Original Paper

Leveraging Electronic Patient-Reported Symptoms to Optimize Family Caregivers' Symptom Support for Patients With Cancer: Qualitative Formative Evaluation of the FamilyAWARE Intervention Concept

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Abstract

Background: Each year, family caregivers help the 2 million patients newly diagnosed with cancer manage their symptoms; however, few interventions have been developed and proven efficacious to enhance their symptom-support role. The recent expansion of electronic patient-reported outcomes (ePROs), including remote symptom monitoring, presents an opportunity to explore novel approaches to supporting caregiver symptom management by leveraging patient ePRO data.

Objective: The objective of this study was to elicit feedback on a theory-based intervention concept, called FamilyAWARE, consisting of one-on-one coaching on providing effective symptom support to patients and access to a web-based dashboard reporting summaries of their care recipient's most recent ePRO symptom reports and tailored recommendations.

Methods: This was a qualitative formative evaluation study (National Institutes of Health stage IA) where family caregivers (n=20), patients with stage I to IV cancer (n=20), and oncology clinicians (n=25) were recruited from a comprehensive cancer center in the US South and participated in semistructured, one-on-one interviews (January 2025-July 2025). Participants were shown an outline of the FamilyAWARE intervention concept and asked open-ended questions about the proposed content, format, and delivery of the intervention. Professionally transcribed interviews were analyzed using a thematic analysis approach.

Results: Analysis yielded 4 primary themes. The first theme was *first impressions and relevance*. Participants' initial impressions of FamilyAWARE were generally positive, with caregivers viewing it as highly relevant and potentially beneficial. Patients and clinicians expressed more cautious optimism, shaped by considerations of relevance and minimizing burden. The second theme was *key factors for acceptability and engagement*. Caregivers showed strong interest in the intervention's potential to increase confidence in symptom support; however, engagement was seen as contingent on the perceived value, minimal burden, and flexible delivery of the intervention, particularly given time and technology constraints. The third theme was *coaching content and delivery*. The proposed format was widely viewed as feasible. Participants emphasized content that helps caregivers balance supporting patients with promoting patient independence while also guiding them in deciding when to seek additional help and providing proactive symptom management strategies. Opinions on delivery by phone, in person, or videoconference varied. The fourth theme was *dashboard design and information access*. Participants emphasized the importance of a simple, mobile-friendly dashboard designed for low digital literacy, with plain language and visual cues. Caregiver access to patient symptom data was broadly supported if patient permission was obtained.

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Conclusions: Findings highlight strong interest and insights into designing a caregiver-focused intervention that integrates one-on-one coaching with ePRO patient symptom reports and tailored recommendations. Participant insights from this study will directly inform refinement of the intervention's content, format, and delivery, with the goal of advancing it to pilot testing.

Trial Registration: N/A

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KEYWORDS

family caregiver; cancer; symptoms; intervention development; Patient Reported Outcome Measures

Introduction

Family caregivers often assume primary responsibility for assisting the 2 million patients newly diagnosed with cancer in the United States each year [1] in managing their physical and psychological symptoms. While this caregiver cosymptom management role is pivotal, up to half of caregivers receive no formal training [2], contributing to many cancer caregivers feeling overwhelmed and underprepared [2-5]. Symptom partnering tasks can include helping patients understand symptoms and their underlying causes, being an observer and assessor of symptoms, managing medications and administration schedules, assisting with daily activities to accommodate any functional limitations imposed by symptoms, and providing emotional and psychological support [6,7]. Performing these tasks can lead to distress and severe strain on caregivers who often grapple with their own feelings of exhaustion, fear, anxiety, and sadness while trying to maintain a resilient front for their care recipient [3-5]. This highlights the need for more robust and innovative strategies and resources to assist and support family caregivers in their symptom partnering role, ensuring they have the necessary tools and preparedness to support their care recipients without compromising their own health and well-being.

