiative takes a multifaceted approach to mental well-being, which includes environmental (eg, managing air quality), physical (eg, eating well), and social (eg, student clubs) health. Universities offer Counseling and Psychological Services (CAPS) with mental health professionals. CAPS further provide campus-wide programs for first-generation college students and underserved students to reduce attrition (eg, drop out) [24-26]. Despite the benefit of these initiatives, the literature still notes the problems of students not utilizing CAPS until emergency situations occur, if they ever do [27]. Nearly 80% of the students who die by suicide never participate in counseling services [28-30]. The reasons for this underutilization include lack of awareness [31], stigma [32], long waiting list times [33], and preference for self-management [34].

Besides the institutional and national effort to support students, many studies showed that students mostly seek and receive

social support from their existing networks in dealing with their struggles. Peer and family support plays a critical role in offering students a sense of belonging [7], affirmation of their concerns [35], encouragement and empathy [36], and facilitation of mental health maintenance as a compensatory measure when other support is unavailable [37,38]. Social support enabled by technology, such as social network sites and Web-based and virtual social communities, has shown the potential benefits to supporting students, such as facilitating students' identity transitions [39], offering access to help when lacking in-person support [40], addressing unpleasant experiences with negative content on the Web [41], and resolving stigmatized concerns [42,43]. However, research indicates that barriers related to seeking and getting social support, including stigma of mental illness [44,45], a sense of autonomy (eg, "I don't need a doctor to solve this problem"), a fear of losing one's positive image (ie, "face") [46], and secrecy and negative cultural attitudes toward mental illness [47], often suppress help-seeking behaviors [48], which hampers students from getting timely and proactive support. These previous studies on emerging adulthood highlight both the critical need for proper support for university students during their stressful life transitional period and the associated barriers that hinder students from seeking and receiving such support.

Researchers developed and evaluated technological interventions for mental health issues such as anxiety and depression. Some examples include Harmony (a mobile health app that assists patients, caregivers, and clinicians in managing serious illnesses) [49], DStress (a mobile app that coaches users in balancing compliance and achievement toward daily goals of stress reduction) [9], the UPRIGHT project (in which researchers designed and validated resilience-based interventions for promoting early adolescents' mental health) [6], and Intellicare (a suite of skill-focused apps that successfully provide users with more flexibility in choosing a suitable treatment) [15]. Furthermore, technology-mediated therapies have been implemented (a conversational mobile app, Pocket Skills, that provides Dialectical Behavioral Therapy [8] and Web-based cognitive behavioral therapy) [50]. Although these interventions have shown their effectiveness and usefulness for treating mental illness, they mainly focus on those who are clinically diagnosed and actively seeking treatment, not those who do not consider their problems as serious mental health conditions but approach them by attempting to maintain their mental well-being.

Upon reviewing the literature on emerging adults' mental health on college campuses, we find examining how students engage everyday life challenges and the everyday maintenance aspect of their mental well-being to be a critical, emerging, and underinvestigated research topic in HCI and Health Informatics communities. As we continue to design health technology to support students' mental health needs, it is imperative to understand the fundamental needs and issues particular to this phase of their life to effectively engage and lower the barriers to seeking help. Building on the previous work summarized here, this study includes the following research questions (RQs):

- RQ1: How do university students perceive their problems and maintain their mental well-being while going through various, frequent life events?

- RQ2: What are the implications for designing sociotechnical systems that are tailored to meeting university students' unique needs around life events?

Methods

We conducted interviews with 19 university students (6 undergraduate and 13 graduate) from a large US Midwest university for a semistructured interview study. The inclusion criteria were as follows: (1) English speaking, (2) interested in speaking about their mental health or well-being, and (3) enrolled either as an undergraduate or a graduate student of the university. We recruited the participants through school-wide departmental email lists and word of mouth, and we stopped data collection when saturation was reached.

The study was approved by the Institutional Review Board (IRB) of the first author's university, and all coauthors who had access to the transcripts were registered as study team members. Our interview sessions were conducted in private rooms on the university campus. A member of the research team began the interview by informing the participants about the study's goals and interview procedures and assuring them that they could skip any questions they did not feel comfortable answering or stop the interview at any point. The participants were told that confidentiality would be maintained and that they could withdraw their participation at any time without any consequence. This study followed IRB guidelines, which state that if any crisis situation was observed (eg, threats and suicidal posts), the participant would be immediately referred to the staff at the University CAPS. Each participant received US \$15 for study participation.

The duration of each interview session ranged from approximately 1 to 1.5 hours. The questions were designed to help us gain further insights that might not be uncovered in public reports on overall campus climate, where we see increases in student struggles with stress, anxiety, depression, and requests for on-campus counseling services. The interview questions probed the students' process of identifying their stressors, their experiences of seeking and receiving support or help, their development and adaptation of coping strategies to maintain mental health or well-being, and the tools and technologies they used in this process. At the end of the interview, the researchers offered information about college counseling services and other mental health support resources available on campus to those who were in need or had no previous experience of them.

All of the interviews were audio recorded and transcribed for the analysis. This study followed all of our institution's confidentiality, privacy, and security policies for handling and storing all the participants' data. Three researchers analyzed the data using the open coding method [51], using the Atlas.ti 7 (ATLAS.ti Scientific Software Development GmbH) qualitative coding software program. We conducted axial coding to explore and develop the key attributes and dimensions of each theme particular to the RQs. Working collaboratively, we explored, compared, and revised the themes as the analysis progressed. We revised the themes through a series of discussions and iterations until consensus was reached. We also conducted affinity diagramming [52] to generate common themes and

identified any breakdowns and design implications during the analysis process. We followed the Contextual Inquiry Design process [52] to identify common themes from the affinity diagram to generate design requirements.

Results

Overview

In this section, we first provide demographic information on this study's participants and then present the three needs that were identified in this study. These three needs are critical to understanding how students maneuver through various life

events, seek help, and maintain their mental health and well-being.

Study Participants

Table 1 shows the overall participant demographics. The students ranged in age between 20 and 29 years (mean 25 years, SD 4 years), and 13 students were female, and 6 students were male. In all, 7 students were international students. Reported ethnicities were as follows: East Asian (6), non-Hispanic white (6), Indian (5), and African American (2). A total of 14 out of the 19 students had had experiences with professional counseling services. Two (P7 and P19) students were clinically diagnosed with a psychological disorder.

Table 1. Demographic information about our study participants.

| Participant number | Age (years) | Gender | Ethnicity | Counseling and psychological services, or professional service experience |
|--------------------|-------------|--------|------------------|---|
| P1 | 28 | Male | Chinese | Yes |
| P2 | 24 | Male | Korean | Yes |
| P3 | 30 | Female | Taiwanese | Yes |
| P4 | 20 | Female | Indian | Yes |
| P5 | 21 | Female | White | No |
| P6 | 29 | Male | White | Yes |
| P7 | 20 | Female | White | Yes |
| P8 | 29 | Male | Indian | Yes |
| P9 | 20 | Male | Indian | Yes |
| P10 | 27 | Female | Taiwanese | Yes |
| P11 | 23 | Female | White | No |
| P12 | 20 | Male | Indian | No |
| P13 | 24 | Female | White | Yes |
| P14 | 24 | Female | Indian | No |
| P15 | 25 | Female | White | Yes |
| P16 | 25 | Female | Chinese | Yes |
| P17 | 30 | Female | Korea | Yes |
| P18 | 25 | Female | African American | No |
| P19 | 28 | Female | Middle Eastern | Yes |

The Need to Receive Help That Aligns With the Severity of the Problem

The participants emphasized the importance of how and when they receive help for their problems based on how they perceived the severity and duration of the problem they were struggling with. We found that knowing or not knowing when a problem would end and having multiple stressful events accumulate at once mainly affected students' perception about the severity of their problems. This perceived severity then affected the students' expectations about help seeking. Below, we describe how life events affected perceived problem severity and what students considered "good help" to be as a result.

The Severity of the Problem Is Perceived Differently Based on Life Events

The problems students struggled with in maintaining their mental well-being included adjusting to new cities and life on new campuses, meeting new people, paying for tuition, examinations, and job searches. Some of these problems involved more certainty in terms of how long they would last, such as final exams; others, on the other hand, seemed to last forever, such as job search-related stress. Accordingly, uncertainty regarding how long their problem would last affected how students perceived the severity of the problem and how they approached it. For instance, until receiving her recent job offer, P3, who was an international graduate student, had been "really, really stressed." She explained the following:

The past year, when I was first year [of the graduate school], I was really stressed... I would never go back

to my home [in China] during the time because I can only come back with a job offer.

Here, P3 described the stressful event as having lasted for a year, which significantly affected her mental well-being during that year. She did not previously know, nor could she have predicted, how long the job search would take while it was happening. The job search was stressful, and the fact that it occurred over an indefinite period of time added a considerably increased amount stress. P3 was expressing the severity of the problem in relation to the event duration because she was unable to start or plan other things until her job status was secured, directly affecting her legal status to live in the United States after graduation.

In perceiving the severity of their problem, we found that a few students even put a predefined time boundary on the problem (how long it would last) and remarked that their current problems would pass and there would eventually be closure. This perception helped them get through the problem. For instance, when P3 was having a problem with her boyfriend during her job search period, she mentioned that she had given herself 3 months (a limited amount of time) to deal with the stress and move on when she would start a new job:

I told myself just three months to get over it. I was eating snacks, watching TV shows, and doing exercises. [P3]

Starting college as an independent young adult brought multiple problems in school, work, and relationships at the same time. These multiple problems occurring in the same period exacerbated the perceived severity of each individual problem. For instance, P5 experienced a high level of stress when she had a serious problem with her boyfriend while also applying for summer internships and working on her final exams. P8, similarly, shared an extreme, distressing moment because of the stress brought on by multiple, urgent work responsibilities:

There was this one time when I had a very large amount of work to do. I had a part-time job, had one big [class] assignment, and had one [class] project due, all within the next 48 hours. Even if I stayed up the entire 48 hours, there was no way I was going to finish everything. I knew that because of the amount of work involved, and that was really causing me stress because either the assignment, the project or the part-time job had to suffer, and I wasn't sure which. I was being paid for the part-time job, the project was a group project and if I don't do the work then nobody gets a grade, and the assignment was an individual assignment for me, but it was a large part of the grade, so I had to leave at least one. [P8]

P8 further explained that he had to seek emotional support from family members and friends and go to his academic advisor for useful advice. As in the case of P8, multiple problems could occur during the same transitional period, thus requiring the student to navigate the different types of support resources available to receive the proper help. This indicates that merely having one therapist may not work well for students.

Seeking Help That Is Accessible and Available at an Appropriate Time

The urgency and timing of seeking help varied together with whether the students framed the problem as having ended or as ongoing. All students in the study commented on the importance of receiving support during the particular period when the struggles were still happening to effectively deal with their struggles. However, ensuring timely support was challenging because seeking support required a great amount of effort in their hectic daily lives. For instance, students mentioned that they often found resource constraints in their existing support environments on campus. Several participants mentioned that existing support resources such as CAPS and other professional services sometimes failed to address their need to receive help at the right time, especially for time-pressured and serious concerns. This was because of tedious nature of scheduling phone calls, long wait times for in-person appointments, inflexible working hours, and an inefficient screening process, all of which made it difficult to access care in a timely manner:

There was a pretty long waiting time. The initial session was I think after a week and a half, and then the next appointment was after a couple of weeks. Time is the only problem [with CAPS], and I realize that the timing is not in their control because of the number of people here. [P8]

Another student described his experience:

I decided to go to CAPS, and was kind of disappointed because at first I filled out that whole questionnaire and the first meeting wasn't even an actual meeting it was just going over the questionnaire with a counseling student. [P9]

These factors that delayed the timing of receiving help frequently made the students uninterested in reaching out to CAPS for help.

As their perception of the problem severity was time bound, when students were unable to find proper help in a timely fashion, they tried to manage it on their own or consider that the problem might go away some time after they endured that particular stressful event. We found that after a certain amount of time passed, the students did not necessarily want to be reminded of an issue, nor did they feel the need for professional help anymore. Rather, they wanted to put their problems behind them, letting them resolve on their own over time or trying to ignore them. Ensuring help at the appropriate time was particularly tricky for students who were required to change their locations periodically:

I came back home for the summer so I couldn't see them [therapists at CAPS] again. I could have come in the fall but it wouldn't have been the same. It would be a long break and I would have thought through some things on my own and stuff like that. I didn't go to them afterwards. [P9]

As the participants, including P9, left the campus for summer and winter breaks for various reasons such as internships, vacations, or other duties, many had to leave in the middle of

getting help without fulfilling their needs, and they felt that the help that came later was meaningless.

In addition, we found that when seeking and receiving help, some students experienced a discrepancy between what they expected and how the help was actually delivered. Types of problems they had might be similar to those of their peers, as emerging adults on campus were going through similar life events. Although the perceived severity might differ, students felt that their struggles might not look as serious to others as they perceived them to be. In fact, they experienced difficulty in getting proper recognition or serious consideration from others. Consequently, students quickly lost interest or motivation to actively seek help when they did not feel they were getting enough recognition or empathy from others upon initial sharing. P3 mentioned how her problem was not appropriately acknowledged or addressed by the therapists' consultation:

The therapist said, 'Ok it's been one hour, I think we are going to wrap up.' Then I was so surprised, what!? Are we finished? I thought you were going to give me some suggestions. At least some homework for what I am going to do... Then, she [therapist] said, 'no, no you have so many stress to relieve, so this time you just relieve all your tension, you just let your sore come out. And next time we will talk about others.' [P3]

In this quote, P3 showed her frustration about how her severe problem was mostly treated as one of the many other stresses without the proper understanding she expected. In this study, this kind of experience, not getting sufficient recognition of the severity of their problems, made even those students who initially sought help consider that their problems might not be serious enough for professional treatment and that they might need to be manage the problem themselves.

Many of the students in the study wanted to receive help in a more casual way through frequent and informal conversations, instead of fixed (regular but limited) and formal conversations. As most students saw their problems as issues that could come and go and get better or worse, and as similar to what their peers were all dealing with, rather than as mental health issues requiring formal diagnoses, they preferred casual and frequent interactions, which allowed them easy access when needed. P15 expressed the need to see mental health practitioners more frequently and informally as a preventative approach, rather than seeing them only when "something was going wrong," such as "when feeling depressed, when feeling anxious, when having maniac episodes whatever it might be."

Similarly, a couple of students proactively managed their stress through frequent hangouts with friends. P14 shared her experience of using her regular get together as an outlet for her distress:

It makes me feel good about how things are. I get to offload my emotional stress. I do that [talk about things in mind/head] once a week when we all get together. But on a daily basis we don't talk as much about anything emotional or anything about our job,

just like, have you had food, where are you going, things like that. [P14]

P14 designated a weekly time to "talk about things" with a small group of friends who she hung out with on a daily basis as a way to focus on sharing stressful issues, as they might go through similar stressful life events and share similar struggles. Having weekly gatherings with close friends made sharing problems comfortable instead of awkward or uncomfortable.

In sum, students struggled with various problems brought by life events, especially multiple problems concurrently happening during a transitional period, and they tried to look for help that could effectively address the problems. Despite the seriousness of a problem and the critical need for help, the problems students struggled with were mostly considered to be part of normal emerging adulthood-related issues, not "serious" ones, by the students themselves and even by others whom they tried to ask for help. Students thus preferred casual help, or they took a preventative approach so that those "normal" problems would not develop into "serious" ones.

The Need to Build, Rebuild, and Maintain Support Givers for Frequent Life Events

All students participating in the study had recently gone through major life events and changes: they had left their hometowns or relocated, sought or made new friends in college or at work, or made changes in their career—for example, switching majors, changing schools, delaying their degree, and coming back to school from industry. These transitions caused changes in social support structures, exacerbating stress and problems in maintaining their mental well-being. The following quote from P8 illustrates the highly stressful period of transitions and the loss and regaining of social support:

The transition time was very rough because I was used to a place with a lot of people and a lot of activities. When I first came here... I don't know, I found a lot of simple things to be very difficult. I didn't have my own mode of transportation, so had to rely on the bus services. Small experiences like that really added to my stress levels and I found the fact I lived away from the main campus, [which] meant that I had to spend a lot of time on my own, which I didn't like because I like hanging around people. When I was staying alone it was quite difficult for me. [P8]

Relationship Building Is Constantly Needed to Have Access to Potential Support Givers

The various life events the participants experienced not only forced them to quickly adjust to new life contexts and rebuild their social connections but also made it difficult to maintain their existing social connections. For this reason, students often felt that the support they wanted was not readily available or workable, but inconsistent; supportive social groups or support givers were likely to come and go. For instance, P18 described her premed group members with whom she initially developed deep relationships, and she described how these relationships were enhanced by their common struggles and active support for each other. Later, she felt helpless and discouraged when

all the members of the group transferred to other universities or decided to pursue something else:

I think with pre-med courses, it's nice to have a community where you can be stressed out together and fall on each other for advice and study together and help each other. But then when everybody dropped, and it was just me, I think that's when it got to be very stressful because I was doing everything on my own. [P18]

The short-term and inconsistent social support received from their existing support givers was somewhat detrimental to the students' mental health, often resulting in sudden feelings of being lost or alone. Although some relationships were strong and long lasting, the students needed to be prepared to lose connections and relationships they often put a large amount of time and effort into building and rebuilding.

Most of the students in this study experienced the diminishment, disappearance, or replacement of intimate friends they previously relied on to receive support, such as the replacement of high school friends with a small group of close friends from the freshman cohort, or they experienced the quality of relationships with old friends changing over time. P9 explained how the friendships he had with close friends growing up and their support for each other became rather unstable and shifted after 3 years of college as they experienced conflict and disagreement:

These were probably the two people I would go to if I had trouble with school and things, but after I had a disagreement with them, I felt very alone and isolated. Now, I'm a better friend to them but I think because we had that break we're not as close as we used to be. It's always in the back of my mind that we had this fight so I'm not that close to them as much anymore. [P9]

This shows that even with existing support givers (eg, intimate friends), effort was still needed to maintain relationships as all parties went through different stages and events of their own lives during emerging adulthood, affecting their current or future situations, viewpoints, and needs.

While going through different life events and needing to seek appropriate help, the students encountered situations where they needed to determine how to disclose and share their problems with the new social connections they had just built or developed. The new social connections were usually people they had recently met in classes, at work, at various events, or where they lived. For instance, P10 shared her experience of sharing her concerns with a new friend she had started to get close with recently:

I talk a lot this semester with Olivia [her classmate], but like until the end of the semester, not really earlier. I feel like this semester, the early part of this semester I'm always alone because I am mostly in Fishbowl to finish 520 assignment or something. (...) She also shares her concern as well. I think for the academic part, we are very similar. In the same situation, I guess. And we haven't got internship yet

and we're also worried about finding a project, final exams, so it's hard. Our schedules are more similar. We sometimes work together on weekends. [P10]

Having similar situations, interests, or struggles as other individuals helped students quickly build new relationships and potentially share their problems, although the sharing might initially be limited to their common interests.

While sharing problems with newly developed social connections, students did not share their real, deep problems upfront, unless those were the commonly shared issues they already knew about each other (eg, met at a counseling session). They wanted to share problems in a friendship after building a relationship and worried that sharing such issues in the beginning of the relationship could lead to making some "unattractive" or "undesirable" impressions:

I wouldn't necessarily want people to know that to be the first thing they know about me. I want them to know me as a person. I feel like, yes, that's an important thing to know about me in a friendship and stuff, but I don't want that to be the first thing. [P13]

Seeking Alternatives to Support Givers on the Web

Owing to the challenges of having a constant change of support givers while going through frequent life events, the students often sought alternative forms of support, such as making new Web-based social connections and asking for help (eg, Facebook groups, mental health-related web forums, and anonymous others on Reddit or Instagram). As Web-based support is always accessible, students found that this served as a support baseline that they could contact regularly or whenever they wanted to check in as a casual (not as structured and serious as a CAPS or professional service) but also steady (with minimum effort to set up) way of maintaining their mental well-being. However, despite the benefits of having Web-based help, students reported issues with the sustainability and the consistency of support based on their experiences. They believed that the size of the group, the qualities of the anonymous members, and whether there was guidance and a moderator within the Web-based communities often affected the quality of the support they received. Many, including P19, mentioned the double-edged sword aspect of anonymity in Web-based groups and communities regarding the anonymous members and expected behaviors:

I don't like Reddit, not at all! 'Cause Reddit is totally about anonymity. And I don't enjoy that. I think anonymity is to some degree dehumanizing. It's really unaccountable. And people allow their worst selves out because they don't understand impact when they're anonymous. [P19]

According to the participants, the size of the group mattered for the perceived quality of group dynamics and conversation. When the Web-based support group was too large, the conversation among the group members would become disorganized and derailed by new information, which often made participants feel less valued. In contrast, with small groups, the students often felt they did not get enough diverse opinions, which could lead to a lack of effective solutions or ideas to address their

problems. Nearly all of the participants advocated 7 to 10 members as an ideal group size for sharing their concerns and having effective group discussions:

Less than 10 participants [would be good] in order to have sufficient dialogue and participation among everyone. [P4]

The personal qualities of the web members were also seen as an important consideration to ensure that the support was sustainable. Students considered being faithful, committed, and respectful of others' privacy the most needed qualities of support members as potential support givers, especially given the relative anonymity of many support spaces. The students also commented on their desire to engage both intimate friends and strangers in their envisioned Web-based support group to receive the most useful help, as each provided different types of support on different subjects. In addition, moderated interactions within support groups were seen as critical for students to better receive quality social support. They remarked that careful moderating and monitoring helped maintain the support environment as a healthy and useful place for everyone to get consistent support for the long term. A few students (P8, P12, P14, and P16) who had never used any Web-based support group expressed their interest in joining a small group conversation moderated by professionals who could understand the members, properly react to what was said in the group, and maintain group positivity:

You have a different mental state when you're talking to a therapist compared to talking to just anonymous people. I might not be able to respond if one [a person] was sad or depressed. In a sense, a therapist response would be much nicer and much more understanding compared to what I can provide. [P14]

Similarly, some who already had experience with moderated Web-based support groups also preferred to have a more structured support environment where a moderator provided group therapy or assigned particular goal-oriented tasks to help members achieve their goals. Several advocated for having more than one moderator or professional monitor to track the conversations to ensure that the members would interact appropriately, particularly in anonymous environments.

The Need to Negotiate Tensions Between the Benefit of Disclosure and the Stigma Associated With Disclosure

The last challenge that students mentioned was balancing self-disclosure to seek help and the stigma that prevents such disclosure. To express a need for help, the students attempted to find ways that allowed them to avoid the stigma associated with the disclosure while also maintaining their mental well-being.

Students Hold Tension in Maintaining Desirable Presentations of Self

One common concern related to transitions across frequent life events, particular to emerging adulthood, was maintaining and developing a desirable presentation of self in social interactions. Although wanting to maintain a "positive" image or reputation is a well-known phenomenon in social science research [53], it becomes particularly challenging when one's network keeps

changing, as was the case for the students participating in this study. Students commented that the stigma associated with sharing personal problems could hinder the development of positive social relationships, often discouraging them from openly sharing their concerns with their social connections, such as friends, family, and the people with whom they had recently developed relationships. Particularly, as many students considered their problems might be trivial and common, they considered that what they were going through should not be overestimated as a serious problem. This thinking process aggravated their stressful situations.

The transitions during emerging adulthood made it difficult to keep up with their original support givers (ie, old and intimate friends), and it forced them to build new connections (ie, new friends). The new social connections students built were the ones with whom they wanted to further develop intimacy. These new connections were critical to their emerging adulthood in that they were the students' most preferred source of support. Thus, to further develop these new relationships in the ways they desired, students did not want to disclose their problems too much, but they preferred to maintain a positive self-presentation toward their new connections. For example, some students wanted to maintain an image of being fun and outgoing. They worried that if they disclosed too much about their depression, sadness, or struggles, their new friends would view them differently and categorize them as "not a fun friend to be around" or "problematic." P2 described hiding his concerns from friends in an effort to maintain the character of being fun and happy:

You have five friends and they expect you to be very fun and outgoing, you can't help but stay in that character. It's very difficult or you feel uncertain that if you were to reveal a little bit [of your] personal self, would they still be the same towards you now, [the] friendship or not. [P2]

As in the case of P2 above, many students worried that the negative, long-term impact of sharing their concerns with their social connections, particularly with newer ones, would outweigh the potential benefits, which ultimately prevented them from getting effective help.

Owing to the tension between their need to share with friends and the associated stigma, many students put a lot of effort into sharing their problems in ways they perceived to be less risky. They would slowly and carefully bring their concerns into the conversation or look for the right time to bring up an issue. For example, we saw that some students waited to share their concerns until a friend approached them first, instead of asking for help directly; others tended to hide their true feelings, pretending to live and act in a way that conformed to how their friends viewed them, until they felt more comfortable talking about their problems. P6 explained how long it took him to feel comfortable sharing his struggles with others, explaining that there was a certain time at which such disclosure would be allowed normatively:

At the end of April when everyone is getting ready to [graduate] and started to pull out their hearts and essentially had a very close talk. That was with

everyone else, and I was just sitting there and said I'm not graduating, they are, so I should at least tell them something that has been on my mind for the past few years. There was that instance where I felt should tell them. [P6]

Here, the fact that his friends were all graduating and would not be around anymore made it easier for P6 to disclose the issues that he was holding onto. His friends' transitions also made it less burdensome to deal with their reactions, which was why he chose to disclose at that time.

Disclosure was difficult when students experienced pressure to follow and meet societal expectations or standards, such as being independent financially, accomplished educationally or professionally, or settled at a culturally expected age. This finding was more apparent among the Asian students, who felt pressured to be "good" or "mature" for their families in their particular culture. For instance, P10 who started her graduate study in her late 20s explained her struggle with feeling stigmatized by her age and financial situation:

I actually borrowed money from my parents. At my age I shouldn't do that, and especially, my parents used their retire money to support me. That's a big issue. After graduation I will definitely have to find a good job and pay back. My family invested [in] me to go abroad, so that means I will have the responsibility to support my family back as well. I think that's a concern I have. (...) The other thing is my age, I would say. I think relationship and marriage is also very...not super stressful, but when I think about it, I will kind of worried about that. Because I've never had a relationship before and right now I'm almost 30. Especially my parents worry about that. I feel everything is related to my family. If my family worry about this then I will worry about that too. I know they want me to have a family in close future, but so far in my situation I don't think I have enough time to do that, seeking one and building a relationship..." [P10]

Like P10, even though students talked to their parents every day to share their thoughts, we found that many of them tried not to reveal struggles related to their schoolwork because they wanted to present themselves as a smart, hardworking daughter or son.

Exploring a Casual, Nuanced Way of Sharing Problems

As a way to deal with the stigma associated with sharing problems, students favored communicating with their social connections (potential support givers) through images. Image-based communication included any images, such as the students' own drawings, famous paintings, landscapes, body parts, any artifacts from their daily lives, funny or abstract pictures, and funny memes, shared through mobile or Web-based messages or social network sites. This was popular among the participants, especially for when they just wanted a small amount of casual support that could cheer them up in their daily lives or for when they wanted to provide support for someone else, without anyone explicitly seeking help:

I use Facebook and Instagram basically just to see what people are up to and for funny videos and photos of dogs and videos of dogs. I like memes a lot, so if I see a funny meme I just like it. (...) so like funny pictures and funny comments, internet memes. If I see one, I'll just click like so that my friends will see it, and my friends will start laughing about it. I use that as a stress buster really. [P16]

Similarly, sharing dog and cat photos on the Web was also a popular form of support during less energized moods.

Image-based communication allowed the students to indirectly express their nuanced feelings, as they could use some of the affordance images offer to express and share their feelings in a very subtle and subjective way, without directly revealing their true feelings or intentions. It also enabled students to adjust their own moods while sharing or posting images as a way to overcome negative feelings or curate their own feelings. Students (P11 and P16) used their social media as a digital diary, using images to share and record their moods:

I think this semester I post a lot less, but usually I post a lot. Facebook is almost like one kind of my diary. I post everything, [including] not good [ones]. Especially not good things on that. (...) I don't know [the motivation], but I think it's just like, letting it go, away for me to like expressing my anger or depression. Because I feel, if I cannot find a person to talk, because on Facebook it's also a way for me to let it go and let the others know that I'm not good. [P11]

Like P11, other participants expected image sharing and posting to enable them to feel more comfortable and embedded during their everyday lives, while reducing the stress and stigma related to their support-seeking behaviors. By using a platform that people use to communicate about everyday situations, the shared problems are portrayed as mundane and normal problems of daily life rather than as serious mental health problems.

Discussion

Overview

University students go through a critical transitional life phase of emerging adulthood between adolescence and young adulthood. This life phase requires increased responsibility, maturity, and independence, causing more stress and problems with maintaining mental well-being. For this reason, there have been increased mental health incidents on college campuses [13,54], and more researchers have been exploring technological interventions for emerging adults on university campuses [50]. Below, we describe the maintenance work required for students' mental well-being using the literature on self-disclosure [55]. We also discuss the boundary students perceive between mental well-being and illness, which played a critical role in students seeking help. We then discuss implications for potential sociotechnical systems that can support the needs of students in better maneuvering through this important transitional phase of life.

Negotiating Time, Audience, and Disclosure for Mental Well-Being Maintenance Work Across Life Events

This study revealed that students' mental well-being needs constantly shift and evolve as they go through the life events associated with emerging adulthood. These transitions, shaped by life events, critically impact their mental well-being. This study's findings draw attention to how students negotiate the three needs in their lived experiences related to time, audience, and disclosure. The severity and duration of the life events (*time*) defined the expectations of how help should be delivered. Students encountered new social relationships, which they had to constantly rebuild and maintain as sources of support. These relationships at the same time served as the *audience* for whom the students had to balance the tension between the stigma and *disclosure* of problems and seeking help. As such, these three needs are closely interconnected and constantly negotiated to maintain their mental well-being. This interconnected relationship has been identified in the studies about disclosure in HCI and Communication fields.

For instance, "time" has been found to be a critical component in when, how, and whether disclosures occur, exploring the facilitation and hindrance of disclosures [55,56]. Reasons for delayed disclosure [56,57], a delay between a significant, stressful event and the time of disclosure, include fear that the disclosure will be poorly received and not supported by others as well as moving on from the event and not feeling the need to share or reopen wounds [56]. Although delayed disclosures have primarily been studied in the context of abusive and traumatic situations (eg, sexual abuse) [58], this study shows that delayed disclosure also happens when students wait for the right "timing" to disclose their problems and seek help. An example from this study's findings showed that one student (P5) waited until his friends' graduation to reveal his issue to reduce the burden of having to manage friends' reactions to his disclosure. Moreover, this was during a moment when the friends had mutually agreed to share intimate experiences as a way to reflect on their college years. The reciprocity norm of mutual self-disclosure in dyadic relationships [59] explains this observation of mutual sharing at the right time.

"Audience" is another important factor in explaining why people disclose or do not disclose stigmatizing experiences (eg, depression) in the Disclosure Decision-Making Frameworks [55,56]. The concept of audience connects with our findings on rebuilding relationships, such as the new social connections students need to build. According to Goffman, "audience" refers to the individuals for whom one performs and who might be the recipients of one's direct or indirect disclosures as part of a help request [53]. The disclosing person assesses how these individuals, that is, the audience, might react and respond to the disclosure or lack thereof and makes a (non)disclosure decision accordingly. In this study, such an assessment includes balancing the potential benefits of disclosure with the risk of losing the status of being a fun friend to be around, especially when the goal is to rebuild and maintain new relationships with the audience. This negotiation is fraught as these new relationships entail potential disclosure to audiences who can be a source of support.

Furthermore, this study also showed that as a result of the risk of stigma associated with disclosing problems, students used fun and positively valued social media sharing to release stress for themselves and others. Previous work has argued that social media design should facilitate the disclosure of stressful situations directly or indirectly [56]. This study added to this conversation by arguing that sharing positive content is not necessarily shallow or "just for fun"; it can, in fact, be part of an activity that releases tension and stress among individuals.

Understanding the Perceived Boundary Between Mental Wellness and Illness as a Collective Effort

In this study's findings, students perceived most of their problems to be either normal or on a continuum between normal and serious. The latter would imply the need for seeking immediate help from a professional source, compared with the former, where the problem may resolve on its own as time passes. Students view the problem as fluctuating day to day, or even hour by hour, and as being influenced by many things in their daily lives, just like physical health. They think normal problems can progress to become serious and serious problems can revert to being normal as time passes (after a certain stressful life event is over). Coupled with stigma and barriers to self-disclosure [55], students attempted to avoid as much as possible the need to label their problems as illness problems.

The students in this study tended to consider their problems within the realm of wellness—a state where they think they have abilities to cope with the normal stresses of life and manage on their own. However, students also worried that their wellness problems could potentially develop into more serious ones and become illness problems. To prevent this progression, students actively and proactively tried to seek effective, workable resolutions. This study's findings showed that students set a maximum time (eg, three months and two weeks) in which to resolve problems (eg, relationship breakup and being stressed about grades or job search) to prevent the problems from overwhelming their overall well-being. Having a social network to share their problems with, whereby students could set up regular weekly hangouts with close friends to prevent the problems from progressing into more serious ones helped.

In this study, we reported different perspectives between the mental health literature and findings in terms of when a problem is considered as part of "wellness" vs "illness." This difference makes it difficult to determine when and how we should intervene to support students' help-seeking behaviors effectively. The traditional mental health literature on emerging adulthood problematizes the students' perceived, self-endorsed boundaries between wellness and illness, defining it as a barrier to mental health care and support [60]. The literature legitimizes self-management activities for mental health but only to a certain extent. Self-management activities, referring to seeking help from family and friends and going to meditation groups, are largely described as barriers to mental health care access. Rickwood et al [61,62] found that participants preferred to talk to friends and family rather than health care professionals, which might prevent access to health care when added to participants' lack of emotional competence and negative attitudes toward seeking professional help. Biddle et al [63] showed that

participants continuously self-assessed whether they could accommodate high levels of distress and avoid seeking help.

The health care stance on interventions is that the earlier the intervention, the better. However, students are not inclined to seek professional care easily or early on [64]. As shown in this study's findings, students did not feel the need to continue existing professional help or start seeing a doctor or therapist because of their strong tendency to perceive their problems as normal. This tendency aligns with recent studies that show individual beliefs and perceptions, such as newly acquired independence and autonomy [65-67], as stronger factors in whether emerging adults will seek mental health support [65,68]. This study's findings highlight the urgent need to not only better understand university students' individualized perceptions but also help them self-reflect and re-evaluate their own perceived boundaries of where illness begins so that they can receive the support they need—whether from their social network or through professional care.

Where the boundary between wellness (ie, whether a problem is a normal part of emerging adulthood) and illness (ie, a symptom of a serious mental health disorder) lies or whether the boundary should even exist remains an open question. This might be an applicable question for the general population, such as those with mental health issues in the workplace [69], but it is the salient case for students as they are especially close to their peers who go through similar types of problems and life events during their emerging adulthood, which can make the students more ignorant or blunt about their problems. The question about the boundary has often been unclear even for health professionals because of individualized, situational factors [70]. Health care workers need to individually assess how much the unstable, uncertain experiences of a student should be treated as a healthy part of self-development and how much should be treated as a symptom of a serious mental health disorder [70]. This nuanced boundary as well as the differing viewpoints between health care professionals and students can add to maintaining student mental well-being negatively. This problem forces students on college campuses to be tolerant of severe problems and to ignore the need to get help.

We argue that this boundary between wellness and illness needs to be carefully negotiated, evaluated, and coordinated for each individual student through collective efforts among the social systems made up of responsible stakeholders: university students themselves, health care professionals, family, friends, educators, designers, institutions, and the public health sector.

Reconceptualizing a Support Group as a Place for Colearning

In examining the ways in which students received support, including from their groups of intimate friends, Web-based groups, and social media, we noticed that being part of a “support group” had a negative connotation for our students. Many students avoided labeling the wanted help as a “support group,” as the term problematizes what should be a normal process of being supportive of each other in a seamless way throughout everyday contexts. The negative connotation associated with support groups served as a barrier to students accessing helpful resources, such as CAPS or related peer

groups, on campus. It is worth investigating how to engage and assist students with various stressors in their emerging adulthood more effectively.

Accordingly, this study calls for an urgent need to reconceptualize the existing notion of support as a colearning space where individuals learn to maintain their own mental wellness: how to be aware of it, how to keep it healthy, and how to prevent potential risks. This knowledge is not something normally gained from formal education, although it should be. Importantly, in this reconceptualization, each individual can be a help giver as well as a receiver. This sort of mutual exchange has been discussed in the literature as the helper therapy principle [71], which is the central concept for building support groups. In this study, a few of those who wrote blogs or made images related to mental wellness awareness expressed their interest in working with counseling services to help their peers, based on their own experiences. At any given time, one can be a helper for multiple people on different issues, while seeking help for one's own mental well-being maintenance work. This multiparticipatory nature of a support exchange can facilitate accountability among the helpers and the individuals receiving help.

Design Implications

We discussed university students' challenges and efforts to maintain their mental well-being around time, disclosure related to stigma, and the right audience. This study indicated that it is important to facilitate the negotiation of students' own perceived boundaries of where illness begins through self-reflection and evaluation so that they can receive appropriate help. To that end, ideal sociotechnical systems should be designed in more inclusive ways that allow self-reflection to support students in managing their mental health in a casual, informal, and positive manner, rather than approaching the challenge from a mental illness perspective.

To our knowledge, only a few existing technical interventions support students' mental health from the mental well-being maintenance perspective [14,17,72]. These systems exist either for tracking students' mood and emotions or encouraging social support. For example, Mind Tracker [14], a tracking tool kit, uses a journal, graphic chart, and tangible modality-like clay. Its main function is to engage users in the process of emotional data collection and self-reflection in everyday life. Using Mind Tracker, the study found that having an expressive tool was beneficial to express and track students' emotions and that this tool also served as a self-healing tool by providing a moment of mindfulness, rather than as an automatic sensing tool to detect negative emotions. In addition, Buddy [17] is a social media-based support system that offers Bell features, where users can indicate posts that they think need more careful attention than others, Special Feeds that curate those posts requiring more attention (instead of popular or trending posts) and Hug Bots that automatically deliver hugs when creating a post (instead of a Like button that often creates competition). This Buddy system was designed to help identify students who need more attention and encourage students to share their struggles with others, particularly those who need more social support in adjusting to college life.

This study's findings show value in integrating functionality from such systems to support students' mental well-being maintenance work. They call for investigating how existing systems and applications for the general population can be extended and designed to offer self-reflective and self-evaluative mechanisms for students' mental well-being. For instance, existing practices, such as Expressive Art Therapy (EAT), which offers individuals the opportunity to use any expressive and creative art form (eg, singing, poetry, art, dance, or performance) to reflect on and identify what the root of a problem is, increase self-awareness, enhance social relationships, and foster emotional growth and development [73-75]. EAT can then be integrated into existing everyday systems and applications to provide nonclinical solutions. Specifically, existing media applications for self-expression, such as video blogs, amateur music sharing, sharing creative artwork or images, drawing, or poetry sharing forums, can be used to support these varieties of forms of expression as a form of EAT. Similarly, doodling can be used to benefit the process of mindfulness training with some guidance (eg, "Choose whether to document a current happy moment or think back to a happy time and doodle your memory") [76]. Integrating such expressive capabilities into existing applications could enable students to be mindful and aware of their mental health status. In addition, integrating such an approach with Positive Psychology [6,77,78] can help students release their stress and discover positive moments and strengths, instead of focusing on the problems and the negativities. Examples include enabling the platform to suggest recording a thankful moment from the day through a photo, writing, or drawing and sharing it with friends on Instagram or in a group chat or cocreating humorous internet memes with friends on Sketch as a positive mood booster. These activities can foster emotional growth, enhance social relationships, and improve self-awareness [22,35]. These outcomes will eventually help young adults define their own perceived boundary of mental health and receive proper help when needed.

Upon developing the platform, we argue that it should be designed to facilitate the involvement of a community of all relevant stakeholders in supporting the mental well-being maintenance work of an emerging adult on campus (eg, students, health care providers, practitioners, institutions, designers, and app developers). This platform will not only help students to self-reflect and evaluate their mental well-being maintenance activities but also help stakeholders to easily analyze functionalities, use cases, and user populations of existing applications. It will also help them analyze new applications as they are developed and suggest potential connections to existing therapeutic practices of mental well-being. The platform could show usage trends of user populations, along with new features that these applications might be able to provide. It could also offer a database of EAT curated by health care professionals. The stakeholders could then exchange feedback regarding how these existing and newer applications could work together to support therapeutic mechanisms according to the life events of an individual.

The findings also indicate that it is critical to support the process of navigating and renegotiating time, audience, and disclosure. The aforementioned platform could provide a variety of approaches to requesting as well as receiving situated help, ranging from the immediate and direct to the more casual and abstract. On the basis of the mood or level of activity of a user or a particular life event, a platform could directly intervene by matching or suggesting appropriate helpers or by nudging and casually connecting with family and friends to encourage students to share their struggle with others. This could help with providing support within the appropriate time window when the impact of that event is still active. For instance, the findings showed students did not want to be reminded of their problem after a certain amount of time had passed after the issue occurred. Such a platform could also pick up on and identify potential emotional breakdowns or challenges that might come up, based on their behavioral and emotional patterns. In addition, in terms of suggesting an audience, selecting helpers from social group contacts or outsourcing highly customized help based on the topic or similar interests and needs (eg, nearby peer groups, mentors, and professional consultants) could be done for the user. Matching with others based on similar needs or interests was found to be helpful in previous work using others' life transition trajectories as a form of social support among peer patients [79]. The incentive for anyone to become a helper could be established by keeping them informed of both the short-term and long-term positive outcomes of addressing a problem through feedback, thus alleviating tension related to stigma and facilitating the rebuilding and maintenance of relationships between users and new and potential helpers.

Conclusions

We investigated the mental well-being maintenance practices of emerging adults on a university campus: how students perceive problems, set expectations for help, and go through the work of from whom, when, and how to seek help. We identified three needs that are required for students to maintain their mental well-being: (1) getting help at an appropriate time and in an appropriate form that aligns with the severity of the problem, (2) building relationships with potential support givers, and (3) negotiating tension between disclosure and the associated stigma. This formative study informed how sociotechnical system support for this population should be sensitive to how help is framed and offered to make it easier to embrace. We also discussed how and when help should be delivered through technology and argued for reconceptualizing help as a colearning process. This research was conducted with a subsample of emerging adults, focusing on those at a large university in the Midwest. Although the participants do not represent the broader population of emerging adults nor all university students, this study's findings demonstrate a unique set of needs and challenges that should be acknowledged and supported in the population to which these findings theoretically generalize. This study contributes to helping mental health practitioners, researchers, and system designers understand and support students' mental well-being maintenance practices as part of the normal course of life beyond the clinical context.