Prior intervention research for family caregivers of patients with cancer has focused largely on psychosocial and emotional support and less work has focused on training and providing resources to caregivers to provide effective symptom management support to their care recipients [8,9]. The dearth of caregiver intervention development in the area of patient symptom management [10,11] is particularly significant as cancer care shifts to the home setting where families will be relied upon more heavily to assist patients with complex medical care [12]. To begin addressing this gap, the recent development of proactive, electronic tracking of patient-reported outcomes (ePROs) to facilitate remote symptom monitoring (RSM) and its recommended implementation into standard cancer care represents a potential opportunity to develop novel parallel caregiver symptom management support that centers on patient ePROs. ePRO-enabled RSM has been shown to both reduce symptom burden and lower health use among patients with cancer [13-16]. While there is abundant evidence that ePRO symptom monitoring can improve patient outcomes, it is unknown whether more robustly training family caregivers to assist patients with their symptoms, further augmented with patient ePRO symptom monitoring, might improve patient and caregiver outcomes.

To begin addressing this intervention gap and opportunity, our group undertook a formative-stage National Institutes of Health stage IA study to elicit feedback on an ePRO-RSM web-based dashboard plus coaching intervention for family caregivers of patients with cancer, called FamilyAWARE. Based on the theory of dyadic illness management [17] and social support effectiveness theory [18-20], the goal of this new intervention would be to enhance the awareness, skill, and effectiveness of caregivers providing support to patients experiencing cancer-related symptoms. Evolving from our team's prior work and expertise in ePRO-enabled RSM [14,21] and cancer caregiving intervention development and testing [22-26], the tentative FamilyAWARE concept includes one-on-one supportive care coaching on being an effective partner in symptom management, access to patient-reported symptom data via a custom web platform, and tailored recommendations for home symptom management. The study objective was to elicit feedback from family caregivers, patients with cancer, and oncology clinicians on the relevance, acceptability, content, format, and delivery of the FamilyAWARE intervention concept.

Methods

Study Design

One-on-one, digitally recorded qualitative interviews with family caregivers, patients with stage I to IV cancer, and oncology clinicians and administrators were conducted in this formative evaluation study to gather feedback on the content, structure, and delivery of the FamilyAWARE concept. Participants were recruited from a large academic cancer center in the US South between January and July 2025. Interviews were conducted by telephone, in person, or by HIPAA (Health Insurance Portability and Accountability Act)–compliant Zoom. This report followed the COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines and its attendant checklist [27].

Ethical Considerations

This study was approved by the institutional review board (IRB) at the University of Alabama at Birmingham (IRB-300007406). All participants provided informed consent and were paid US $50 as an incentive for participating in the study. The study team established and enforced measures to protect against unauthorized access, use, and disclosure of personal health information to ensure confidentiality and data integrity. Participants' names were not transcribed, and all other identifiers were removed.