Conflicts of Interest

None declared.

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Abbreviations

CAPS: Counseling and Psychological Services

EAT: Expressive Art Therapy

HCI: human-computer interaction

IRB: Institutional Review Board

RQ: research question

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Original Paper

Developing SMS Content to Promote Papanicolaou Triage Among Women Who Performed HPV Self-collection Test: Qualitative Study

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Abstract

Background: SMS interventions are effective in promoting a variety of health behaviors; however, there is limited information regarding the use of SMS for cervical cancer screening and follow-up care. The Application of Communication and Information Technologies to Self-Collection study aims to evaluate a multicomponent mobile health intervention to increase triage adherence among women with human papillomavirus (HPV)-positive self-collected tests in Jujuy, Argentina. Here, we describe the formative results used to design the content of the SMS to be tested in the trial.

Objective: This study aimed to understand the cultural and contextual elements, women's beliefs, and perceptions regarding the use of SMS by the health care system and women's preferences about the message content.

Methods: We conducted five focus groups (FGs), stratified by rural or urban residence and age. All participants were aged 30 years or older and had performed HPV self-collection. Participatory techniques, including brainstorming, card-based classification, and discussions were used to debate the advantages and disadvantages of messages. We openly coded the discussions for agreements and preferences regarding the SMS content. Messages for both HPV-negative and HPV-positive women were validated through interviews with health authorities and 14 HPV-tested women. The final versions of the messages were pilot-tested.

Results: A total of 48 women participated in the FGs. Participants rejected receiving both negative and positive HPV results by SMS because, for them, the delivery of results should be done in a face-to-face interaction with health professionals. They stressed the importance of the SMS content informing them that results were available for pick up and reflecting the kind of relationship that they have with the community health workers and the nearest health center. Women considered that a personalized SMS was important, as was the use of a formal yet warm tone. Owing to confidentiality issues, not using the word "HPV" was also a key component of the desired SMS content; therefore, the final message included the term "self-collection" without the mention of HPV infection. Results from the validation stage and pilot test showed high acceptability of the final version of the message.

Conclusions: The results suggest that SMS is accepted when notifying women about the availability of the HPV test result, but it should not replace the delivery of results in face-to-face, doctor-patient encounters. In addition, messages must be tailored and must have a persuasive tone to motivate women to adhere to the triage.

KEYWORDS

text messaging; cell phone use; telemedicine; human papillomavirus DNA tests; triage; health behavior; Argentina

Introduction

Background

In Latin America, the high mortality rate of cervical cancer (CC) is related to problems with continuity in the screening process, including low participation in screening and abandonment of follow-up care procedures [1,2]. In recent decades, the development of the human papillomavirus (HPV) test has changed the screening paradigm: the HPV test has high sensitivity and negative predictive value [3,4] and has been demonstrated to reduce the incidence of CC and mortality [3]. Importantly, HPV testing allows for self-collection (SC), a method that is effective in detecting precancerous lesions [5] and has the potential to reduce barriers to screening, especially among underserved women [1,4,6,7].

SC is highly accepted by women in several countries, and studies have demonstrated that SC increases screening coverage [6,8-10], especially when the test is offered door-to-door by community health workers (CHWs) [6,11]. However, SC introduces an obstacle: women who test positive for HPV must undergo triage tests to identify those who must be referred for diagnosis and treatment. Although several triage methods are available for detecting precancerous lesions, cytology has been validated in several randomized trials [12] and is part of the screening policy recommended by the World Health Organization [13].

Using cytology as triage implies an additional appointment at the health center, which increases the risk of abandonment of follow-up care. A high triage adherence can be difficult to achieve in real-life programmatic contexts [14,15], especially among underscreened women [5,7]. In Argentina, 34% of HPV-positive women who performed SC at home during a CHW's visit completed follow-up within 120 days after screening [14,15]. Studies that have analyzed adherence to different follow-up steps after abnormal cytology [15-18] showed that the delivery of test results presented an obstacle: women either did not receive or did not pick up the test results. In Argentina, not receiving SC results was one of the most reported barriers to follow-up care by HPV-positive women who were not adherent to the triage [15]. A separate study conducted in the context of cytology-based screening in Argentina also found that not receiving results was one of the most reported barriers to follow-up care by women who were not adherent to diagnosis and treatment [17].

In Jujuy, Argentina, where door-to-door HPV SC has been implemented since 2014, triage adherence increased to 77% in 12 months after a significant effort by CHWs to contact HPV-positive women in their homes [14]. However, home visits to all HPV-positive women as a public health strategy is difficult to sustain because of the high proportion of screened women who would need to be contacted (approximately 13%) [7]. In addition, CHWs are a scarce resource, and CC prevention is

one of the many health services they provide to the population. In this sense, it is crucial to develop innovative strategies to improve the delivery of results and increase the adherence of HPV-positive women to the triage.

Various studies have shown that mobile health (mHealth) interventions are effective in changing health behaviors, such as following doctors' recommendations, and in strengthening communication between users and health care professionals [19-23]. The use of text or SMS is the most frequently used mHealth strategy. Owing to its low cost, accessibility, and simple technology, SMS is appropriate for low- to middle-income settings [24-26]. In addition, specifically with respect to CC prevention, evidence has suggested that SMS-based interventions might increase screening uptake [24,27,28]. SMS interventions are accepted by women, and they have been shown to increase screening uptake among women who face cultural obstacles [29]. Hence, SMS could be used as a strategy to increase adherence to Papanicolaou (Pap) triage, without increasing the workload of CHWs (eg, door-to-door notification of availability of HPV SC results).

Despite its advantages, sending an SMS about a sexually transmitted infection (STI) such as HPV is complex. Patients' privacy and confidentiality need to be protected and at the same time, the message must be short, easy to understand, and also culturally appropriate. In addition, it is important to use keywords to make the content clear without upsetting the recipient [30-32]. A study conducted in Chile about the SMS preferences of underscreened women showed that clarity and simplicity of the received message were very important for them [33]. The legitimacy of the sender and privacy issues, such as disclosing a result to a third person in shared cell phones, have also been shown to be relevant topics on SMS content [34,35]. Not taking into account the patients' opinions about the SMS content, its design, and validation before the implementation of mHealth strategies have been pointed out as obstacles to the acceptability, effectiveness, and scalability of SMS-based health interventions [36-38].

Objectives

Therefore, the objective of this study was to understand women's beliefs and perceptions regarding the use of SMS in health care and their preferences regarding the message content, in addition to collecting data on cultural and contextual aspects. This formative research is part of a larger trial—the ATICA study (Application of Communication and Information Technologies to Self-Collection, for its initials in Spanish), a hybrid type 1 cluster randomized trial conducted in Jujuy, Argentina. The trial will evaluate whether SMS sent to HPV-positive women increases Pap triage among HPV-positive women with self-collected tests [39]. Results from the ATICA trial on the effectiveness of the use of SMS will be published in forthcoming papers. In this paper, we present the results from

the formative research conducted to design the content of the SMS messages sent to women.

Methods

Theoretical Foundation

The methodological design of the study has been described elsewhere [39]; in brief, it involves sending SMS messages to HPV-positive women who have performed SC offered by CHWs during home visits. When women do not adhere to Pap triage within 60 days of a positive HPV test result, an email and SMS will be sent to the CHWs to alert them to visit the HPV-positive women who have not responded to reminders and encourage follow-up. The ATICA study is conceptually guided by the health belief model (HBM) [40,41], a framework that has been extensively used to explain cervical screening-related behaviors [42-45]. The HBM has 6 constructs: (1) *perceived susceptibility* of getting a disease or condition, (2) feelings about the seriousness of contracting it (*perceived severity*), (3) *perceived barriers* to address a recommended behavior to prevent or treat the disease, (4) the individuals' evaluation about the *benefits-costs* of doing it, (5) the confidence in one's ability to attend a health issue (*perceived self-efficacy*), and finally, (6) the *cues to action*, that is, external factors that potentiate the readiness to follow a new behavior [40]. Following the HBM, sending an SMS would work as a cue to promote actions and therefore prompt HPV-positive women to undergo Pap triage. In this sense, the SMS must address beliefs, values, and shared perceptions to encourage the prevention behavior [31,46,47].

We created a semistructured moderator guide for focus groups (FGs), including sections on (1) cell phone and SMS use, (2) dimensions of the HBM regarding SC and Pap triage, (3) perceptions and opinions about women's relationship with the health system, (4) barriers for Pap triage, and (5) SMS content.

We used an array of participatory methods to create the SMS content [48,49]. The steps proposed by Abroms et al [37] were taken into account to create a health communication strategy oriented toward prompting behavior change via SMS. Following other proposals, we used a card sorting technique to debate predesigned content with the participants [32,49].

Following Muench and Baumel [32], SMS was divided into the following five structural elements:

- Greetings: terms of address that abide by the rules of etiquette in each cultural context and suitability for SMS communication in Spanish [50,51]
- Sender: source of the message and the authority that legitimizes the content [30]
- Message topic: preferences on how to refer to HPV SC
- Recipient: advantages and disadvantages of including the recipient's name
- Closing and cue to action: purpose of the message of either notifying the results (HPV-negative) or availability of the SC results (HPV-positive)

Figure 1 shows different options for the five structural elements that were discussed by women.

Thereafter, different versions of each structural element were combined, which resulted in a total of 37 predesigned SMS messages (16 for HPV-negative results and 21 for HPV-positive results). Owing to the SMS restrictions, if the message combination was more than 140 characters, it was excluded from the research. Figure 1 shows different versions of the structural elements of the SMS messages used during FGs.

Finally, during FGs, the SMS content was determined through 3 activities: (1) brainstorming, which allowed spontaneous suggestions by participants, (2) pile sort method and ranking, in which participants sorted predesigned SMS (HPV-negative and HPV-positive) depending on whether they liked the content or not and then selected two cards from each pile (two most liked and two least liked), and (3) group debate, wherein each participant shared her motives for choosing each card.

On the basis of the results from the FGs, 2 messages were designed and subjected to a double process of validation: (1) with the provincial health authorities (Primary Health Care Department and Program on Cervical Cancer Prevention) and (2) with the recipients, by means of a pilot survey to 14 women with characteristics similar to those of the FG participants. The survey included an assessment of the message comprehension, content appropriateness (words and tone), and perception of efficiency in increasing Pap triage (see Figure 2).

Figure 1. Different versions of the structural elements of the SMS used in focus groups. HPV: human papillomavirus.

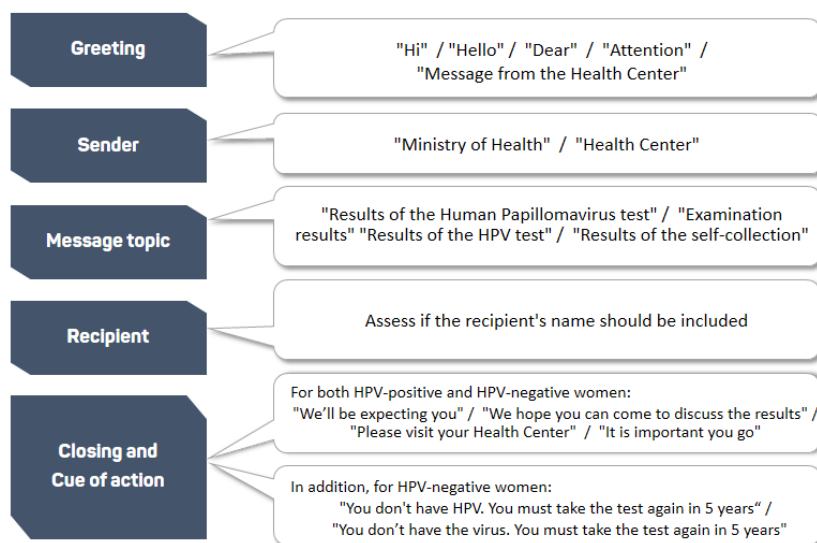
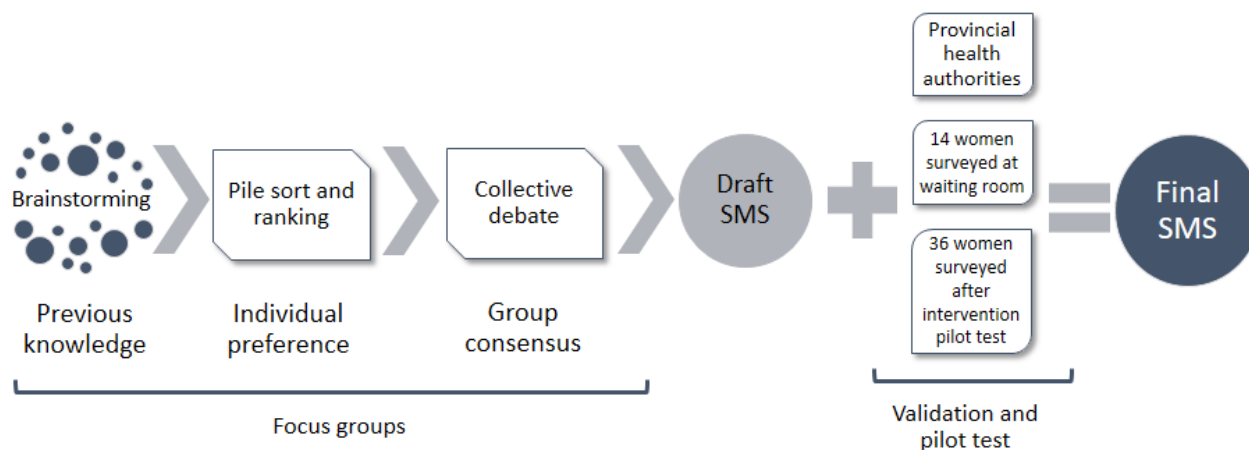


Figure 2. Stages of the SMS content design.



Setting

According to the latest available data (2010), 673,307 people lived in Jujuy (343,387/673,307, 51.00% of them are women; 587,530/673,307, 13.00% of the people lived in rural areas). Furthermore, 3.00% (20,199/673,307) of the Jujuy population aged 10 years or older was illiterate, of which 68.60% (13,857/20,199) were women. Overall, 45.20% (304,335/673,307) of the total population of the province had public health insurance. In 2018, 30% of the urban population of the capital city (San Salvador-Palpalá) lived below the poverty line [52].

HPV testing has been the primary screening method for the prevention of CC since 2012 [7], targeting women aged 30 years and older who attend the public health system. HPV samples are collected by clinical staff at health centers. The screening protocol in use in Jujuy has been described elsewhere [7], but succinctly, HPV-positive women are triaged with cytology and those with the finding of atypical squamous cells of undetermined significance or worse, are further referred to colposcopy and biopsy if needed. Women with histologically confirmed cervical intraepithelial neoplasia grade 2 or worse are referred for treatment. HPV-negative women are

recommended rescreening in 5 years. When HPV testing is done at health centers, HPV testing and cytology triage are conducted simultaneously, but cytology is read only if the HPV test is positive. Since 2014, HPV SC offered by CHWs during home visits was introduced as a programmatic strategy to increase screening coverage. In total, around 700 CHWs visit approximately 110,000 households twice per year for health services such as height/weight measurements and child vaccination. HPV SC is offered during these routine visits, which are conducted without a previous appointment. Owing to the large number of people each CHW is responsible for, scheduling visits by phone or other means is currently not feasible. If a woman performs SC at home, she is currently instructed to go to the health center within 30 days to retrieve her results, and if her results are positive, then she must have triage cytology at the health center [39].

The Automated Messaging System

The Jujuy's provincial program for the prevention of CC uses the National Screening Information System (SITAM, for its initials in Spanish) [7]. SITAM works as a Web-based screening registry that tracks all CC-related events of women screened in the public health system (screening, diagnosis, and treatment

data). When a woman performs SC at home, the CHW collects the patient's contact information and HPV sample data, which are entered into SITAM at the HPV provincial laboratory.

For the ATICA study, we developed a computerized messaging system, Automatic Messaging for Screening and Follow-up Care (MATYS, for its initials in Spanish), to send SMS messages to HPV-tested women and emails to CHWs. MATYS was linked to SITAM via an interface to access SC and Pap results, if any. Then, MATYS used these data to send a tailored SMS to the woman's cell phone. Although MATYS is a one-way system and women were not expected to reply during the ATICA trial, MATYS registered any message sent by women, for the purpose of analysis.

Participant Selection

Potential participants for the formative research stage were contacted by CHWs and were required to meet the following inclusion criteria: women had to be aged 30 years or older, should have performed HPV SC, should have the ability to read and write, and should be cell phone users.

Data Collection

A total of six FGs were conducted using age (women aged 30-50 years, 40 years or older, and 51 years or older) and residence (rural or urban) as stratification criteria. Both variables are considered crucial in understanding the differences in cell phone usage [53,54]. FGs were conducted in Spanish by 2 female social science researchers: one acted as the moderator (VSA) and the other as the observer (MC); both of them neither lived in the Jujuy province nor had any relation whatsoever with the health care facilities or their authorities. The fieldwork was conducted in January 2018.

The FGs were conducted in locations that were easily accessible to the participants; no health care professionals or CHWs were present. Before each FG, the participants provided written informed consent to participate and to allow the audio recording of the discussions. Once the purpose of the study was explained to them, none of the participants refused to participate. Each FG lasted for an average of 2 hours.

Analysis

The results of only five FGs are presented because participants of the another FG (FG4) did not meet the inclusion criteria. For the analysis, audio recordings from the FGs were transcribed and coded following the structural elements of the SMS. The women's preferences and debates were coded to each element of the SMS (predefined themes): greeting line, message topic, sender, recipient, and closing line and persuasive phrase used as a cue to action (see Figure 2). This allowed the researchers to conduct a thematic analysis of the debates [55]. We used HBM constructs to explore the women's beliefs, feelings, and opinions about the prevention of CC (SC and Pap) and how they linked their experiences with each SMS content. Atlas.Ti (version 7.5.4, ATLAS.ti Scientific Software Development GmbH, Berlin) was used for data processing. The transcripts were analyzed independently by 2 researchers (VSA and MC) to later compare, debate, and resolve the inconsistencies with the other members of the ATICA team.

The details of the methods and the results from the FGs are presented following the Consolidated Criteria for Reporting Qualitative Research [56].

The ATICA study's protocol was registered in Clinicaltrials.gov (NCT03478397). In all its stages, including the formative research phase, ATICA study was approved by the Institutional Review Board of Center for Medical Education and Clinical Research, the Ethics Research Committee of the Jujuy Ministry of Health, the Institutional Review Board of the Harvard TH Chan School of Public Health, and the Deakin University Human Research Ethics Committee.

Results

Focus Group Characteristics

A total of 44 women participated in the five FGs. The majority resided in low-income urban areas in the capital of the province (San Salvador), 70% (31/44) had received secondary education or less, 75% (33/44) had public health coverage, and 90% (40/44) of the women shared their cell phones with their children and/or partners. In rural areas, cell phones were considered the home phone (FG5). In Table 1, a summary of the characteristics of the FGs is presented.

Table 1. Focus group participant characteristics.

| Age (years) | Urban areas | Rural areas | Total |
|--------------------------|--|--|----------|
| 30-50 | FG ^a 1: 8 participants, majority completed their secondary school | FG2: 9 participants, majority completed their postsecondary school | 17 women |
| 51 or older | FG3: 9 participants, majority completed their primary school | FG4: Excluded from this analysis | 9 women |
| 40 or older ^b | FG6: 6 participants, majority completed their post-secondary school | FG5: 12 participants, majority completed their primary school | 18 women |
| Total | 23 women | 21 women | 44 women |

^aFG: focus group.

^bOriginally, four FGs were proposed. For deeper understanding, two additional FGs were conducted with women aged 40 years and older. In those cases, age segmentation was defined to obtain more data related to the use of technology.

SMS Structure

Greeting

The women agreed that a simple “Hi” was unduly informal for an SMS. They considered that despite it being the characteristic tone of their relationship with the CHWs, the informal nature of the greeting line could discredit the whole message if included in the SMS. The option “Attention” was rejected for being too cold and inciting fear. It was only chosen by some women who would describe themselves as people who often hesitate going to a health center and to whom an imperative tone would “help” to cope with that hesitance (FG5). With regard to the option “Message from the health center,” women stated that even though it would help the reader understand the nature of the message, it was too distant to begin an SMS conversation in such a way. The option “Hello” was considered warm and formal.

Tone and Terms of Address

The preferences on the tone of the message and the terms of address were related to the issues that affected the overall content of the message. Therefore, women emphasized that the SMS should balance the formal nature of an institutional message “to transmit professionalism” (FG2) and the warmth intrinsic to their relationships with the CHWs.