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Eligibility and Recruitment

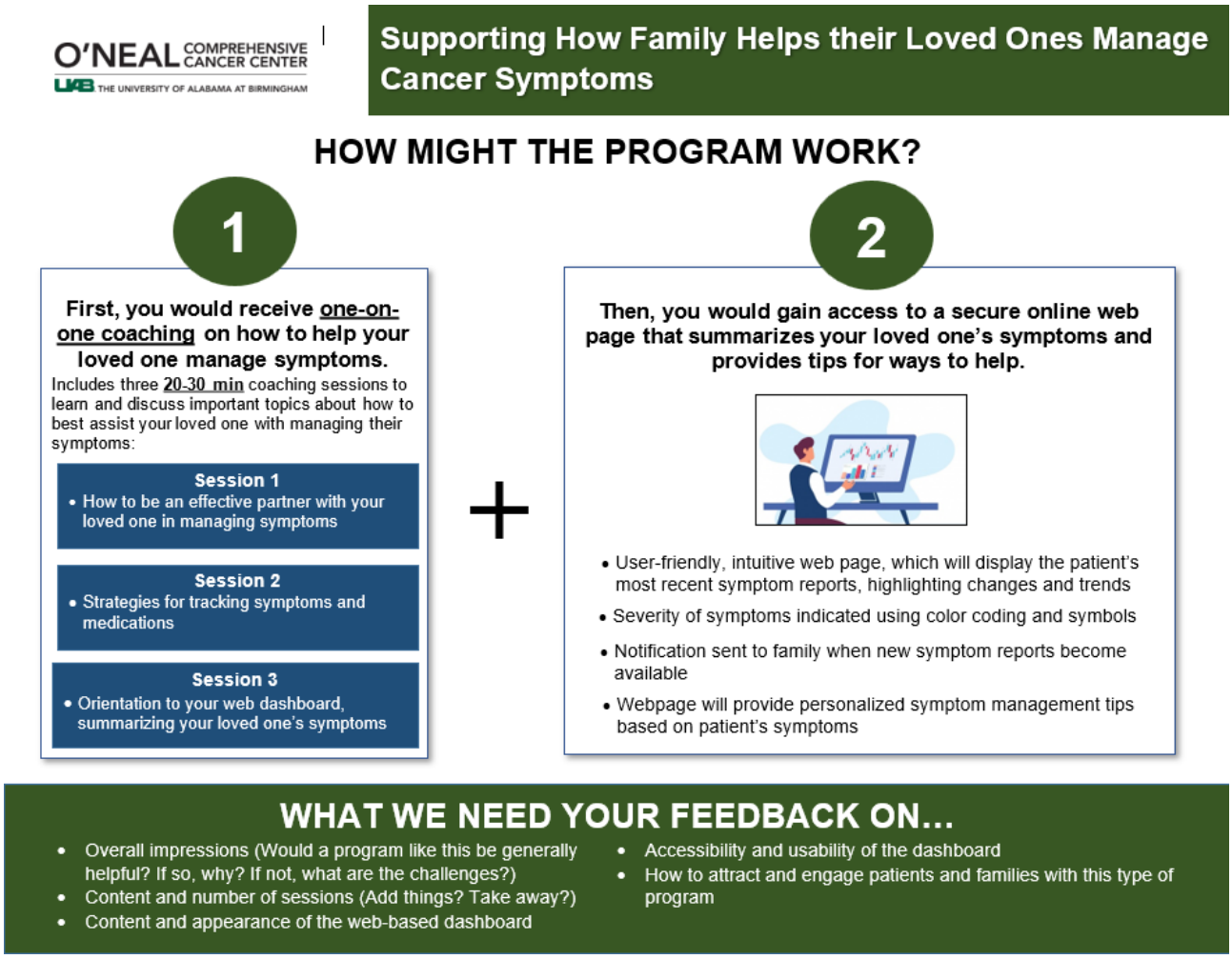
Family caregivers were eligible if they were aged ≥18 years, self-endorsed or identified by their care recipient as "an unpaid relative or friend who knows them well and who provides regular support due to their cancer," caring for a patient with stage I to IV cancer receiving active treatment, and English speaking. Caregivers were excluded if they self-reported severe, untreated mental illness (eg, schizophrenia, bipolar disorder, or major depressive disorder), dementia, active suicidal ideation, uncorrected hearing loss, or active substance abuse. Patients were eligible if they met the following inclusion criteria: aged ≥ 18 years and diagnosed with a stage I to IV cancer (including hematologic cancers) and receiving active treatment (ie, chemotherapy, targeted therapy, or immunotherapy). Patients were excluded if their electronic health record (EHR) documented active severe mental illness (eg, schizophrenia, bipolar disorder, or major depressive disorder), dementia, active suicidal ideation, uncorrected hearing loss, or active substance abuse. Oncology clinicians—including (but not limited to) physicians, physician assistants, nurse practitioners, nurses, social workers, psychologists, behavioral health counselors, navigators, and administrators—had to have at least 1 year of experience working with patients with cancer and their caregivers. A targeted sample size of 12 to 25 individuals (per constituency) was targeted to achieve saturation [28,29].

Purposive sampling was used to ensure representation across cancer diagnoses (patients and caregivers) as well as professional backgrounds (clinicians). A clinical research coordinator (EO) invited patients receiving active cancer therapy and their caregivers to participate, while clinicians were recruited via email based on their engagement with the cancer center's preexisting RSM initiative [21,30-33].

Data Collection

Interviews were conducted by trained study staff using an interview guide adapted from the team's prior qualitative formative evaluation work (available upon request) [34,35]. Before the interview, participants received a 1-page outline of the FamilyAWARE intervention concept (Figure 1), either in hard copy or by email. During the interview, participants were oriented to the outline. The FamilyAWARE intervention concept and outline were grounded conceptually on the theory of dyadic illness management [17] and social support effectiveness theory [18-20] and structurally developed based on social support and symptom management coaching content from the Project Cornerstone and CASCADE family caregiver interventions developed by the first author (JNO) in prior work [23,25,36-39].

Figure 1. Outline of the FamilyAWARE intervention concept.



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The tentative intervention outline was proposed to consist of two major components: (1) coaching sessions about how to best help the patient manage symptoms and (2) access to a secure online web page that summarized their loved symptoms (as tabulated from the patient's ePRO symptom reports) and provided tips on how to help. The coaching sessions would comprise 3 semistructured, weekly coaching sessions lasting 20 to 30 minutes each. Sessions would focus on how to be an effective partner with your loved one in managing symptoms, strategies for tracking symptoms and medications, and orientation to a web-based dashboard that would summarize your loved one's symptoms. The secure online web page, or "dashboard," would be designed to be user-friendly, displaying the patient's most recent symptom reports and providing personalized symptom management tips based on the patient's symptoms. Caregivers would receive a notification when new symptom reports became available. Participants were informed that any aspect of the intervention could be modified and were asked about their overall impressions; the topical content, number, and length of coaching sessions; the accessibility and usability of the dashboard; and strategies to attract and engage patients and families with this type of intervention. All interviews were transcribed by a professional transcription service (Landmark Associates, Inc). Deidentified transcriptions were uploaded into NVivo (version 14; Lumivero) qualitative data analysis software.

Analysis

Following a thematic analysis approach [40,41] aligning with our prior work [34,35], an interactive series of steps was taken to analyze the data, including (1) immersing in the transcribed interviews through careful reading, (2) open coding, (3) generating initial overarching themes, (4) using within- and across-case comparison [42] to further refine and define themes, and (5) having additional members of the study team (RB and MLS) review audit trails of the developing themes to assess fit of the raw data. For steps 1 and 2, the principal investigator (JNO), who has extensive experience and expertise in family caregiving and qualitative research, carefully read all transcripts and conducted line-by-line open coding. Following initial coding to reduce the data, codes and their associated data were grouped into broader thematic categories in step 3, using matrices to support both within- and across-case comparisons. To refine the preliminary themes as part of step 5, additional members of the study team (RB and MLS) reviewed the audit trail of supporting quotations and evaluated the coherence and comprehensiveness of the themes in relation to the entire corpus of supporting data.

Qualitative rigor was guided by the criteria of credibility, transferability, dependability, and confirmability proposed by Lincoln and Guba [43]. Credibility was supported through purposive sampling across family caregivers, patients, and oncology clinicians; continued recruitment until thematic saturation was reached; iterative within- and across-case comparisons; and review of the developing themes by multiple members of the study team. Transferability was supported by detailed reporting of the study setting, participant characteristics, proposed intervention components, and example participant quotations. Dependability was addressed through a systematic, documented analytic process and maintenance of an audit trail describing coding decisions and theme development. Confirmability was supported by grounding themes in the underlying participant data and having additional investigators review the audit trail of quotations and assess the coherence and comprehensiveness of the themes in relation to the full data corpus.

Results

Participant Characteristics

Participant characteristics are shown in Table 1. Family caregivers (n=20) had a mean age of 59.2 (SD 12.6) years and were mostly female (n=14, 70%), White (n=12, 60%), employed full or part time (n=12, 60%), married or living with a partner (n=13, 65%), and the husband or wife of the patient (n=8, 40%). Most caregivers provided support to patients 4 or more days a week (17/20, 85%) for 3 or more hours a day (13/20, 65%). Patients (n=20) with a wide range of cancers had a mean age of 57.9 (SD 12.3) years and were mostly female (n=15, 75%), White (n=12, 60%), and employed full or part time (n=10, 50%). Clinician participants (n=25) were mostly female (n=21, 84%) and included physicians (n=6, 24%), nurses (n=8, 32%), or nonclinical navigators (n=5, 20%).

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Table 1. Participant characteristics.