With regard to the formal vs informal pronoun and verb conjugation use, the predesigned SMS cards using the formal “you” (“usted” in Spanish) were chosen. Furthermore, in the brainstorming activity, participants spontaneously proposed the use of the formal tone as well. For example:

[Spanish] *Necesitamos su presencia en el centro de salud.* [Author emphasis added]

[Translation] *We need your presence in the health center.* [FG1: 30-50 years, urban area]

Sender

In general, women considered that even though the message would be sent through MATYS, the sender of the SMS should mention a health authority as this would legitimize the content. In the women’s words, “It’s a message that isn’t just sent by anyone” (FG6).

After considering the different alternatives, “Health center” was the preferred option, instead of “Ministry of Health.” Participants mentioned that the Ministry of Health was an institutional figure, which they felt had little presence in their everyday life and, in some cases, was associated with negative past experiences. In the case of participants from the rural FG, they also added that the health center had geographic proximity which no other public health institution had (FG2 and FG3). Furthermore, most of the FG participants emphasized that the “Health center” was the CHWs’ reference institution, representing their relationship with CHWs, which, they stated, “it is founded on trust and familiarity” (FG2 and FG6):

...there’s a better relationship with the health care center. If you put “Ministry of Health” [in the SMS], maybe it’s like “Oh, it’s coming from San Salvador

[the capital city],” but not really... [Woman 1; in a dismissive manner]

...the difference between the city and the village...here what makes the difference is the closeness, we all know one another, it’s more familiar. The relationship with the professionals isn’t as distant as with the professionals in the city. [Woman 2; FG2: 30-50 years, rural area]

Message Topic

The FGs included debates on how to mention the HPV test in the SMS. The debated options were “Results of the Human Papillomavirus test,” “Results of the HPV test,” “Results of the self-collection,” and “Examination results.”

In this regard, the private or shared use of cell phones was the main factor for diverging preferences. For example, women who shared their phone with other family members expressed privacy and confidentiality concerns and proposed avoiding the term HPV “to not worry their family” (FG5) and to avoid the social stigma surrounding HPV diagnosis (FG1). Some women mentioned that they would feel embarrassed should anyone find out that they had been tested; they expressed fear of the possibility of leaking private health information if a third party saw the SMS (FG1, FG3, and FG5).

Women who shared cell phones suggested using “self-collection” as an alternative to guarantee more privacy. Despite it being a technical term, women stated that they were familiarized with its use as it was the term CHWs used when offering HPV testing during home visits. “Self-collection” was considered more discreet than alternatives such as “human papillomavirus” or “HPV,” which not only explicitly named a stigmatized STI but were also confused with HIV and was difficult to comprehend for those with poor reading and writing skills. Furthermore, “self-collection” was more accepted than “Examination results” because the latter was considered too generic and would be confusing when trying to determine what the message was about. For example, some women joked, “Which of all the medical examinations I take [is the SMS referring to]?” (FG3).

Recipient

The advantages and disadvantages of SMS personalization by including the recipient’s name were also debated. Women from different FGs argued that using the recipient’s name was a safeguard against possible errors such as receiving an SMS meant for someone else. Moreover, including the name would be an indicator that it was a personal SMS, not a generic or mass message often sent by companies to their clients: “it’s an SMS sent to me, it’s not for anybody” (FG6).

Women with shared cell phones expressed the importance of including the name; otherwise, they would have no way of knowing if the SMS was for them or for another woman in the family. However, those who were against including the recipient’s name based their arguments on confidentiality issues: if a third party gained access to their phone, they would know that the woman had been tested.

The shared use of cell phones introduced a confidentiality issue. At the same time, women stressed that they needed help to get access to the information received through their cell phone, especially those who had vision problems, were not familiar with cell phones, and/or had poor reading and writing skills. In those cases, family members such as children or husbands helped them in the use of cell phones. This contradiction between confidentiality concerns and the need to ask for help to use a cell phone was pointed out by the moderator. To settle this contradiction, women highlighted that an SMS including the name of the recipient and using the term “self-collection” would take into account both concerns.

Closing and Cue of Action

For the closing sentence, FG participants discussed the different options proposed to encourage women to go to the health center. Participants found that phrases such as “We’ll be expecting you,” “We hope you can come to discuss the results,” and “Please visit your Health center” would have a persuasive effect. In the predesigned SMS to be sent to HPV-positive women, the phrase “It is important” was also included to emphasize the importance of contacting the health center. According to the women, this would help them anticipate an HPV-positive result. This was the option chosen by most participants:

Yes, because it is telling you to go to talk about it. I don't know...it's like they're softening the blow of...

There's something odd, something's wrong, so they want to talk about it.

Of course, that “let's talk” means “the test came back positive.” [FG2: 30-50 years, rural area]

Women also discussed variations of the SMS to be received by women who tested negative for HPV. The initial proposal of the SMS implied sending the actual negative test result via SMS. The proposed phrases were “You don't have HPV. You must take the test again in 5 years” and “You don't have the virus. You must take the test again in 5 years.” All these options were rejected across all FGs. According to the women, the SMS should promote contacting the health system to request information about their health in general and about HPV/CC in particular. In their opinion, receiving the HPV results via SMS could hinder the possibility of going to an appointment with the health care team and receiving information during a personal encounter:

What should not be included in the SMS? [Moderator]

If it's positive or negative [Woman 1]

Not saying the result. Not even if it's negative? [Moderator]

No, because when you go to the health clinic, the professional will explain it there. [Woman 1]

It's better if a professional tells you, in private. If your cellphone tells you “It's negative...” [Woman 2]

Then you wouldn't go to learn more, it's better to leave it unknown so you visit the health clinic. [Woman 1]

To leave you with the idea that you have to go. [Woman 2]

Right, because then a professional will explain it there. [Woman 3; FG1: 30-50 years, urban area]

During the FGs, participants also suggested additional information that should be included in the SMS, such as regular hours of the health centers, the name of the specialist, and how to make an appointment. Thereafter, we explained why introducing this information would be unfeasible and might be confusing.

The Draft Version of the Message

On the basis of the results of the FGs, study researchers produced a draft version of the SMS, as follows:

Dear [Woman's Name].

The results of your self-collection are ready.

Please visit your health care center for a medical consultation.

It is important that you go.

This preliminary message to HPV-positive women based on the results from the FGs was presented to the provincial health authorities. In this draft version, “Dear” was used instead of “Hello” to respond to the women's preferences regarding personalization and formality. The last sentence was used to emphasize the importance of them going to the health center, as a trigger to action.

Validation and Pilot Test

The validation stage with the provincial health authorities did not present relevant divergences or inconsistencies in the results of the FGs with regard to the interpretation and understanding of the proposed message. However, they noted that “Dear” was not suitable for locals: “it is too formal and old fashioned.” As in the FGs, “Hello” was chosen as the best option.

In addition, the provincial health authorities pointed out that the phrase “Please visit your health care center for a medical consultation” could be understood by women in a restrictive manner. They could interpret that they should only see a physician. However, in health centers, very often Pap smears are taken by nurses or midwives. Therefore, the final version of the SMS excluded the term “medical.” Thus, the final version of this line was “Please visit your health care center for a consultation.”

Finally, the information suggested by the women about regular hours of the health centers to have a Pap smear or doctor's name had to be dismissed. Provincial health authorities highlighted that this information was heterogeneous from one center to another and could therefore be confusing. Moreover, in case of a national scale-up of the intervention, these proposals would have to be dismissed as it was considered that it would be too complex to include this information for health centers of other provinces.

On the basis of the results of the FGs and the validation with the provincial health authorities, two final versions of SMS were designed: one for HPV-positive women and one for HPV-negative women. Neither SMS delivered the HPV test

result. However, both SMS included the name of the recipient, used the term “self-collection,” and used formal language. The main nuance was in the intensity of the persuasive closing and cue to act. In the case of women with HPV-negative results, the SMS notified them of the availability of the result at the health center and encouraged them to retrieve them. In the message for HPV-positive women, the closing emphasized the importance of going to the health center for a checkup (see Tables 2 and 3).

Both SMS messages were validated by a survey with a sample of 14 women. This sample was taken in a hospital’s gynecological services waiting room (sample by convenience). Therefore, we excluded the CHWs’ mediation. The validation stage was useful for evaluating the understanding and wording

preferences. The results of this stage showed that there were no important divergences or inconsistencies in the interpretation and understanding of the proposed message by women. As a result, new changes were not introduced.

In addition, a pilot test of the ATICA study’s intervention was conducted in July 2018. A total of 7 CHWs invited 36 eligible women to participate in the pilot test during their home visits. Once their HPV results were entered into SITAM, MATYS sent the corresponding SMS messages. Overall, 15 women did not receive the SMS because of errors in the procedure (eg, wrong cell phone numbers and errors in SITAM). In total, 21 eligible women received the SMS messages; of them, 18 (86%) were interviewed; all of them stated that they were highly satisfied with receiving the reminders via SMS.

Table 2. Final version of SMS contents for women who test negative for human papillomavirus.

| Structural elements | Section |
|-----------------------------------|---------------------|
| “Hello” | Greeting |
| “[Name]” | Recipient |
| “The results of” | Informative element |
| “your self-collection are ready.” | Message topic |
| “We’ll be expecting you” | Persuasive element |
| “in the health center” | Sender |
| “to retrieve them.” | Cue of action |

Table 3. Final version of SMS contents for women who test positive for human papillomavirus.

| Structural elements | Section |
|-----------------------------------|---------------------|
| “Hello” | Greeting |
| “[Name]” | Recipient |
| “The results of” | Informative element |
| “your self-collection are ready.” | Message topic |
| “Please visit” | Persuasive element |
| “your health center” | Sender |
| “for a consultation.” | Cue of action |
| “It is important that you go.” | Persuasive element |

Discussion

Principal Findings

This paper presents the results from FG debates to develop an SMS to increase the adherence of HPV-positive women to Pap-based triage, taking into account the women’s preferences regarding the content of the SMS. The study showed that women rejected receiving both negative and positive HPV results by SMS and stressed the importance of SMS content, highlighting the link they had with CHWs and the nearest health center. Women strongly preferred a personalized SMS; not using the word “HPV” was also a key component of the desired SMS content.

In our study, both women and health authorities were against receiving results via SMS, mainly because they considered that

this type of news must be provided in a face-to-face health consultation so that the patients are able to ask questions and get rid of their doubts. The women’s rejection of receiving results by SMS was also mentioned in a study conducted in Chile, which found that Chilean women expressed concerns regarding the *impersonal nature* of the communication by SMS to communicate medical results [33]. Similarly, a colorectal cancer screening study in the United States found that patients did not want to receive results via SMS [57], particularly as it was not an appropriate communication mode to receive what they considered to be bad news. Our finding contrasts with a study conducted with low-resource women from Ohio, United States, which found that women preferred immediate phone calls to know the results (whether negative or positive) rather than waiting for an in-person medical consultation. In the Ohio study, providers favored withholding the HPV SC results as a

strategy to bring women into the clinic [58] because they thought that the delivery of positive results over phone may scare women into denial and be a barrier to follow-up. Interestingly, this was not the reason put forward by women from our study, for whom it was mainly a question of not losing the opportunity to engage with the health system.

In our study, SMS messages were sent to women who were offered HPV SC by CHWs, community members with whom women have a relationship based on trust and familiarity [6,59]. Results from the FG discussions showed that this close link between women and the CHWs permeated the women's choices regarding the greeting line, the overall tone of the SMS, and the selected sender. The need for messages to come from a trusted source has also been shown by studies analyzing mHealth interventions related to other health conditions in different contents [60,61].

The tone of the SMS was an important topic in the FG discussions related to the feeling of a close relationship between the sender and recipient. Women considered that the greeting line and message personalization were important to transmit the warm tone used by CHWs in face-to-face communication. In the same way, a study about blood pressure prevention highlighted the relevance of the SMS tone, wherein participants valued the polite tone of the text messages because it infused a sense of being recognized, respected, valued, and cared for [62].

The importance of a message reflecting the close relationship between women and the CHWs was also highlighted when discussing the sender. The health center, where CHWs are based, was the preferred message sender. Previous research in Jujuy also showed that CHWs are the key link between underscreened women and the health care system [6,59,63]. Similarly, one study on testing HIV among African immigrants in the United Kingdom observed that a trustworthy sender would be important to engage the recipient and avoid the SMS being deleted without a recipient reading it [60].

In text messaging-based health promotion interventions, a personalized SMS (eg, with the recipient's name) has been associated with greater intervention efficacy [64]. A systematic review of behavior change interventions delivered by SMS messages showed that studies using personalized messages had higher follow-up care rates [65]. In our FGs, the inclusion of the recipient's name was highly valued among Jujuy's women. Similar to the aforementioned colorectal cancer screening study [57], our findings indicated that women might dismiss impersonal SMS messages as they may be interpreted as massive bulk texting.

However, several authors have noted that SMS delivered to shared cell phones to promote the treatment of STI presents the challenge of handling confidentiality [66-68]. In studies on STIs and SMS interventions, the main concern mentioned regarding confidentiality was the danger of disclosing results among relatives. In our study, confidentiality concerns mainly influenced how the HPV test was named in the SMS. The tension was between not mentioning the term "HPV," which could increase the risk of misunderstanding, and including the term "HPV" in the SMS, which could result in breaking the women's confidentiality. Thus, similar to findings from studies

on HIV [35,38,69], Jujuy's women preferred an indirect but understandable way to refer to the HPV test using the term "self-collection" and omitting "HPV" in the text message body.

Even though sharing a cell phone may be a confidentiality challenge, our study found that for many women, phone sharing was not necessarily an obstacle. On the contrary, in many cases, relatives acted as facilitators to help women access the information received through their cell phones. A similar finding was described in an HIV study in Uganda [38,70], where participants received their laboratory results by SMS, and if they had abnormal outcomes, they received a request to return to the health care center for treatment. The authors found that participants who had disclosed their HIV status to relatives and coworkers received help using the cell phone and/or reading the information in the SMS. The Ugandan participants with supportive and reliable networks could improve adherence by obtaining support to overcome barriers such as transport costs or asking for permission for time off work [38]. Therefore, to achieve a confidentiality balance in our study, we proposed including a woman's name to personalize the SMS and using the term "self-collection" to indicate what the SMS was about.

Limitations

The FG participants were recruited by the CHWs, which may have biased our sample selection. For example, some FG participants had another type of disease or a relative with a health problem (in two groups). This introduced a bias in group perceptions as they had a profound knowledge of certain health procedures. As we previously mentioned, the recruitment of one group failed: CHWs invited women without cell phones, and we were obligated to exclude this FG from this analysis.

Nevertheless, during the validation of the results by means of the survey, no significant discrepancies were presented in the FG findings. Another limitation is that the predesigned content used only affirmative phrases. A study on the promotion of colorectal cancer screening found a slightly higher effect in the groups that received invitations containing interrogative sentences than those that received declarative ones [71]. This modality should also be tested in future studies (eg, scaling-up evaluation). Despite the mentioned limitations, our approach of combining theory-informed content with user-driven feedback and local expert advice strengthens the potential of the SMS intervention.

Conclusions and Implications

This formative research has shown women's preferences with regard to greeting, mentioning the recipient, and the tone of the message (warmth and formality) to avoid the SMS from the health care system from being dismissed. The key terms of the SMS (in this case, the HPV test) must be carefully chosen in an endeavor to guarantee both confidentiality and comprehension of the content by the recipient.

Our findings have some implications for the design of mHealth interventions targeted at improving adherence to diagnoses and treatment of HPV-tested women. A personalized SMS may quickly notify the availability of HPV result; however, its content has to be carefully designed to transmit a health system's proactive intention of caring for the population.

In our study, women preferred to not receive negative results via SMS because they believed that the communication between them and the health professionals during the delivery of the results should be prioritized. Although this was in agreement with other studies, it is necessary to determine if this preference is generalized to women from other settings.

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Conflicts of Interest

None declared.

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Abbreviations

ATICA: Application of Communication and Information Technologies to Self-collection (for its initials in Spanish)
CC: cervical cancer
CHW: community health worker
FG: focus group
HBM: health belief model
HPV: human papillomavirus
MATYS: Automatic Messaging for Screening and Follow-up Care (for its initials in Spanish)
mHealth: mobile health
NIH: National Institutes of Health
SC: self-collection
SITAM: National Screening Information System (for its initials in Spanish)
STI: sexually transmitted infection

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Original Paper

A Walking Intervention Supplemented With Mobile Health Technology in Low-Active Urban African American Women With Asthma: Proof-of-Concept Study

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Abstract

Background: Physical inactivity is associated with worse asthma outcomes. African American women experience disparities in both physical inactivity and asthma relative to their white counterparts. We conducted a modified evidence-based walking intervention supplemented with mobile health (mHealth) technologies to increase physical activity (PA).

Objective: This study aimed to assess the preliminary feasibility of a 7-week walking intervention modified for African American women with asthma.

Methods: African American women with suboptimally controlled asthma were identified from a health system serving low-income minorities. At a baseline data collection visit, participants performed spirometry and incremental shuttle walk test, completed questionnaires, and were given an accelerometer to wear for 1 week. The intervention comprised an informational study manual and 3 in-person group sessions over 7 weeks, led by a nurse interventionist, in a community setting. The supplemental mHealth tools included a wearable activity tracker device (Fitbit Charge HR) and one-way text messages related to PA and asthma 3 times per week. A secure Web-based research platform, iCardia, was used to obtain Fitbit data in real time (wear time, moderate-to-vigorous physical activity [MVPA] and sedentary time) and send text messages. The feasibility of the intervention was assessed in the domains of recruitment capability, acceptability (adherence, retention, engagement, text messaging, acceptability, complaints, and concerns), and preliminary outcome effects on PA behavior (change in steps, duration, and intensity).

Results: We approached 22 women, of whom 10 were eligible; 7 consented, enrolled and completed the study. Group session attendance was 71% (5/7), 86% (6/7), and 86% (6/7), respectively, across the 3 sessions. All participants completed evaluations at each group session. The women reported being satisfied or very satisfied with the program (eg, location, time, and materials). None of them had concerns about using, charging, or syncing the Fitbit device and app. Participants wore their Fitbit device for at least 10 hours per day in 44 out of the 49 intervention days. There was an increase in Fitbit-measured MVPA from week 1 (19 min/week, SD 14 min/week) to the last week of intervention (22 min/week, SD 12 min/week; Cohen $d=0.24$, 95% CI 0.1 to 6.4). A slight decrease in step count was observed from week 1 (8926 steps/day, SD 2156 steps/day) to the last week of intervention (8517 steps/day, SD 1612 steps/day; Cohen $d=-0.21$, 95% CI -876.9 to 58.9).

Conclusions: The initial feasibility results of a 7-week community-based walking intervention tailored for African American women with asthma and supplemented with mHealth tools are promising. Modifications to recruitment, retention, and the intervention itself are needed. These findings support the need to conduct a further modified pilot trial to collect additional data on feasibility and estimate the efficacy of the intervention on asthma and PA outcomes.

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KEYWORDS

activity trackers; text message; physical activity; asthma; African-American; women; mHealth; smartphone; mobile phone

Introduction

Background

Asthma is a highly prevalent chronic disease that affects 1 in 12 people in the United States [1]. However, asthma disproportionately impacts African American women [1]. African American women have higher rates of asthma exacerbations and health care utilization, worse lung function, poorer asthma-related quality of life, and a higher crude asthma mortality rate compared with white women [1-3].

Research to date shows that engaging in regular, moderate physical activity (PA) improves asthma-related quality of life and asthma control and decreases asthma health care utilization [4-6]. Despite the benefits of PA in asthma and guideline recommendations to engage in PA, individuals with asthma, particularly women, are less likely to engage in PA than women without asthma (odds ratio [OR] 3.66 vs 4.37) and men with asthma (OR 3.66 vs 4.57) [7-10]. Given the connection between poor asthma outcomes and physical inactivity, addressing PA among sedentary African American women with asthma is imperative [11,12].

Of the existing PA interventions tested in people with asthma, only 2 have focused on walking. The first was a long-term (1 year) community-based study but was not a randomized controlled trial; the second was a 12-week randomized controlled trial in an academic center's fitness center [5,13]. Both studies demonstrated the safety of walking interventions in asthma and improvements in asthma control or quality of life but included predominately white women (>50%). As promising as these limited results are, no PA interventions to date have tailored to the needs of African American women with asthma.

Although African American women with asthma are faced with many of the same barriers to PA as other women with and without asthma, this population faces unique barriers. Specifically, the barriers identified among African American women, in general, include a lower self-efficacy for PA, lack of social support, culturally based preferences for body type and hair, community safety concerns, lack of sidewalks, and a lack of physically active role models [7,14-17]. All of these barriers combined make taking on a new behavior such as PA in the face of a chronic disease difficult. Research supports the development of tailored PA interventions in African American women as there is a need to consider the particular needs of African American women, which is a missing component in current PA interventions for asthma [12,18].

The Women's Lifestyle Physical Activity Program, a group-based behavioral intervention developed for low-active

urban African American women, found an improvement in daily steps and high adherence to the walking program [19]. Although this program was tailored for African American women, an exclusionary criterion was chronic pulmonary disease. Using feedback we obtained from African American women with asthma who examined materials from the Women's Lifestyle Physical Activity Program [16], we tailored a PA intervention to meet their needs specific to asthma and lifestyle preferences. The modifications included an asthma education session, led by an asthma educator, the use of mobile health (mHealth) tools such as SMS (to deliver advice, reminders, and motivational support to increase walking), and the utilization of commercial wearable activity tracker devices ([Multimedia Appendix 1](#)) [19,20]. Technology-based interventions have a high level of user satisfaction, especially among ethnic and racial minorities and urban or low-income individuals with asthma and have been used to promote PA in African American women without asthma [21-25].