	Family caregivers (n=20)	Patients (n=20)	Clinicians (n=25)
Age (years), mean (range)	59.2 (34-81)	57.9 (34-80)	37.3 (23-53)
Gender, n (%)			
Female	14 (70)	15 (75)	21 (84)
Male	6 (30)	5 (25)	4 (16)
Race, n (%)			
African American or Black	8 (40)	8 (40)	6 (24)
Asian	0 (0)	0 (0)	4 (16)
White	12 (60)	12 (60)	15 (60)
Employment, n (%)			
Full time or part time	12 (60)	10 (50)	N/A[a]
Retired	6 (30)	8 (40)	N/A
Unemployed	2 (10)	2 (10)	N/A
Marital status, n (%)			
Married or living with a partner	13 (65)	15 (75)	N/A
Divorced	4 (20)	1 (5)	N/A
Single	2 (10)	3 (15)	N/A
Widowed	1 (5)	1 (5)	N/A
Hispanic, Latino, or Latina, n (%)			
Yes	0 (0)	1 (5)	0 (0)
No	20 (100)	19 (95)	25 (100)
Highest education level, n (%)			
Eight grade or less	0 (0)	0 (0)	N/A
Some high school	2 (10)	6 (30)	N/A
Associates degree or vocational or technical school	2 (10)	2 (10)	N/A
Some college	8 (40)	4 (20)	N/A
College graduate	5 (25)	1 (5)	N/A
Master’s degree	1 (5)	6 (30)	N/A
Doctoral degree	2 (10)	1 (5)	N/A
Religious affiliation, n (%)			
Protestant	6 (30)	9 (45)	N/A
No religious affiliation	2 (10)	2 (10)	N/A
Other	12 (60)	9 (45)	N/A
What type of cancer do you have or does your care recipient have? n (%)			
Bladder and/or kidney	1 (5)	2 (10)	N/A
Breast	3 (15)	5 (25)	N/A
Colon and/or rectal	1 (5)	0 (0)	N/A
Head and neck	0 (0)	0 (0)	N/A
Leukemia and/or NHL[b]	2 (10)	1 (5)	N/A
Lung	1 (5)	3 (15)	N/A
Ovarian	3 (15)	2 (10)	N/A
Pancreatic	3 (15)	2 (10)	N/A

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	Family caregivers (n=20)	Patients (n=20)	Clinicians (n=25)
Other	6 (30)	5 (25)	N/A
What stage of cancer do you have or does your care recipient have? n (%)			
1	3 (15)	4 (20)	N/A
2	5 (25)	5 (25)	N/A
3	4 (20)	2 (10)	N/A
4 (including hematological cancers)	8 (40)	9 (45)	N/A
What is the relationship with the person you are caring for? This person is my... n (%)			
Husband or wife	8 (40)	N/A	N/A
Partner	0 (0)	N/A	N/A
Son or daughter	1 (5)	N/A	N/A
Sister or brother	3 (15)	N/A	N/A
Friend	1 (5)	N/A	N/A
Other	7 (35)	N/A	N/A
Days per week providing care, n (%)			
≤1	2 (10)	N/A	N/A
2-3	1 (5)	N/A	N/A
4-5	4 (20)	N/A	N/A
6	4 (20)	N/A	N/A
Every day	9 (45)	N/A	N/A
Hours per day providing care, n (%)			
<1	2 (10)	N/A	N/A
1-2	5 (25)	N/A	N/A
3-4	3 (15)	N/A	N/A
5-6	2 (10)	N/A	N/A
7-8	4 (20)	N/A	N/A
>8	4 (20)	N/A	N/A
Clinical role, n (%)			
Physician	N/A	N/A	6 (24)
Nurse	N/A	N/A	8 (32)
Nonclinical navigator	N/A	N/A	5 (20)
Other	N/A	N/A	6 (24)

[a]N/A: not applicable.

[b]NHL: non-Hodgkin lymphoma.

Qualitative Themes

Main themes are presented in the following sections. Table 2 depicts these main themes with additional example quotes.

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Table 2. Key themes with additional example quotes.