Objective

The objective of this study was to assess the feasibility (recruitment, retention, adherence to group meetings, and adherence to Fitbit device wear time) of the modified 7-week walking intervention (ACTION) and assess preliminary outcome effects on PA behavior (change in steps, duration, and intensity).

Methods

Design

This proof-of-concept study was a prepilot test of the ACTION study funded by the National Heart, Lung, and Blood Institute. The aim of this prepilot study was to recruit up to 10 African American women with asthma over a period of 3 months to test and refine the study procedures and materials, including recruitment methods and content of the ACTION intervention.

Setting and Participants

Participants were recruited from a large urban medical center serving approximately 60% African Americans. Potential participants were approached in a subspecialty asthma clinic after being informed by their physician of the study and agreeing to be contacted or were previously screened for asthma studies and provided consent to be contacted for future studies. Participants were screened in-person or by phone and were eligible for the study if they had a physician diagnosis of asthma, self-identified as African American and female, were between the ages of 18 and 70, registered as a patient at the medical center, were low-active as defined by self-report of <150 min of moderate to vigorous PA per week ("On average, how many

minutes per week of moderate to vigorous intensity physical activity do you engage in?"), and had suboptimally controlled asthma (Asthma Control Test score <20) [26]. If eligible, the woman was invited to participate in the study. Interested participants came for a baseline assessment visit at the Clinical Research Center at the University of Illinois at Chicago, where written informed consent was obtained from each participant before any study procedures. All participants received US \$25 in remuneration for their time and travel after completion of the baseline assessment visit and at the last intervention group session (total US \$50). The study (protocol #2016-0466) was approved by the University of Illinois at Chicago Institutional Review Board.

Procedures

Participants attended a baseline assessment visit approximately 1 to 3 weeks before the start of the intervention ([Multimedia Appendix 2](#)). The visit consisted of informed consent procedures, baseline data collection pertaining to demographics, PA and asthma-related study measures (spirometry without

bronchodilation, incremental shuttle walk test [ISWT], Asthma Control Questionnaire [ACQ], and Asthma Quality of Life Questionnaire [AQLQ]), provision of a research-grade activity monitor (ActiGraph GT3X+), download of the Fitbit mobile app on participant's mobile device (eg, smartphone or tablet), and pairing process of the Fitbit activity tracker device with the mobile app. After pairing the Fitbit device with the participant's mobile device, the Fitbit device was kept in the possession of the study team until the first group visit and given to the participant at that time to begin wearing. Participants were asked to wear the research-grade activity monitor on their nondominant wrist for 7 consecutive days during their waking and sleeping hours, except when bathing. A wrist-based accelerometer was used to enhance wear compliance, which has been observed by the 2011-2013 National Health and Nutrition Examination Survey group [27]. The 7-week intervention began after all participants completed the baseline data collection, including wearing the accelerometer. We collected the feasibility and acceptability of the intervention both during and/or after completion of the intervention, when applicable ([Table 1](#)).

Table 1. Feasibility metrics, assessment strategy and methods used, and timepoint measured.

| Feasibility metric and assessment strategy | Assessment method | Timepoint measured |
|--|--|--------------------|
| 1. Process recruitment capability | | |
| 1.1. Recruitment length, rate, and eligibility criteria | Recruitment length was reported as the length of time it took to recruit the desired sample size. Recruitment rates were reported as the number of people approached (phone or in-person), screened, eligible, and not eligible. Reasons for ineligibility were recorded if applicable. | Weeks –2 to 0 |
| 1.2. Recruitment strategies and barriers | Recruitment barriers were identified by research staff and recorded in field notes and transferred to a Microsoft Excel sheet. Recruitment barriers and strategies were reviewed by the research team at weekly meetings. | Weeks –2 to 0 |
| 2. Feasibility: acceptability and suitability | | |
| 2.1. Adherence | Adherence was calculated as a percentage of sessions attended. Adherence to wearing the Fitbit device was measured as wear time using Fitbit data. Adherence to step goals was measured as percentage of days in a week that the step goal was met by participants using Fitbit data. | Weeks 1 to 7 |
| 2.2 Retention | Retention rate was calculated as the number of participants who completed the postintervention evaluation subtracted from those who were enrolled in the intervention. Participants were categorized into 2 groups: those who completed ≥ 2 group sessions and used technology components, and those who wore the Fitbit device during the intervention and received SMS ^a but attended < 2 group sessions. | Weeks 1 to 7 |
| 2.3. Engagement | Participant engagement was assessed by the same nurse interventionist at each group session using a 7-point Likert scale with 1=not at all engaged and 7=very engaged. | Weeks 1, 3, and 7 |
| 2.4. Text messages delivery and content appropriateness | Text message delivery was measured as the number of SMS successfully delivered in relation to the number of planned SMS to be sent. | Weeks 1 to 7 |
| | Content appropriateness was assessed by feedback provided by participants using a 5-point Likert scale with 1=not at all appropriate to 5=very appropriate. | Weeks 1, 3, and 7 |
| 2.5. Acceptability | Location, time, text message, Fitbit (device, app, and syncing), and overall program acceptability. Overall satisfaction was measured using either a 5-(text message) or 7-point (location, time, Fitbit, and overall program) Likert scale with 1=not at all satisfied to 7=very satisfied. We used 7-point Likert scales for satisfaction (1 representing not satisfied and 7 representing very satisfied) of (1) intervention location, (2) time of intervention sessions, (3) Fitbit (charging, syncing, and app use), and (4) overall intervention. | Week 7 |
| 2.6. Complaints and concerns | Complaints and concerns about the program were recorded when participants reported to the research team or by written feedback. | Weeks 1 to 7 |
| 3. Preliminary outcome effects (PA^b and asthma): assessments of the safety, compliance, and treatment effect of the study. | | |
| 3.1. Adverse events and serious adverse events | Participants were asked about minor events at each session and they were recorded in the REDCap database. | Weeks 1 to 7 |
| 3.2. Participants demographic/clinical data | Demographic data were obtained via a self-report questionnaire at the baseline. Baseline clinical data (asthma and physical activity measures) included ACQ ^c [38], mini-AQLQ ^d [39], FEV ₁ ^e % predicted, mean daily steps per day measured by ActiGraph GT3X+, and ISWT ^f . | Week 0 |
| 3.3. Preliminary outcomes effects | Primary outcome of exercise was daily step count from Fitbit raw data. Secondary outcomes from Fitbit included time spent in moderate-to-vigorous physical activity, termed by Fitbit as <i>active minutes</i> at ≥ 3 METs ^g , and sedentary time (≤ 1 METs) | Weeks 1 to 7 |

^aSMS: short message service.

^bPA: physical activity.

^cACQ: Asthma Control Questionnaire.

^dAQLQ: Asthma Quality of Life Questionnaire.

^eFEV₁: forced expiratory volume in 1 second.

^fISWT: incremental shuttle walk test.

^gMET: metabolic equivalent.

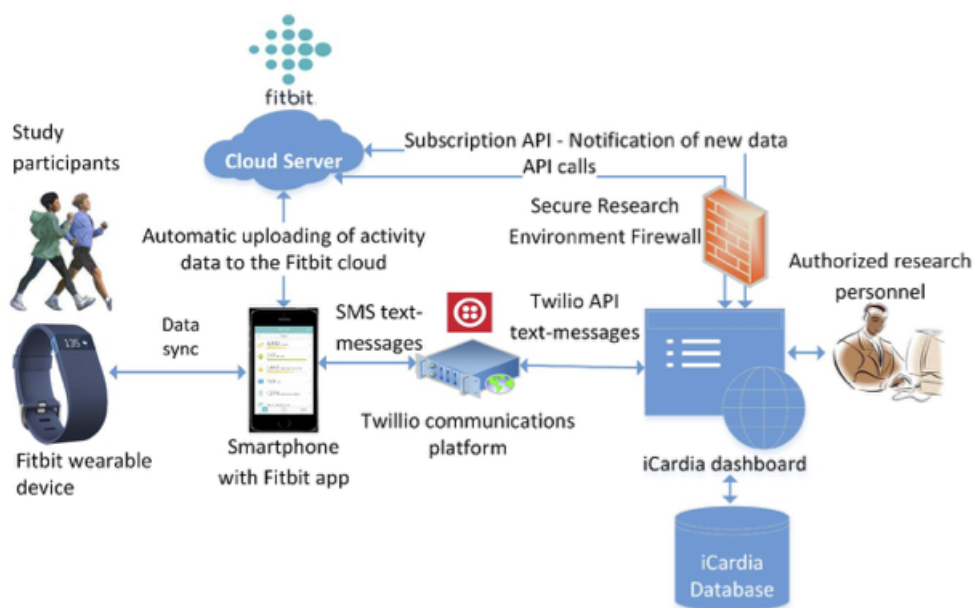
Intervention

The Women's Lifestyle Physical Activity Program is a 48-week evidence-based moderate-intensity walking intervention designed for urban low-active African American women [19]. The intervention used social cognitive theory strategies that were applied systematically throughout to target specific barriers that African American women face when engaging in PA, including lack of social support, self-efficacy, and environmental barriers. The intervention components included a tailored walking prescription, a PA self-monitoring tool (pedometer), group discussions to address goals and barriers, and motivational telephone calls (automated vs personal). We adapted this intervention using the Behavior Change Wheel and Theoretical Domains Framework to address the unique barriers to PA experienced by urban low-active African American women with asthma [16,20,28]. The adaptations included a 45-min dedicated asthma education session (based on the American Lung Association's Asthma Basics course) at the start of the intervention, motivational text messages, group sessions with African American women with asthma, an optional walking session, and informational written materials on exercising with asthma. Women participated in the modified 7-week intervention (ACTION) after completing baseline data collection. The intervention consisted of (1) self-monitoring and self-regulation

of PA through the use of a wrist-based wearable activity tracking device (Fitbit Charge HR) and Fitbit mobile app, (2) PA goal-setting, (3) in-person group sessions, and (4) text messages (Multimedia Appendix 1).

Intervention data were managed through iCardia, a secure research platform that enables remote collection of patient-generated health data from multiple connected health devices, including Fitbits, through the use of Web-based application programming interfaces (APIs) [29]. iCardia comprises user-friendly visualization and data exporting tools that allow authorized study researchers to view and analyze objectively measured Fitbit data pertaining to PA (eg, step count, PA intensity, type, and duration) and sedentary behavior. iCardia's dashboard presents all incoming data to researchers in the form of graphs and allows them to send text messages to participants' mobile phones. Study participants did not have access to iCardia; they only interacted with their Fitbit mobile app and PA monitor. The text messaging feature is integrated with the iCardia clinical dashboard and utilizes Twilio's API to send messages via the SMS protocol. In the context of this study, iCardia was used to facilitate remote monitoring of PA measures from Fitbit devices and delivery of text messages each week to increase PA levels in patients with asthma (Figure 1). Text message content is described in more detail below.

Figure 1. iCardia platform.



Self-Monitoring of Physical Activity With Fitbit Charge HR

Fitbit Charge HR is a reliable and user-friendly tracker that collects a wide range of PA and biological data, including step count, PA intensity (*light*, *fairly active*, and *very active*), sedentary time (any waking behavior characterized by an energy expenditure ≤ 1 metabolic equivalents [METs] while in sitting or lying posture), calories burned, sleep, and continuous heart rate [30-33]. Coded individual Fitbit user accounts were created for study purposes for each participant before the distribution of the devices. The accounts were linked to the iCardia platform

to enable study investigators to remotely collect and monitor all Fitbit data from study participants in near real time. Participants received in-person training and printed instructions on how to perform the following tasks: (1) sync the activity tracker with the app, (2) view PA data on the app and tracker, and (3) charge the tracker at the initial group meeting. At the subsequent group meetings, this information was reviewed with participants upon request.

Physical Activity Goal Setting

Participants received an initial step goal in the first week of the intervention based on their average daily steps recorded during

baseline (week 0) with the ActiGraph accelerometer (ActiGraph GT3X+). At every group session, the step goals were updated based on participants' average daily Fitbit steps in the period between each group session. The step goal was based on the mean weekly step count for the weeks before the study visit. We based our goal setting on the Women's Lifestyle Physical Activity Program. The goal of that program was to increase each woman's PA above baseline by at least 3000 steps per day, approximately 30 min of PA, over 24 weeks [19,34]. This is equivalent to 145 steps per day to achieve the program's goal of 3000 above the baseline over 24 weeks. Therefore, the goal of this study was to increase, on average, 150 steps per day for each week between the study visits. For example, there were 3 weeks between group sessions 1 and 2, so the step goal the participant received in group session 2 was the mean of the 3 weeks plus 450 (150 steps \times 3 weeks). The first step goal at visit 1 was set based on baseline step count captured by the ActiGraph, and the second and third step goals were set based on step count data captured by the Fitbit Charge HR. If the step goal was met, the participants were encouraged to increase their walking intensity. If not met, the step goal was the same as the previous group session.

In-Person Group Sessions

The intervention comprised 3 in-person group sessions, each lasting 2 hours, held at a Chicago Park District location. At the first group session, participants were given back their Fitbit Charge HR and were trained on how to use the device and app. They also received an asthma education session and an introduction to the walking program. The other 2 in-person group meetings occurred approximately 3 weeks apart and included a short video on overcoming barriers to engaging in PA and meeting PA goals. The video was followed by a group discussion led by a nurse interventionist.

Text Messages

Text messages (Multimedia Appendix 3) were developed using existing literature on text messaging to monitor asthma symptoms, and to promote asthma medication adherence and walking [25,35,36]. The sample text messages were reviewed by 10 African American female patients with asthma and by the nurse interventionist for the study, an African American woman with asthma, for further cultural modification before the start of the study. The text messages were at a fourth-grade reading level (measured by the Flesch-Kincaid Grade Level test) to account for differing education levels of women in the study.

Study participants received up to 5 text messages per week via the iCardia platform during the 7-week intervention. Messages containing personalized weekly step reports, educational content on asthma, and motivational/inspirational content to be physically active were sent to all participants 3 times a week (Monday, Wednesday, and Friday). An additional 1 to 2 messages per week were sent to remind participants of upcoming group sessions and to charge/sync the Fitbit device when applicable. The SMSs were reviewed by members of the research team each week and sent by the same research assistant throughout the entire study. The personalized weekly step reports were sent on Mondays and included a short report about

their PA performance from the previous week praising the participants for meeting their step goal or encouraging them to achieve the step goal if not met. The nature of these text messages was adapted based on Fitbit data from the previous week and the progress of each participant. The educational text messages were sent on Wednesdays, were related to pollution and pollen warnings, and included tips on how to be more physically active and exercise, taking into consideration weather conditions and asthma. Participants also received 1 inspirational message each Friday. All participants received the same educational and inspirational messages each week.

Feasibility and Outcome Measures

The feasibility of the intervention was assessed in the domains of recruitment capability, acceptability/suitability (adherence, retention, engagement, text messaging, acceptability, and complaints/concerns), and preliminary outcome effects on PA behavior (change in steps, duration, intensity, sedentary time, and adjusted sedentary time) and asthma measures (control and quality of life). These metrics, assessment strategy, and methods are summarized in Table 1. A Fitbit-based adjusted sedentary time measure was automatically calculated by iCardia to distinguish the minutes of true sedentary behavior from those minutes that users were simply not wearing their device. Fitbit classifies *sedentary* when MET values are ≤ 1 , but this does not account for device wear time. Using wear time data as measured by heart rate, iCardia calculates an adjusted sedentary time by summing the number of Fitbit-based sedentary minutes when heart rate was nonmissing. Subsequently, we assessed differences between these 2 measures to determine the feasibility of measuring adjusted sedentary time, and also to determine the degree to which nonwear time impacts the actual Fitbit sedentary time measure under free-living conditions.

Data Analysis

We collected accelerometer raw data at 30 Hz and uploaded using the ActiLife software (version 6.13.3, ActiGraph) at baseline. We converted raw files to counts per minute using the normal filter. A minimum of 10 hours of wear time, for at least 3 days, was retained for data analysis [27]. Accelerometer data were processed and analyzed after sleep time was excluded. The data were downloaded as step count and activity counts, which represents processed accelerations summed to a 60-second epoch length. PA intensity cut points were not applied to accelerometer data. Descriptive statistics are presented as means (M), standard deviation (SD), and relative frequency (%). Effect sizes (d) were calculated using the Cohen formula for paired samples. We performed visual inspection and the Shapiro-Wilk test of normality, which depicted normal distribution of the data [37]. Therefore, to compare sedentary versus adjusted sedentary time between week 1 to week 7, we conducted paired t tests at 5% significance level. We used Microsoft Excel and SPSS version 23 (IBM) for statistical procedures.

Results

Participant Demographics and Baseline Characteristics

Participants included 7 overweight or obese (BMI 34 kg/m², SD 10 kg/m²), middle-aged (48 years old, SD 11 years) women.

Overall, the participants' asthma was not controlled ($ACQ \geq 1$ =uncontrolled) and had evidence of moderate airflow obstruction (forced expiratory volume in 1 second % predicted $< 70\%$) [40]. The mini-AQLQ revealed some impairment in all domains (symptoms, activity limitation, emotional function, and environment stimuli). The greatest impairment was found in the environment stimuli domain, which included questions

about feeling bothered by dust, cigarette smoke, and weather/air pollution [39]. At baseline, the mean ISWT was 400 m, which is similar to what has been found in a study of severe asthma patients [41]. At baseline (Table 2), the mean activity step count per day of the participants, as measured by ActiGraph, was over 10,000 (10,482 steps/day, SD 3170 steps/day).

Table 2. Baseline characteristics.

| Variable | Value, mean (SD) |
|---|---------------------|
| Age | 48.29 (11.22) |
| BMI | 34.12 (9.68) |
| FEV ₁ ^a % predicted | 65.14 (14.11) |
| ACQ ^b score | 1.85 (1.54) |
| ISWT ^c distance | 400.00 (116.04) |
| Steps (ActiGraph accelerometer) | 10,481.85 (3169.75) |
| Mini-AQLQ^d | |
| Symptoms | 5.22 (1.79) |
| Activity limitation | 5.32 (1.62) |
| Emotional function | 5.76 (1.19) |
| Environment stimuli | 4.42 (2.21) |
| Overall AQLQ score | 5.18 (1.55) |

^aFEV₁: forced expiratory volume in 1 second.

^bACQ: Asthma Control Questionnaire.

^cISWT: incremental shuttle walk test.

^dAQLQ: Asthma Quality of Life Questionnaire.

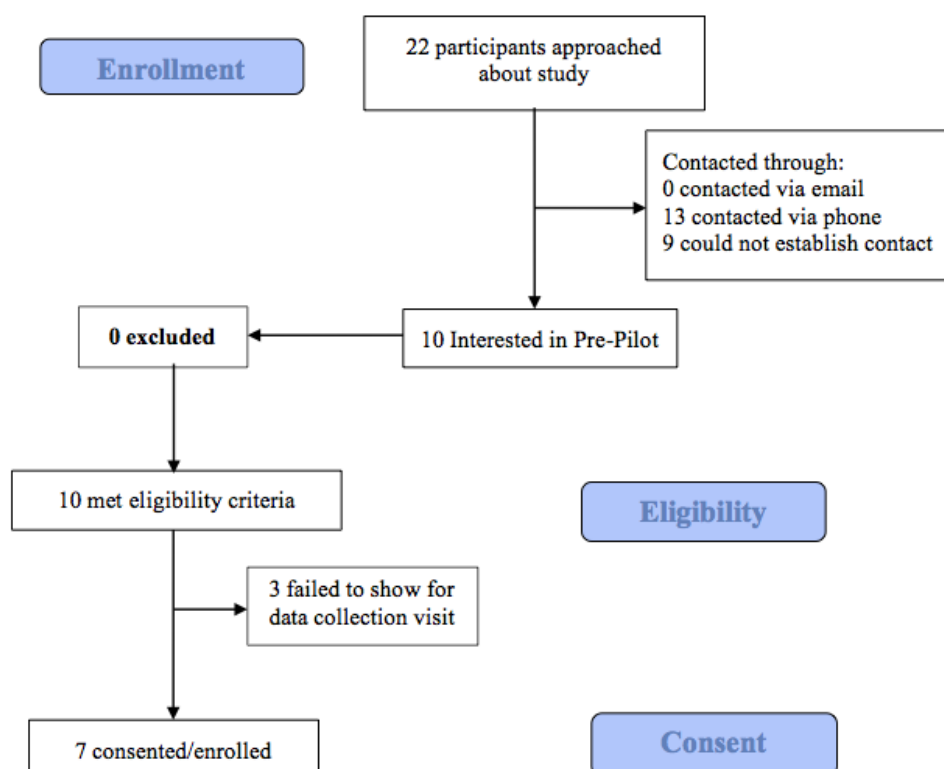
Process Feasibility

Recruitment

The Consolidated Standards of Reporting Trials (CONSORT) diagram in Figure 2 outlines the details of participant flow. A

total of 22 asthma patients were contacted (in-person or by phone) to assess interest and eligibility in the study over 5 weeks. Of those, 10 eligible patients completed screening and offered enrollment; 3 participants did not attend the baseline visit, yielding a final sample of 7 asthma participants consented and enrolled in the study (Figure 2).

Figure 2. CONSORT flow diagram.



Barriers to recruitment included incorrect phone information from electronic medical record for potential participants, limited physician engagement in recommending the research program to their patients, recruitment only from the University of Illinois Health asthma specialty clinics, study staff availability to conduct study visits in the evenings, and space availability to accommodate for weekend appointments.

Feasibility: Acceptability and Suitability

Adherence to Group Sessions

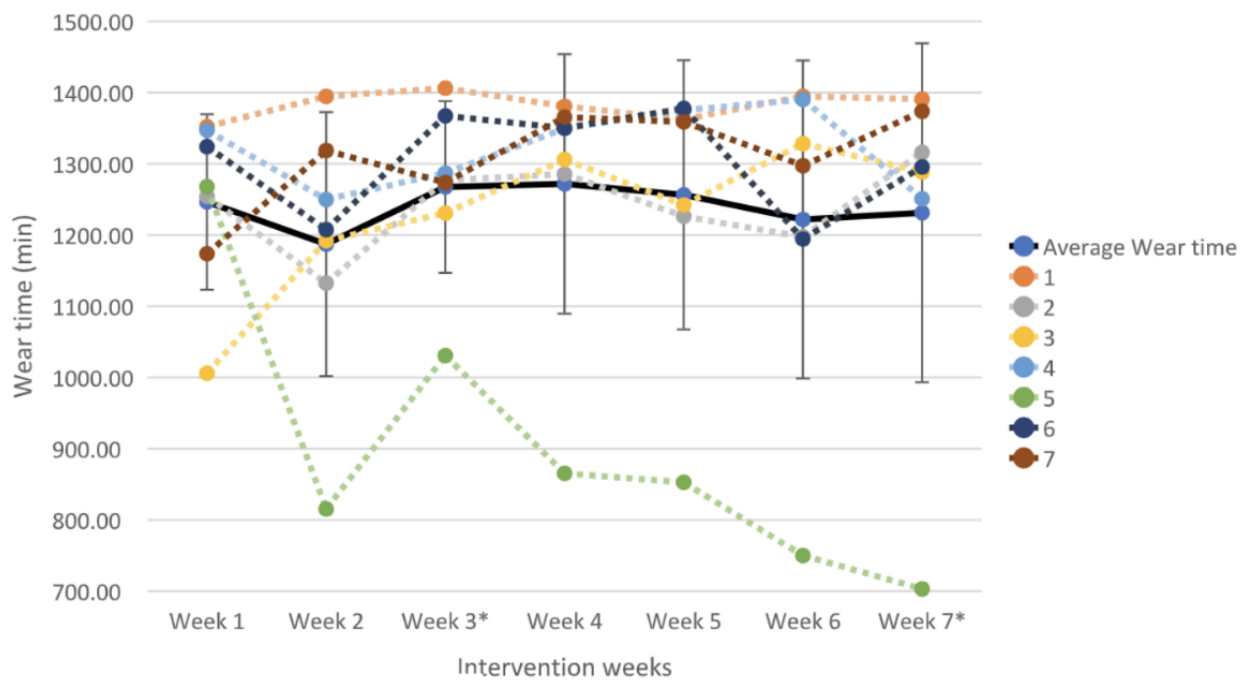
Participant attendance rate for each of the 3 group sessions was 71% (5/7), 86% (6/7), and 86% (6/7), respectively. The overall

mean participant adherence for all the group sessions was 81%. Reasons for not attending the group sessions included family obligations and lack of transportation.

Adherence to Wearing the Fitbit

During the 7-week intervention period, all participants adhered to wearing their Fitbit device for more than 600 min per day (valid day) most of the days, exceeding the minimum threshold for daily adherence. The overall mean fluctuated from 1247 (SD 123) min in the first week of the intervention, with a peak of 1272 (SD 183) min in week 4, and small decrease (1231 min, SD 238 min) in the last week of the intervention (Figure 3). Participants had on average 43.71 days of valid days (89.2%).

Figure 3. Mean, standard deviation, and individual Fitbit wear time over the 7-week intervention period.



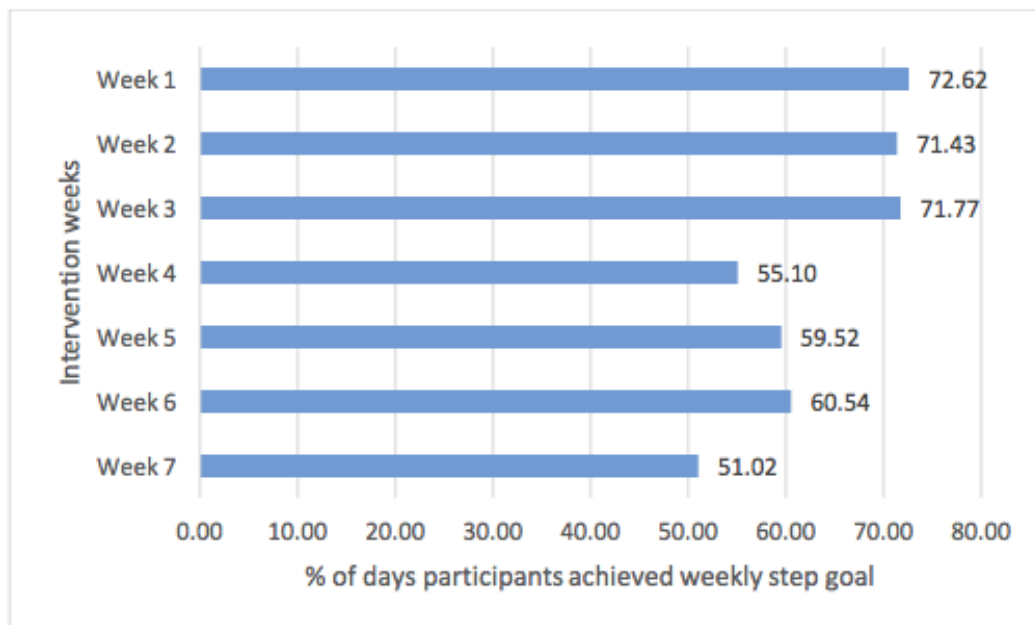
*Week when a group session was held

Fitbit Step Goal Adherence

The step goal was met on more than 70% of the days in the first 3 weeks for all participants. From week 4 to 7, the percentage

of days the participants met their step goals decreased to just above 50% (Figure 4).

Figure 4. Mean weekly goal achievement over the 7-week intervention period.



Retention

The retention rate was based on the number of participants who completed the postintervention evaluation subtracted from those who were enrolled in the intervention. Only 1 of the 7 women were unable to complete the postintervention evaluation in-person but completed the evaluation over the phone (retention rate=100%). This participant was categorized into the group

who wore the Fitbit device during the intervention and received SMS but attended <2 group sessions. This participant only attended 1 group session and indicated that she was unable to attend the group sessions because of competing family commitments.

Engagement

The women that attended the group sessions were very engaged (1=not at all engaged to 7=very engaged) based on their engagement scores determined by the nurse interventionist. The mean engagement for each group session was 7 (SD 0), 6.8 (SD 0.4), and 6.8 (SD 0.4), respectively.

Text Messages Delivery and Content Appropriateness

A total of 217 text messages were successfully delivered to the participants over the 7 weeks. Each participant received an average of 31 (SD 1.3) messages over the intervention period, averaging 4.4 (SD 0.2) messages per week. The frequency of text messages was considered enough by 6 participants, although 1 participant mentioned she would have liked more, and indicated that 10 SMSs per week would be enough. All participants indicated the content of the messages was very appropriate or appropriate.

Acceptability

All 7 participants provided their input on acceptability of the intervention components (location, time, text messages, and Fitbit device and app) and the overall intervention at the completion of the last group session. All participants were very satisfied/satisfied with the text messages and with the Fitbit Charge HR. All participants felt very comfortable/comfortable charging and syncing the device with the app. All the participants were also comfortable using the Fitbit mobile app to view their data. None of the participants mentioned being unsatisfied with any of the aspects of the program. Most participants were satisfied/very satisfied with the location (6/7,

86%), time (6/7, 86%), and the intervention program as a whole (7/7, 100%).

Complaints and Concerns

Only 1 participant expressed that she expected more organized walking during the group sessions.

Scientific Outcomes: Safety, Compliance, and Treatment Effect

Safety

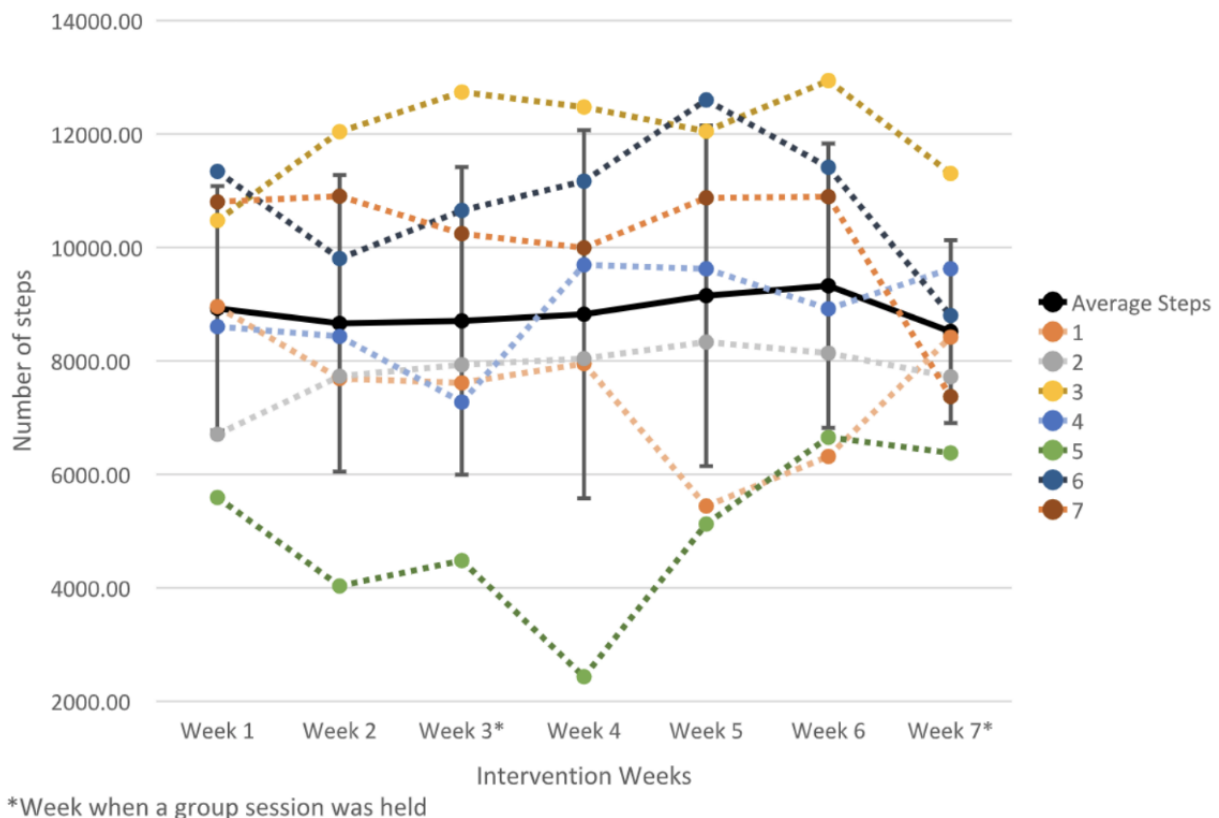
No serious adverse events were reported during the intervention, although 1 participant noticed “a little skin irritation” because of the Fitbit device use. She indicated that her wrist just needed some “air time,” which resolved the irritation.

Preliminary Outcomes Effects

Fitbit Steps

Participants had a mean step count of 8926 (SD 2156) steps per day after the end of the first week of intervention. At the end of week 3, participants had maintained or increased their step goal. After the participants received their updated step goal, a slight increase in daily step count was observed from week 4 (8705, SD 2712) to week 6 (9325, SD 2505). In the last week of the intervention, only 2 of the 7 participants (#1 and 4) increased their daily step count. The other 5 participants (#2, 3, 5, 6, and 7) decreased their daily step count by 275 to 3522 steps per day (see Figure 5). An effect size calculation showed a small, not statistically significant, negative effect of the 7-week intervention on steps count (Cohen $d=0.28$, 95% CI -876.9 to 58.9).

Figure 5. Mean weekly goal achievement over the 7-week intervention period.

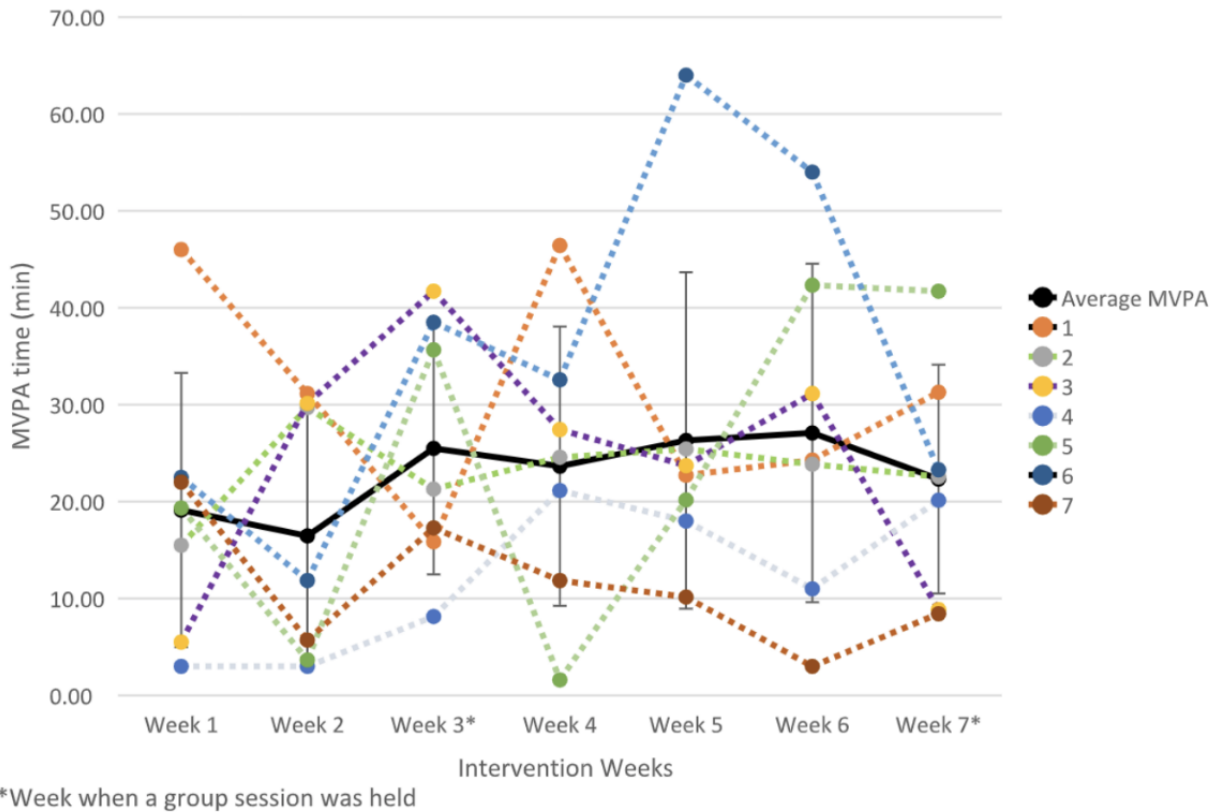


Fitbit Moderate-to-Vigorous Physical Activity

In general, we observed an increase in MVPA. After the first week of intervention, the participants averaged 19 (SD 14.15) min per day of MVPA. At the end of the last week, the time

spent in MVPA averaged 22 (SD 12) min per day. We detected a small positive effect of the 7-week intervention on MVPA (Cohen $d=0.24$, 95% CI 0.1 to 6.4). All participants showed fluctuation in time spent on MVPA, with accentuated increases followed by steep decreases (Figure 6).

Figure 6. Weekly mean, standard deviation, and individual time spent in MVPA over the 7-week intervention period.

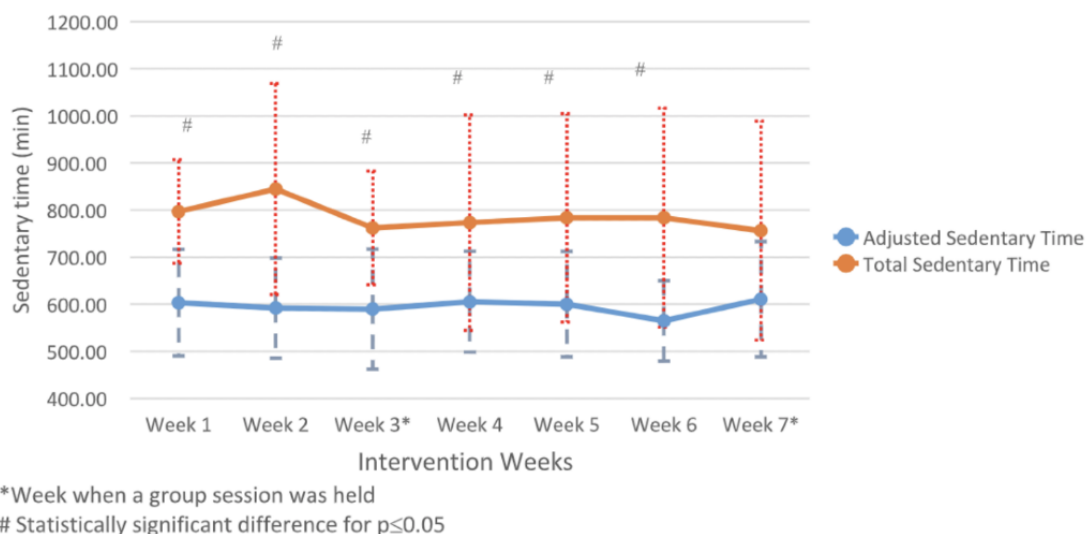


Fitbit Sedentary Time

Participants showed a mean adjusted sedentary time of 595 (SD 110) min per week, with a peak of sedentary time during the last week of intervention (611 min/week, SD 122 min/week; Figure 7). We observed a statistically significant difference

between the total and adjusted sedentary time in weeks 1, 2, 3, 4, 5, and 6 (week 1: Cohen $d=-1.73$, $P=.006$; week 2: Cohen $d=-1.26$, $P=.01$; week 3: Cohen $d=-1.39$, $P=.009$; week 4: Cohen $d=-0.80$, $P=.049$; week 5: Cohen $d=-0.95$, $P=.04$; week 6: Cohen $d=-1.23$, $P=.04$).

Figure 7. Comparison of the weekly mean time spent in total and adjusted sedentary behavior over the 7-week intervention period.



Discussion

Principal Findings

This study reports on the feasibility (process, acceptability, and scientific outcomes) of a walking intervention adapted for urban, low-active African American women with asthma. Our recruitment rate of 32% (7/22) is similar to what has been reported by another PA intervention in adults with asthma (32%) [13]. Although many of the recruitment barriers we encountered were similar to what has been reported in other clinical trials (incorrect patient contact information, limited physician engagement, and study staff and space availability to accommodate for evening and weekend visits), these issues are often augmented in low-income minority populations [42]. Frequent changes in phone numbers, an inability to take off from work, or childcare responsibilities may be contributing factors, and a multipronged approach is needed to overcome these recruitment barriers [43,44]. In future pilot testing, we will obtain multiple numbers of contact for potential participants, adjust study staff hours to accommodate for off-hour visits, and consider offering childcare during study visits. To address the physician engagement barrier, we plan to introduce our study at internal medicine and pulmonary faculty meetings and provide in-person reminders to physicians before seeing asthma patients in clinics.

In our outcomes of resource feasibility (acceptability and suitability), we had a high retention rate with no dropouts. In previous PA interventions in adults with asthma, 2 studies had dropout rates between 19% and 25%. Both studies had a similar intervention duration (8-weeks) to our study. One of them required attendance of 3 high-intensity interval exercise sessions per week in a hospital setting [45]; the other one included 6 group educational sessions, and a minimum of 20 home-based sessions of exercise training, during the 2-month study period [46]. Both studies found that younger employed adults were more likely to drop out. Our study included middle-aged adults, some of which were employed, and others were not. The less intensive group schedule that accounted for weekday workers and lifestyle-based PA program of our study may have contributed to our lack of dropouts, high participant engagement, and overall acceptability. Additionally, it was easier to coordinate and accommodate the schedules of a smaller group of women. The overall adherence to the intervention (group sessions and Fitbit device wear time) was high. The wear time was high likely because of our ability to remotely monitor participants' adherence to wearing their Fitbit device regularly and address any adherence issues promptly using personalized text message reminders and behavior prompts. Most of the days throughout the intervention period were valid data, given the average daily wear time was well-over 600 min, which is often used in interventional studies as a cutoff point for determining a valid day of PA assessment [47]. Previous studies have shown self-reported wear time to decrease over time [48]. We saw high levels of adherence to the step goals during the first half of the study, which began to decline gradually in the second half of the intervention. These fluctuations in PA have been found in other PA interventions [48].