Theme	Example quotes
Theme 1: first impressions and perceived relevance	• "I'd say overall I have a really good impression on it sounds like it'd be very helpful. The coaching sessions especially are the thing that sound most helpful to me, but also having that visual cue on what the symptoms are and being able to see it as it progresses over the course of the week and kind of track it." [Caregiver #1] • "…it would just depend on if your caregiver's willing to participate...if the caregiver was willing to participate in it, I think it would probably be helpful." [Patient #28] • "a lot of caregivers get very uneasy because they feel like they don't have any official training. They don't know what they're doing, and they want to take care of their loved one. ...So I think anytime we can provide formal training or coaching and, and make them feel empowered, it's incredibly beneficial." [Clinician #10]
Theme 2: key factors for acceptability and engagement	• "...make it easy... [is] somebody in their 70s or 80s going to be able to do it?.. there's some people that don't have the patience showing them over and over and over again." [Caregiver #5] • "Sounds wonderful, but you to have people that are computer savvy." [Patient #38] • "I think the buy-in is if it's easy and convenient and potentially beneficial. If those three things are in alignment...I think that they would embrace it...but once it gets even the least bit hard or they don't feel like they've benefited from it in any way, that's when you're going to lose your audience." [Clinician #11]
Theme 3: coaching content and delivery	• "...not in person because we live about 2 hours and 45 minutes away...so phone would be fine...and I do work [but] don't know the hours." [Caregiver #3] • "...Those are three great topics that y'all got because it's really going to help caregivers." [Caregiver #6] • "Talk about what to expect from my cancer, what she should expect...like that I'm going to be sleeping a lot...I'm going to be in a lot of pain, or I might get irritable." [Patient #26] • "I think how to be an effective partner, that would really be a concern of mine because after a while, even though you caregiver that's caring for this person, you love this person, sometimes things become frustrating." [Clinician #17]
Theme 4: dashboard design and information access	• "And [the cellphone] is something right at your fingertips as compared to going to get my computer, pull it up, type into this website, and I'm just not going to do that today. I think an app-based application would probably be a lot better." [Caregiver #13] • "...the ones that's not computer oriented, they definitely going to have a big problem." [Caregiver #6] • "Overall for everyone 'being easy to navigate' is the key to it... [caregivers] are going to want it to be simple and easy to use and easy to understand." [Patient #28] • "When you come to the dashboard...you want to have it labeled so it can be easy, accessible and patient friendly for the caregiver...because sometimes big words don't register with everyone, so you got to bring it down a notch where the patient and the caregiver can understand what is exactly on that dashboard." [Clinician #16]

Theme 1: First Impressions and Perceived Relevance

In general, participants' first impressions of FamilyAWARE were generally positive, especially among caregivers who viewed it as highly relevant to their experiences in the role and potentially beneficial. Several participants described the concept as something that could be "very helpful," particularly in reducing uncertainty through the provision of helpful information. Other caregivers described it as "another tool in my toolbox" that complemented their current efforts and as a "valuable resource," especially for caregivers who were new to the role. Patients and clinicians were more cautiously optimistic, with mostly positive reactions sometimes tempered by several considerations. Both groups expressed that different caregivers with varying levels of involvement, experience, and skills might correspondingly have varied levels of interest in the intervention. One of the patients conveyed the following:

> *It's not going to be everyone...but it would be for the ones that need it. So I think that's great.* [Patient #30]

Several clinicians, in particular, emphasized concerns about inadvertently creating additional burden for caregivers who may already be overwhelmed:

> *My major concern...is caregiver burnout...I want to make sure [FamilyAware] doesn't add to that.* [Clinician #14]

Theme 2: Key Factors for Acceptability and Engagement

While there was generally a positive response to the intervention concept, participants discussed that the acceptability of the intervention and a caregiver's engagement with the program would depend on several factors. One frequently expressed factor was the extent to which caregivers would perceive the intervention as "a frame of how to support somebody" (clinician #8). To optimize initial interest and engagement, caregivers would need to view the intervention as adding value to their role and to the assistance they gave to patients. One caregiver advised the following:

> *You kind just need to explain to them how it's going to benefit them and the patient.* [Caregiver #4]

A related factor emphasized was the need for the intervention to impose minimal burden with respect to time constraints and complexity. If the intervention was perceived or experienced as too time consuming, confusing, or difficult to use, caregivers would disengage or avoid participating in the program altogether:

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> *...keep it simple...if you put too much in there, people are going to get overwhelmed and get disinterested in it.* [Caregiver #15]

A final major factor identified by all participant groups was the intervention's apparent reliance on caregivers who were "tech savvy" and had access to and comfort with computers and smartphones, which could present a significant barrier to engagement for some:

> *Some people may feel like they're not tech savvy enough.* [Clinician #17]

Some participants pointed out that older caregivers, in particular, may struggle to use the online dashboard as currently conceived. Others noted that even caregivers who use the internet and have access to computers and smartphones may have difficulty navigating complex interfaces and could become frustrated quickly.