The scientific outcomes we assessed included the safety, compliance, and treatment effect of the intervention. Similar to other PA interventions in uncontrolled asthma patients, we did not have any adverse events, which is encouraging for future studies [45,49]. During baseline data collection using accelerometers, we found that the baseline step count in our study population of African American women with asthma was above 10,000 steps per day. This value was higher than expected on the basis of previous literature on urban African American women [19]. Despite the high step counts, participants were not engaging with the recommended amounts of MVPA weekly. Thus, our self-reported screening tool regarding MVPA levels was concordant with the objective measurements of MVPA. A seasonal effect may have occurred as the study was conducted in the summer months when more time is spent doing PA [50,51]. Many of the participants came from a convenience sample of the specialty asthma clinics, which may not represent the general asthma population. Although the accelerometer did not provide a screen for participants to see their step count, the participants may have been more aware of their PA since they knew it was being measured. Our small sample size did not allow for further analysis of other contributing factors to the high baseline step counts. During the intervention phase, the mean step counts captured by the Fitbit Charge HR in some participants exceeded 10,000; yet, much of their PA was of low intensity, not moderate-to-vigorous intensity, and thus met our eligibility criteria of <150 min of MVPA per week. We did see an increase in mean MVPA from just under 20 min per day at week 1 to 27 min per day at week 6, which declined to 22 min per day by week 7. Fluctuations in PA during PA interventions have been reported previously [52,53]. Sweet et al [52] found intrinsic motivation and identified regulation to be positively associated with PA. Other factors, such as stress and depression symptoms, may cause fluctuations in PA and were not assessed in this intervention [54,55]. Future studies should consider focusing on increasing the intensity of PA and better understand fluctuations in PA in this population.

One unique finding we found was in sedentary time measurements. An important issue with Fitbit devices and other wearable activity tracker devices that use proprietary algorithms to calculate activity measures is the misclassification of nonwear time minutes as sedentary time. Our study indicates that this can be a significant problem in research studies using Fitbit devices and may lead to spurious results. Over 7 weeks, there was an important and statistically significant difference between the number of sedentary minutes produced by Fitbit and the adjusted sedentary minutes calculated by iCardia taking into consideration participants' nonwear time minutes. To the best of our knowledge, this is the first study that provides evidence on the feasibility of using real-time data from the Fitbit heart rate sensor to produce a wear time measure and subsequently adjust the number of Fitbit-based sedentary minutes. Future studies should further explore and validate this approach. Also, companies such as Fitbit, which produce consumer-based activity trackers, should leverage the ability of capacitive touch technologies to automatically and reliably detect when a wrist-worn device has been removed. This will facilitate compliance monitoring and improve accuracy of sedentary time measurement.

Limitations

Limitations of this study include small sample size, short duration of the follow-up period, use of a general step goal for all participants, and lack of postintervention data collection. Additionally, our findings may not be generalizable to all low-active African American women as they did have a high baseline step count. However, this 7-week proof-of-concept study was focused on the feasibility of the modified PA intervention using mHealth tools to increase PA among African American women with asthma. We have identified several changes that need to be made in our recruitment and data collection methods and intervention delivery. The information gained from this study has helped us further refine the intervention to promote greater increases in PA and address study feasibility in a larger and longer pilot randomized controlled study, which is ongoing (ClinicalTrials.gov #NCT03265665).

Conclusions

This study suggested that our modified PA intervention is safe and highly acceptable by African American women with uncontrolled asthma. These findings support the conduct of additional pilot testing to assess the feasibility of our modified intervention. We are conducting a 6-month randomized controlled PA intervention with 80 African American women with asthma, which includes the use of mHealth tools (Fitbit and iCardia for PA monitoring and text messages), step goals, group sessions that incorporate longer walking sessions, and asthma education (ClinicalTrials.gov #NCT03265665). Further work in this area will include evaluating the impact of motivational text messages on PA outcomes and assessing the efficacy and implementation potential of this walking program for African American women with asthma more broadly and in different settings.

Acknowledgments

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Authors' Contributions

SN conceptualized and designed the study, analyzed and interpreted data, and drafted the manuscript. GB assisted in the acquisition of data, data analysis, drafted the manuscript and critically reviewed the manuscript. JM interpreted the data and critically reviewed the manuscript. DM interpreted the data and critically reviewed the manuscript. JW interpreted the data and critically reviewed the manuscript. LS interpreted the data and critically reviewed the manuscript. SK analyzed and interpreted data, drafted the manuscript, and critically reviewed the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

ACTION (physicAl aCtiviTy In minOrity womeN with asthma) Pre-pilot Intervention Components.

[[DOCX File, 14 KB - formative_v4i3e13900_app1.docx](#)]

Multimedia Appendix 2

Study Design for ACTION Pre-pilot.

[[PNG File, 68 KB - formative_v4i3e13900_app2.png](#)]

Multimedia Appendix 3

Examples of text messages sent to participants.

[[DOCX File, 16 KB - formative_v4i3e13900_app3.docx](#)]

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Abbreviations

ACQ: Asthma Control Questionnaire
API: application programming interface
AQLQ: Asthma Quality of Life Questionnaire
ISWT: incremental shuttle walk test
MET: metabolic equivalent
mHealth: mobile health
MVPA: moderate-to-vigorous physical activity
OR: odds ratio
PA: physical activity

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Original Paper

Mutual-Aid Mobile App for Emergency Care: Feasibility Study

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Abstract

Background: Improving the quality of patient care through the use of mobile devices is one of the hot topics in the health care field. In unwanted situations like an accident, ambulances and rescuers often require a certain amount of time to arrive at the scene. Providing immediate cardiopulmonary resuscitation (CPR) to patients might improve survival.

Objective: The primary objective of this study was to evaluate the feasibility of an emergency and mutual-aid app model in Taiwan and to provide a reference for government policy.

Methods: A structured questionnaire was developed as a research tool. All questionnaires were designed according to the technology acceptance model, and a Likert scale was used to measure the degree of agreement or disagreement. Moreover, in-depth interviews were conducted with six experts from medical, legal, and mobile app departments. Each expert was interviewed once to discuss feasible countermeasures and suggestions. Statistical Package for the Social Sciences (SPSS version 19; IBM Corp, Armonk, New York) was used to perform all statistical analyses, including descriptive statistics, independent sample *t*-tests, variance analysis, and Pearson correlation analysis.

Results: We conducted this study between October 20, 2017, and November 10, 2017, at the Taipei Medical University Hospital. Questionnaires were distributed to medical personnel, visiting guests, family members, and volunteers. A total of 113 valid questionnaires were finally obtained after the exclusion of incomplete questionnaires. Cronbach α values for self-efficacy (perceived ease of use), use attitude (perceived usefulness), and use willingness and frequency were above .85, meeting the criterion of greater than .70. We observed that the reliability of each subquestion was acceptable and the values for use attitude (perceive usefulness) and use willingness and frequency were more than .90.

Conclusions: The findings suggest that perceived ease of use and perceived usefulness of the app model affect use willingness. However, perceived usefulness had an intermediary influence on use willingness. Experts in law, medical, and technology fields consider that an emergency and mutual-aid model can be implemented in Taiwan. Along with the development of an emergency and mutual-aid app model, we recommend an increase in the number of automated external defibrillators per region and promotion of correct knowledge about CPR in order to decrease morbidity and mortality.

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KEYWORDS

technology acceptance model; cardiopulmonary resuscitation; mobile app; emergency care

Introduction

Internet technology has been gaining momentum in all areas, including health care, and it is showing no signs of slowing down anytime soon. Medical organizations have always been trying to improve staff productivity, frictionless communication, and patient satisfaction [1-4]. However, the quality of human lifestyle has notably increased with improvements in science and technology [3,5,6]. Identifying a sophisticated approach to improve work efficiency and health care quality is still a very important issue [3,4]. Recently, with provision of free and faster consultation services to the public, the Taiwanese government is continuously promoting e-service policies. Owing to the prevalence of the internet and broadband technologies, many emerging online services have already been created [7-9]. Several features, including voice mail, email mailbox, online news groups, online banking, online book purchase, online trading, travel itinerary, online learning, and online instant messaging, have gained popularity [10,11]. According to the Foreseeing Innovative New Digiservices-2014 Taiwan Consumer Mobile Device and App Use Behavior Research Survey Report, it is estimated that the number of individuals aged 12 years or older using mobile devices, such as smartphones and tablets, has reached approximately 14.32 million. The penetration rate of smartphones is about 65.4%, and it will reach 79.6% in 2020 [12,13]. The use of mobile devices has spread among not only younger individuals but also middle-aged individuals, and the survey found that the penetration rate among middle-aged individuals has increased [14]. In addition, it is estimated that the number of users is 16.04 million, and about three out of every four people use mobile devices [14].

Owing to long-term traffic congestion in Jerusalem, ambulances are often associated with a delay in the golden rescue time of patients; therefore, Eli Beer, the founder of United Hatzalah, created a rescue team along with friends through mobile satellite positioning systems [15-18]. Ambulance motorcycles are equipped with various first-aid devices. In an emergency rescue situation, the five volunteers closest to the patient are notified of the location. They can receive relevant information from the mobile phone to rescue and prioritize patients on the scene before the arrival of the ambulance to improve the patient survival rate [19-22]. There are a number of such difficult-to-use apps globally that have already received attention, such as PulsePoint in the United States. In fact, these kinds of emergency and mutual-assist apps are useful to professionals who have received first-aid training and are willing to assist strangers to receive first aid at fire stations. With regard to the satellite positioning system in the smartphone, a message is sent

to emergency personnel near the patient's location and volunteers go to the rescue site according to satellite positioning [23]. This voluntary emergency ambulance network relies on extensive personnel support. The high-tech network system can shorten the time for ambulance personnel to arrive at the patient's location, strive for appropriate time of first aid, and successfully reduce many regrets that can be avoided [24].

The First AED app, which was jointly developed by the Ministry of Health and Welfare and the Taiwan Emergency Medical Association, was officially launched at the end of 2015. It is downloaded and installed on mobile devices to obtain the locations of automated external defibrillators (AEDs) and first-aid materials and obtain other related information. The app includes one-touch dial 119, cardiopulmonary resuscitation (CPR) plus AED teaching, AED search (quickly locate the nearest AED), information on laws, and frequently asked questions. Similar to PulsePoint, an emergency and mutual-aid app could improve the survival rate of patients; however, there is no such app available in Taiwan.

Therefore, the purpose of this study was to understand the willingness and feasibility of implementation of an emergency and mutual-aid app in Taiwan through questionnaires. Expert interviews were also conducted to understand the legal, medical, technical, and other aspects of the feasibility. The findings of this study could be used as a reference for future national policy.

Methods

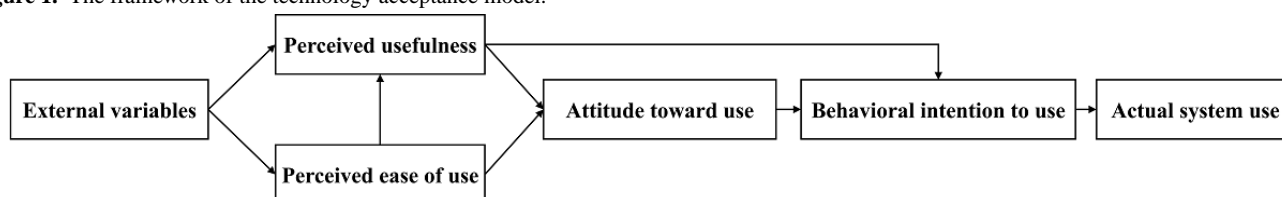
Overview

This study was approved by the Taipei Medical University research ethics board. Participant consent was obtained, and the information of individuals was deidentified. The Institutional Review Board approval number is N2017403068.

Technology Acceptance Model

The technology acceptance model (TAM) is a set of theories developed by Davis et al [25] in 1989 to explain the determinants of information technology acceptance, especially for technology use behavior. This is based on the theory of rational action, which is widely used in the prediction and interpretation of the acceptance behavior of personal information systems. Davis et al [25] demonstrated that attitude is a very important factor influencing user behavior, and attitude is mainly influenced by the two variables perceived usefulness and perceived ease of use. Perceptual ease of use positively affects perceived usefulness, and perceived ease of use and perceived usefulness affect the attitude toward use, which, in turn, affects behavioral intent to use and the use of information systems (actual systems) (Figure 1).

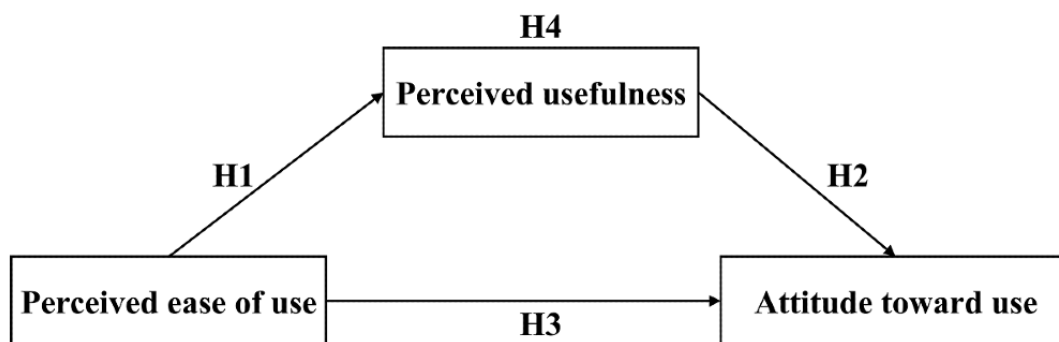
Figure 1. The framework of the technology acceptance model.



According to the TAM in literature verification, we assessed the feasibility factors for the impact of an emergency and mutual-aid app model in Taiwan with self-efficacy (perceived ease of use), use attitude (perceived usefulness), and use willingness and frequency (Figure 2). As a basis for subsequent verification questionnaires and statistical analysis and to verify the research structure and hypothesis, this study proposed the

following four hypotheses: (1) perceived ease of use and perceived usefulness are significantly positively correlated; (2) perceived usefulness is significantly positively correlated with use willingness and frequency; (3) perceived ease of use is significantly positively correlated with use willingness and frequency; and (4) perceived usefulness has a mediating effect on perceived ease of use and use willingness.

Figure 2. Proposed research model. H1: perceived ease of use and perceived usefulness are significantly positively correlated; H2: perceived usefulness is significantly positively correlated with use willingness and frequency; H3: perceived ease of use is significantly positively correlated with use willingness and frequency; H4: perceived usefulness has a mediating effect on perceived ease of use and use willingness.



Questionnaire Design

This was a cross-sectional study. In addition to individual qualitative interviews, a structured questionnaire was used as a research tool (Multimedia Appendix 1). The questionnaire adopted the TAM as a research method. The questionnaire was developed by reviewing extensive literature and expert suggestions to achieve high content validity. Before implementation of the formal questionnaire, 30 pretest questionnaires were sent to subjects from among teachers and students in the laboratory of Taipei Medical University. Cronbach α values above .70 were considered reliable. The questionnaire had four parts. The first part involved the basic information of the subject. The second involved self-efficacy evaluation for an emergency and mutual-aid app model (perceived ease of use). The third part involved a self-use attitude evaluation for an emergency and mutual-aid app model (perceived usefulness). The fourth part involved a self-evaluation for the willingness and frequency of use of an emergency app model. The total score of a Likert scale (strongly disagree, 1; disagree, 2; neutral, 3; agree, 4; and strongly agree, 5) was used to assess the degree of agreement or disagreement.

Data Collection

The study was conducted in a university teaching hospital at Taipei Medical University between October 20, 2017, and November 10, 2017. The questionnaires were distributed in a convenient sampling manner to medical personnel, visiting guests, family members, and volunteers. A total of 113 valid questionnaires were collected after excluding incomplete questionnaires.

Conduction of In-Depth Interviews

To understand the feasibility, advantages, and disadvantages of an emergency and mutual-aid app on mobile phones in Taiwan,

individual qualitative in-depth interviews were conducted with six experts from different fields, including medical, legal, and mobile app development fields, according to the results of the self-evaluation questionnaires. It was hoped that findings from a multifaceted perspective would help in the discussion of the feasibility and possible benefits of such an emergency and mutual-aid app at the technical development and legal levels. Feasible countermeasures and suggestions will be discussed in the future.

Statistical Analysis

Statistical Package for the Social Sciences (SPSS version 19; IBM Corp, Armonk, New York) and Analysis of a Moment Structures (AMOS version 24; IBM Corp) were used to perform all statistical analyses. SPSS was used for descriptive statistics, independent sample *t* tests, variance analysis, and Pearson correlation analysis, and AMOS was used for structural equations and analysis verification.

Results

Basic Information

The basic information of the respondents included gender, age, highest education level, and occupation, as well as perceived ease of use, perceived usefulness, and use willingness (Table 1). We distributed questionnaires to 120 participants. A total of 113 respondents completed all questionnaires (63 [55.8%] male and 50 [44.2%] female respondents). Moreover, of the 113 respondents, 40 (35.4%) were aged 20-39 years, 40 (35.4%) were aged 40-59 years, and 33 (29.2%) were aged 60 years or older. Regarding the highest education level, of the 113 respondents, 8 (7.1%) had junior high school or below education, 20 (17.7%) had high school education, 68 (60.2%) had a bachelor's degree, and 17 (15.0%) had a master's degree or above.

Table 1. Characteristics of the participants (N=113).

| Characteristic | Participants, n (%) |
|--|---------------------|
| Gender | |
| Male | 63 (55.8) |
| Female | 50 (44.2) |
| Age (years) | |
| 20-39 | 40 (35.4) |
| 40-59 | 40 (35.4) |
| 60 or older | 33 (29.2) |
| Highest education level | |
| Junior high school or below | 8 (7.1) |
| Senior high school | 20 (17.7) |
| Bachelor's degree | 68 (60.2) |
| Master's degree or above | 17 (15.0) |
| Occupation | |
| Student | 1 (0.9) |
| Military/public/religious industry | 3 (2.7) |
| Service industry | 14 (12.4) |
| Finance industry | 2 (1.8) |
| Information/technology industry | 5 (4.4) |
| Communication/advertising/design industry | 2 (1.8) |
| Art industry | 0 (0.0) |
| Free industry | 9 (8.0) |
| Medical care industry | 28 (24.8) |
| Agriculture/forestry/fishery/animal husbandry industry | 1 (0.9) |
| Family management/retirement industry | 20 (17.7) |
| Others | 28 (24.8) |

Regarding occupation, of the 113 respondents, 1 (0.9%) was a student, 3 (2.7%) were from the military/public/religious industry, 14 (12.4%) were from the service industry, 2 (1.8%) were from the finance industry, 5 (4.4%) were from the information/technology industry, 2 (1.8%) were from the communication/advertising/design industry, 9 (8%) were from the free industry, 28 (24.8%) were from the medical care industry, 1 (0.9%) was from the agriculture/forestry/fishery/animal husbandry industry, 20 (17.7%) were from the family management/retirement industry, and 28 (24.8%) were from other industries.

Reliability and Correlation Analysis

Cronbach α values for self-efficacy (perceived ease of use), use attitude (perceived usefulness), and use willingness and frequency were above .85, meeting the criterion of greater than .70 (Table 2). When the subquestions were deleted, the Cronbach α values were not significantly larger than the original

Cronbach α values ($P=.54$). Therefore, the reliability of each subquestion was acceptable, and the values for use attitude (perceived usefulness) and use willingness and frequency were above .90. These findings indicate that the reliability of the questionnaire content was satisfactory.

Table 3 shows the correlation analysis among the research variables. There were significant correlations between gender and whether medical staff ($r=0.27;P=.003$), age and highest education ($r=-0.45;P<0.01$), age and whether medical staff ($r=-0.26;P=0.05$), and highest education and whether medical staff ($r=0.39;P<0.01$). There were no differences among the respondents' basic information, such as gender, age, highest education, and whether medical staff. However, there were strong positive correlations between perceived ease of use and perceived usefulness ($r=0.75;P<0.001$), perceived ease of use and use willingness ($r=0.76;P<0.001$), and perceived usefulness and use willingness ($r=0.88;P<0.001$).