Theme 3: Coaching Content and Delivery

The proposed coaching structure of 3 weekly sessions lasting 20 to 30 minutes each was viewed by most participants as "a good ballpark" and "about right," given caregivers' limited time and competing demands. However, some participants preferred shorter sessions, whereas others suggested allowing up to 1 hour per session. Participants also responded positively to the proposed coaching content. Several caregivers strongly endorsed the content on helping them effectively partner with their care recipient and how to navigate finding the right balance between offering hands-on support and allowing patients to do things on their own. Participants also frequently mentioned including content focused on caregivers' own self-care and stress management. Additionally, participants emphasized the importance of practical information, such as what to expect during different phases of illness. Clinicians, in particular, noted that caregivers should receive guidance during the sessions on recognizing signs and symptoms that warrant concern and on when and whom to contact in emergency situations, including helping them "recognize signs and symptoms that they may need to worry about" (clinician #7). Preferences for whether the coaching sessions should be delivered by phone, in person, or over Zoom varied across participants. Many stressed the convenience and accessibility of telephone sessions, especially for those living far from the cancer center sites, working around job schedules, and who do not have access to computers or the internet. Others felt a stronger connection and "feel for the other person" (caregiver #15) could be established through in-person interaction.

Theme 4: Dashboard Design and Information Access

Nearly all participants emphasized that the dashboard should be simple, easy to use, straightforward to interpret, and easy to access, particularly for caregivers with low digital literacy or limited access to computers. Additionally, several participants recommended making the dashboard mobile-friendly or even mobile-based, emphasizing that smartphones are more widely available than computers. A few participants even felt that a text-based approach, rather than one that relied heavily on graphics or complex online browser navigation, would be more user-friendly and efficient. Several features were identified as particularly important. Clinicians, in particular, viewed symptom-specific guidance as essential, including information on how to respond to common symptoms and when to escalate care. Participants highlighted the value of real-time alerts that could notify caregivers or clinicians about concerning symptom trends without requiring constant manual checking. At the same time, caregivers and clinicians emphasized the need to minimize additional burden. The platform should integrate as seamlessly as possible into caregivers' routines and require little to no additional effort from clinicians. Regarding caregiver access to patient symptom data, participants were nearly unanimously supportive, given that access was granted with the patient's permission:

> *As long as the patient had signed off...I think there shouldn't be any concern.* [Patient #30]

Concerns about privacy or overreach were minimal, with participants generally viewing this level of access as appropriate and even necessary for caregivers to provide timely and effective support.

Discussion

Principal Results

Results from interviews with 20 family caregivers, 20 patients with stage I to IV cancer, and 25 oncology clinicians showed overall enthusiasm for the caregiver-focused symptom partnering intervention concept and yielded valuable insights into its design. On the basis of some of the team's prior family caregiving intervention work [23,38], the initial FamilyAWARE intervention concept presented in interviews would integrate one-on-one coaching to train caregivers on how to partner effectively with patients, track symptoms and medications, and access a web-based dashboard summarizing their patient's symptoms with tailored recommendations. Findings endorsed several features of the presented concept, including the coaching session content, the length and number of sessions, caregivers' access to patient symptom data (provided that patient permission was obtained), and the tailored recommendations for providing symptom support. However, participants were more critical of other features and provided insight into additional considerations for refinement.

FamilyAWARE is intended to complement rather than replace validated ePRO measures and existing RSM systems. These systems have demonstrated clinical benefits and are increasingly integrated into EHR and patient portal workflows [13-16,30-33,44]. Although systems may permit authorized caregiver access to patient information [45], access to symptom data alone does not necessarily provide caregivers with structured coaching, tailored interpretation, or actionable guidance about how to support the patient. The proposed contribution of FamilyAWARE is therefore a caregiver-focused layer that translates existing patient-reported symptom information into permission-based coaching and practical recommendations. Future development should prioritize integration with established ePRO and EHR infrastructure rather than creation of a duplicative symptom-reporting platform.

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One feature of the FamilyAWARE concept that participants were the most apprehensive about centered on individuals' digital literacy, access, and willingness to learn and navigate a web-based dashboard. This concern aligns with a growing body of literature, including reports from the National Academy of Medicine [46-50], highlighting the "digital divide," which can undermine engagement among those who may benefit most, including older adults, rural populations, and racial and ethnic minority groups. This suggests that an alternative to a web-based platform is needed for sharing patient symptom reports and recommendations with caregivers. One possibility mentioned by participants was having symptom reports accessible via smartphones, potentially using text messaging. Mobile phone ownership is far more widespread, with smartphones now owned by 90% of the US population [51], making these devices more available and readily accessible for daily use than desktop or laptop computers. Furthermore, a text-based mobile platform typically requires less digital literacy compared to complex web navigation, potentially lowering barriers to caregiver access and engagement. It may also be helpful to view FamilyAWARE not as a single required solution but as 1 option within a suite of caregiver support tools, recognizing that different caregivers will need and prefer different formats.

While first impressions of FamilyAWARE were generally positive across participants, with caregivers expressing the strongest enthusiasm, a critical factor highlighted by participants to optimize the initial "buy in" and engagement by caregivers was framing the intervention in a way that emphasizes its value to their caregiving role and the support they provide to patients. Participants repeatedly described caregivers as operating under considerable time, task, and psychological demands, making caregivers more selective and hesitant about the adoption of new tools and resources. Thus, uptake was believed to be more likely if FamilyAWARE was presented as a program to help optimize their partnership with patients and to streamline existing symptom support responsibilities and not simply add another task to a caregiver's daily routine. This aligns with prior research showing caregiver engagement in research to be influenced by perceived relevance and utility [52,53]. Designing FamilyAWARE to be a flexible resource that can be used more or less to fit a caregiver's needs may further reinforce this framing and avoid the perception of a one-size-fits-all approach. Implementation of FamilyAWARE will thus need to consider this framing as a mechanism to promote intervention fit, using messaging and onboarding processes that connect the intervention's features with caregiver priorities and reduce, rather than add to, their workload.

A final feature of the intervention concept emphasized by participants, particularly clinicians, was the essential need for symptom-specific guidance on what to expect and when to seek additional assistance and guidance. Caregivers talked about uncertainty around what to expect as "typical" for patients' symptoms and desired to have more upfront understanding about what to prepare for. There was also a desire for alerts built into the platform that might flag concerning trends or symptoms that might require special intervention or an escalation in support. This approach is consistent with prior research in RSM, which suggests that symptom reports and automated alerts can improve patient symptom outcomes, quality of life, and health care use [13-15,44].

Limitations

While our study reports critical feedback from caregivers, patients, and clinicians on the FamilyAWARE intervention concept, it is not without limitations. First, because this was a qualitative study, the sample size was small and not representative of the larger population of patients and their families. Moreover, participants were recruited from a single site, further negating generalizability. Second, it is possible that a larger sample size may have increased the amount and depth of feedback acquired. While saturation was obtained, we cannot eliminate this possibility. However, the next phase of this research will involve manualizing and pilot testing the FamilyAWARE intervention with a larger sample using an actual prototype, allowing for additional feedback on its content, format, and delivery and further refinement of the intervention. Third, because study participation and interviews were limited to English-speaking individuals, the findings may not reflect the perspectives of people who require communication in other languages. We also did not formally assess health literacy or language and health literacy concordance, limiting our ability to examine whether intervention preferences varied according to these characteristics.

Conclusions

This qualitative formative evaluation study found strong interest among caregivers, patients with stage I to IV cancer, and oncology clinicians for a proposed intervention concept called FamilyAWARE that combines one-on-one coaching with online dashboard access to patient-reported symptom data. Participants valued the proposed coaching sessions and easy-to-understand symptom guidance, provided that the program minimized burden, was mobile-friendly or mobile-based, and accommodated varying levels of digital literacy. Engagement was viewed as most likely when the program was framed as adding value to, rather than adding tasks to, the caregiver role. Findings will directly inform refinements to FamilyAWARE's content, delivery, and framing for pilot testing, with the goal of enhancing caregiver effectiveness and supporting patient outcomes in cancer symptom management.

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Data Availability

Data are available from the corresponding author upon reasonable request.

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Conflicts of Interest

None declared.

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
EHR: electronic health record
ePRO: electronic patient-reported outcome
HIPAA: Health Insurance Portability and Accountability Act
IRB: institutional review board

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RSM: remote symptom monitoring

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