Table 2. Reliability, mean, and variance analysis.

| Variable and measurement project | Mean (SD) | Cronbach α value after the project is deleted | Cronbach α |
|----------------------------------|---------------------|--|-------------------|
| Perceived ease of use | 18.94 (3.98) | | .85 |
| A1 | 3.49 (1.21) | .86 | |
| A2 | 3.85 (0.95) | .80 | |
| A3 | 3.96 (0.86) | .81 | |
| A4 | 3.90 (0.91) | .82 | |
| A5 | 3.74 (1.02) | .81 | |
| Perceived usefulness | 20.06 (4.37) | | .94 |
| B1 | 4.11 (0.88) | .92 | |
| B2 | 4.01 (0.98) | .92 | |
| B3 | 4.04 (0.93) | .93 | |
| B4 | 3.91 (1.04) | .94 | |
| B5 | 4.00 (0.98) | .92 | |
| Use willingness | 19.71 (4.24) | | .93 |
| C1 | 4.02 (0.91) | .91 | |
| C2 | 3.68 (1.01) | .94 | |
| C3 | 4.05 (0.88) | .90 | |
| C4 | 4.05 (0.94) | .91 | |
| C5 | 3.91 (1.01) | .90 | |

Table 3. Correlation analysis (Pearson r and two-tailed P) among the research variables.

| Variable | Gender | Age | Highest education | Whether medical staff | Perceived ease of use | Perceived usefulness | Use willingness |
|------------------------------|--------------------|---------------------|---------------------|-----------------------|-----------------------|----------------------|--------------------|
| Gender | | | | | | | |
| r | 1 | -0.042 | 0.150 | 0.273 ^a | -0.177 | -0.004 | -0.079 |
| P value | — ^b | .66 | .11 | .003 | .06 | .96 | .40 |
| Age | | | | | | | |
| r | -0.042 | 1 | -0.451 ^a | -0.263 ^a | -0.168 | -0.034 | -0.078 |
| P value | .66 | — | <.001 | .005 | .08 | .72 | .41 |
| Highest education | | | | | | | |
| r | 0.150 | -0.451 ^a | 1 | 0.395 ^a | 0.079 | 0.115 | 0.117 |
| P value | .11 | <.001 | — | <.001 | .41 | .23 | .28 |
| Whether medical staff | | | | | | | |
| r | 0.273 ^a | -0.263 ^a | 0.395 ^a | 1 | 0.085 | 0.157 | 0.116 |
| P value | .003 | .005 | <.001 | — | .37 | .10 | .22 |
| Perceived ease of use | | | | | | | |
| r | -0.177 | -0.168 | 0.079 | 0.085 | 1 | 0.752 ^a | 0.764 ^a |
| P value | .06 | .08 | .41 | 0.37 | — | <.001 | <.001 |
| Perceived usefulness | | | | | | | |
| r | -0.004 | -0.034 | 0.115 | 0.157 | 0.752 ^a | 1 | 0.889 ^a |
| P value | .96 | .72 | .23 | .10 | <.001 | — | <.001 |
| Use willingness | | | | | | | |
| r | -0.079 | -0.078 | 0.117 | 0.116 | 0.764 ^a | 0.889 ^a | 1 |
| P value | .40 | .41 | .22 | 0.22 | <.001 | <.001 | — |

^aThe correlation is significant at a significance level of .01 (two-tailed).

^bNot applicable.

The differential validity of the three main facets of this study is based on the confidence interval in which the correlation coefficient between two facets is estimated. The findings are

shown in [Table 4](#). All confidence intervals did not contain 1, so the validity differed.

Table 4. Trust interval and discriminant validity of the correlation coefficients.

| Parameter | Estimate | Lower | Upper | P value |
|--|----------|-------|-------|-----------|
| Perceived ease of use → Perceived usefulness | 0.72 | 0.52 | 0.84 | .001 |
| Perceived usefulness → Use willingness | 0.93 | 0.86 | 0.97 | .001 |
| Perceived ease of use → Use willingness | 0.20 | -0.03 | 0.43 | .05 |

We also used a structural equation of verification. The verification results are shown in [Figure 3](#). As the structural model adaptation degree in this study did not reach the general recommendation standard, the structural equations with

collinearity doubts were deleted, as shown in [Figure 4](#), and the adaptation test criteria were considered before and after the adjustment.

Figure 3. Standardized structural equations and hypothesis testing. GFI: goodness-of-fit index; AGFI: adjusted goodness-of-fit index; NFI: normed fit index; CFI: comparative fit index; RMSEA: root mean square error of approximation.

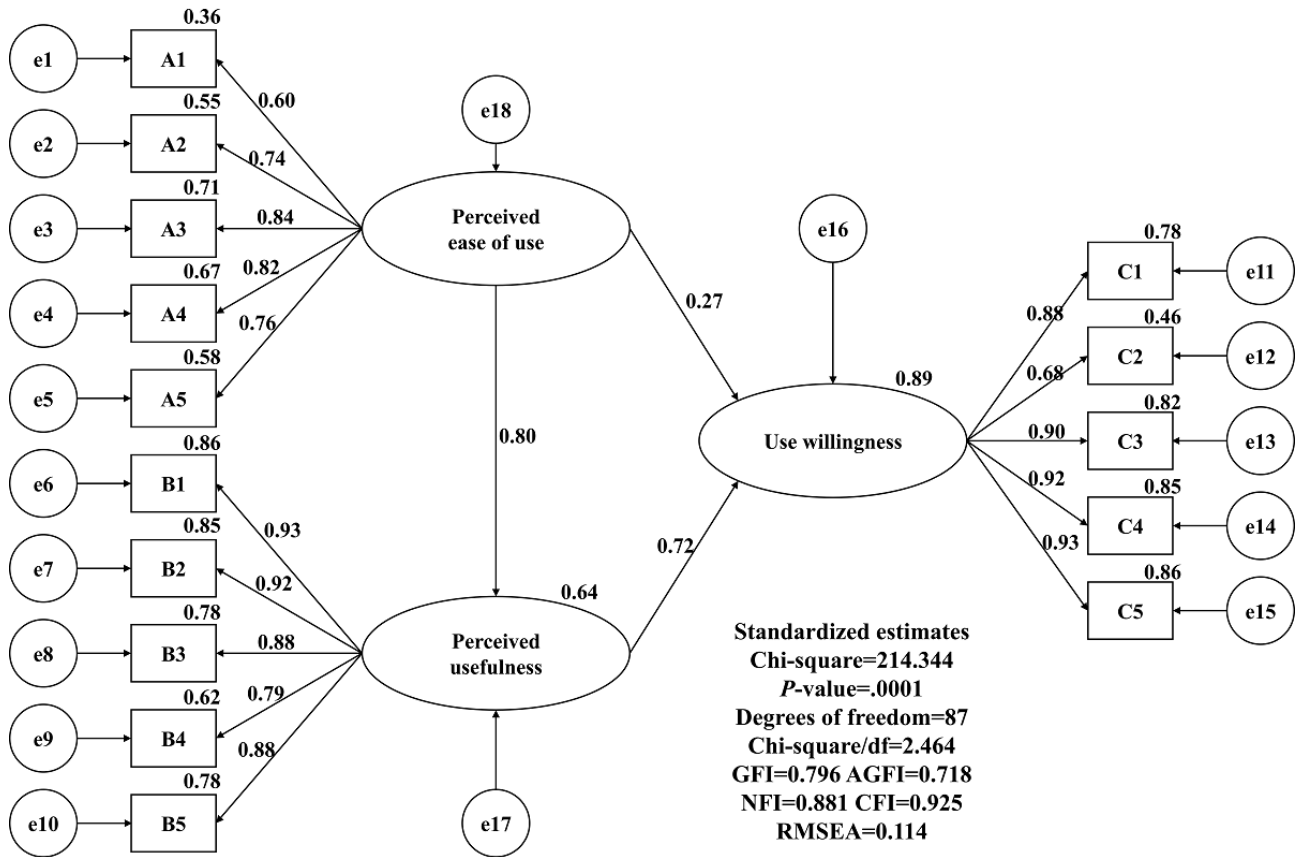
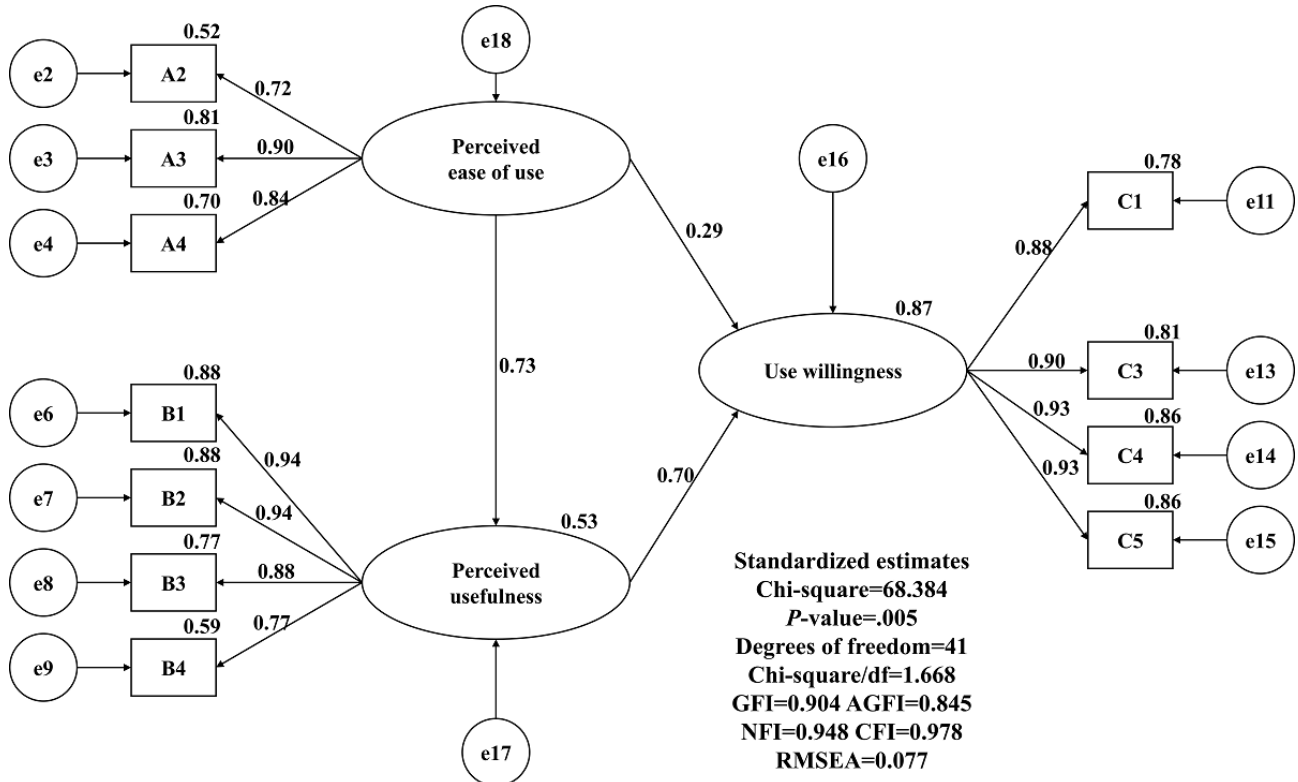


Figure 4. Modified normalized structural equation. GFI: goodness-of-fit index; AGFI: adjusted goodness-of-fit index; NFI: normed fit index; CFI: comparative fit index; RMSEA: root mean square error of approximation.



The standardized path coefficient reached the standard of significance, and perceived ease of use had a positive predictive

power for perceived usefulness. The standardized path coefficient was 0.73, and the explanatory variation was 53%.

Moreover, perceived ease of use had a positive predictive power for use willingness, with a standardized path coefficient of 0.29. Furthermore, perceived usefulness had a positive predictive power for use willingness, with a standardized path coefficient of 0.70 and an explanatory variation of 87%. The findings of this study show that perceived ease of use and perceived

usefulness are significantly positively correlated ($P=.001$), perceived usefulness is significantly positively correlated with use willingness and frequency ($P=.001$), and perceived ease of use is significantly positively correlated with use willingness ($P=.011$). The standardized regression coefficients and significance are shown in [Table 5](#).

Table 5. Standardized coefficients and significance of direct relationships.

| Parameter | Estimate | Lower | Upper | P value |
|--|----------|-------|-------|---------|
| Perceived ease of use → Perceived usefulness | 0.87 | 0.63 | 1.11 | .001 |
| Perceived ease of use → Use willingness | 0.33 | 0.09 | 0.61 | .001 |
| Perceived usefulness → Use willingness | 0.68 | 0.43 | 0.97 | .001 |

Based on the results of the questionnaire survey, the study conducted an in-depth interview with six experts in three different fields, including law, medical, and technology fields. The three aspects of the development of an emergency and mutual-aid app model were discussed separately. The expert opinions at each level are presented below.

According to the survey results in this study, both perceived ease of use and perceived usefulness affect use willingness. If individuals want to implement an emergency and mutual-aid app model in Taiwan, they need to increase public willingness to use the app, as well as design a convenient user interface to improve perceived ease of use.

Discussion

Principal Findings

This study evaluated the feasibility of an emergency and mutual-aid app model in Taiwan and provided a reference for government policy. As the TAM helps in evaluation, users' behavioral intention to use the app might be impacted by perceived usefulness and attitude toward the system [26,27]. The results indicated that perceived ease of use, perceived usefulness, and use willingness are important factors for users' behavioral intention of using the app. Perceived usefulness had a strong relationship with use willingness. The availability and acceptability of an emergency and mutual-aid app model might make it an effective tool to assist people in managing emergencies and reducing mortality. The findings of this study indicate that the three TAM facets (perceived ease of use, perceived usefulness, and use willingness) support the findings of various studies about the impact of the three facets on the adoption of various forms of technology [28-31] and the tendency of people to use location-based emergency apps or any other health care apps [32-34].

Public Health Implications

Perceived ease of use is an important factor influencing user acceptance and willingness to use information technologies, but it depends on a user's experience with information technology [35]. Among the three facets, self-efficacy of an emergency and mutual-aid app (perceived ease of use) had the lowest score. However, "I could use an emergency and mutual-aid app even if no one tells me how to use it" had the lowest score among five questionnaires. Furthermore, "I could

use an emergency and mutual-aid app if I have experience using other software similar to it" had an average score of 3.74. Some of the scores for these two questions were lower than the average score of the perceived ease of use facet, which may be because the respondents did not actually have any experience of using an emergency and mutual-aid app. Participants only relied on their experience of using other apps in the past and the description from the questionnaire. Several published studies mentioned that the effects of perceived usefulness and use willingness on technology adoption are higher than that of perceived ease of use [36,37]. When perceived ease of use and attitude toward information quality are positive, perceived usefulness is often high [38-40]. These findings might help in app design, and developers of an emergency app will need to provide a service that is easy to use, clear and understandable, easy to learn to operate, and easy to navigate and that has clear help messages [41-45].

The perceived usefulness of a location-based mobile app for emergency patient care is a crucial element behind an individual's positive attitude toward using these types of apps and the behavioral intention regarding these apps in the future. User attitude for an emergency and mutual-aid app (perceived usefulness) had the highest score in our study. The services were perceived to be highly useful because (1) participants believed that the model is able to shorten the waiting time for ambulances and increase the chance of survival; (2) the model can function well and provide timely rescue to patients; (3) the probability that patients easily connect to various hospital websites and resources on different occasions is high; and (4) participants felt that the community first-aid resources could be better integrated and more effective. The results indicate that respondents maintained a positive attitude toward an emergency and mutual-aid app, which is supported by the findings in previous studies [46,47].

This study examined whether medical practitioners had a higher level of recognition of an emergency and mutual-aid app model than nonmedical practitioners. In particular, the basic information regarding occupation in the questionnaire assessed whether participants were medical staff. The three facets were perceived ease of use, perceived usefulness, and use willingness. Additionally, the three facets were not significant in terms of whether participants were medical staff ($P=.37$), and there were no significant differences among the facets discussed in this study ($P=.22$). With regard to age and the three facets in variance

analysis, age and the three facets were not significant, and age was not significantly different for the facets discussed in this study. Gender, age, and whether medical staff were not significantly different for the three aspects of perceived ease of use, perceived usefulness, and use willingness in this study [48]. This study examined how the three research facets interact with each other according to structural equation verification. The findings show that perceived ease of use had a positive and significant influence on perceived usefulness ($P < .001$), perceived ease of use had a positive and significant influence on use willingness ($P < .001$), perceived usefulness had a positive and significant influence on use willingness ($P < .001$), and perceived usefulness had an intermediary influence on perceived ease of use and use willingness. Perceived ease of use had a positive predictive power for perceived usefulness, with a standardized path coefficient of 0.73 and an explained variation of 53%. Perceived ease of use had a positive predictive power for use willingness, with a standardized path coefficient of 0.29. Moreover, perceived usefulness had a positive predictive power for use willingness, with a standardized path coefficient of 0.70. Furthermore, perceived ease of use and perceived usefulness accounted for 87% of the interpretation of use willingness. Additionally, there was a complete effect of perceived ease of use on use willingness (coefficient of 0.93), and the confidence interval range was 0.69 to 1.27. It can be judged that perceived ease of use affects not only perceived usefulness but also use willingness.

According to the results of the survey, perceived ease of use and perceived usefulness affected use willingness, and experts, such as those from law, medical, and technical fields, developed approaches to enhance perceived ease of use and perceived usefulness for an emergency and mutual-aid app. They further enhanced use willingness and explored the corresponding policies for the feasibility and recommendation of an emergency and mutual-aid app [49,50]. Moreover, from in-depth interviews with experts, such as those from law, medical, and technical fields, it is known that if the heartbeat and blood flow stop and the organs are hypoxic, brain death might occur after 4 to 6 minutes, and it is important to avoid wasting the golden rescue time [51,52]. During this period, we assume that other people nearby can immediately perform CPR and use the AED to determine whether an electric shock is needed for a patient whose heart has stopped. The public has low willingness to perform CPR or use the AED for an unknown patient. It is recommended to pass a decree, use online media, or provide free first aid. Additionally, relevant courses or other methods can be used for publicity.

Science and technology experts believe that current technology can help develop an emergency and mutual-aid app, mainly depending on the development of labor resources and follow-up system maintenance [53-55]. The user interface should be considered in the use of the interface design to enhance perceived ease of use, and it is recommended to integrate different system resources. Emergency staff or ambulances can help avoid wasting the golden rescue time through information equipment and programming [56,57]. Experts mentioned that the main aspects of the success of emergency aid are implementation of CPR as soon as possible, collection of the

electric shock device as soon as possible, and transport of the patient to a hospital as soon as possible. With an emergency and mutual-aid app, volunteer rescuers can immediately arrive at the accident location, and the information can be combined with a map of AEDs at public places. This might greatly reduce the waiting time of patients with heartbeat issues for CPR and AED use and might help gain the golden rescue time [58]. It is recommended that government agencies develop an emergency and mutual-aid app in Taiwan and enhance the willingness of people to use the app by implementing support policies and measures, publicizing basic public first-aid training, and promoting AEDs in public places to increase density. For a patient with heartbeat issues, information on a volunteer rescuer's mobile phone, access to cardiopulmonary resuscitation, and use of electric shocks as soon as possible can help address the patient's problem. This would ultimately improve the survival rate.

The main factors associated with the success of emergency aid are implementation of CPR as soon as possible, collection of the electric shock device as soon as possible, and transport of the patient to a hospital as soon as possible [59]. If an emergency and mutual-aid app is available, volunteer rescuers can immediately arrive at the accident location, and when combined with a map of AEDs at public places, it can greatly reduce the waiting time of patients with heartbeat issues for CPR and AED use, which might help gain the golden rescue time and improve the success rate of rescue [60]. The advent of the Internet of Things and big data will provide great help to mobile medical care [61,62]. According to the findings of the survey, we suggest that use willingness should be increased by enhancing perceived ease of use and perceived usefulness. It is necessary to take into account the user's habits in the design of the app and pay attention to the operation of the interface [63,64]. This will help users easily start using the app. It is also recommended to connect different system resources in the future. For example, an emergency and mutual-aid app could directly connect to a control center, mobile ambulance, personal cloud medical information system, and medical hospital after reservation. The system might help ambulance staff to provide emergency services through valuable information, equipment, and programming. It therefore helps to avoid wasting the golden rescue time. This will allow the app to have the best benefits.

Strengths and Limitations

The strength of our study is that it explored the use willingness, feasibility, and promotion strategies for the implementation of an emergency and mutual-aid app model in Taiwan through questionnaires and in-depth interviews with experts. However, our study has several limitations that need to be addressed. First, there is an issue with the research design, as the cost of developing and maintaining the app was not considered. For the development of an actual app, we need to consider the cost of research and development or the budget allocated by government agencies for research and development. Second, Taiwan does not have an actual emergency and mutual-aid app yet; therefore, in the questionnaire survey, respondents could not provide information about the actual experience of using such an app, which might have affected the results of the responses and statistical analysis. Third, regarding the

questionnaire, in order to facilitate sampling, we did not use large-scale surveys, and this might have affected the findings of the statistical analysis. Finally, we conducted in-depth interviews with experts, and six experts were interviewed according to the purpose of this study. However, these experts were from different fields and had different experiences, and countermeasure suggestions might not cover all aspects that should be considered. Furthermore, each expert had an interview only once, and there was no meeting to facilitate the integration and exchange of ideas from experts in different fields. Indeed, this study discussed only preliminary ideas, and we look forward to having discussions with more experts and scholars when the development of an emergency and mutual-aid app is complete.

Conclusion

The investigation of a mutual-aid mobile app regarding emergency care acceptance is relatively innovative for health care providers and policymakers. This study used the innovative

aspects of perceived ease of use, perceived usefulness, use willingness, and behavioral use intention and proposed the TAM to evaluate users' acceptance of a mutual-aid mobile app for emergency care. The findings of this study might help the government and policymakers to take decisions on the development of an emergency and mutual-aid app in Taiwan. The findings also suggest that the design should specifically consider increasing convenience and public recognition of the app. User approval of the app could effectively improve use willingness, which could achieve the goal of avoiding wastage of the golden rescue time. Furthermore, findings from our study show that experts believe the development of such an emergency and mutual-aid app model can be undertaken in Taiwan. Professional medical staff who identify patients with heartbeat issues should implement CPR as soon as possible and obtain the electric shock device as soon as possible. This will help to transport the patient to a hospital as soon as possible, reduce irreversible organ damage, and increase survival.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Research questionnaire.

[[DOCX File, 19 KB - formative_v4i3e15494_app1.docx](#)]

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Abbreviations

AED: automated external defibrillator

CPR: cardiopulmonary resuscitation

TAM: technology acceptance model

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