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Caregiver Communication About Cancer: Development of a mhealth resource to support family caregiver communication burden

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Abstract

Objective: The aim of this study is to illustrate an evidence-based and theoretically informed mhealth resource (smartphone app) designed to provide communication support for informal cancer caregivers (friends or family members).

Methods: An eight-step process was conducted: (a) review of existing print resources, (b) selection of theoretical framework for content development, (c) integration of stakeholder feedback and literacy assessment into an alpha print model, (d) review of existing mhealth resources, (e) development of prototype, (f) assessment of caregiver acceptability (n = 5), (g) assessment of quality and perceived impact by cancer providers (n = 26), and (h) acceptability testing with caregivers (n = 6).

Results: Key stakeholders were integrated throughout development and user testing of this iOS smartphone app. The smartphone app consists of talking tips and resources for caregiver communication with the patient, family, far away family, and health care providers, as well as general information sharing features.

Conclusions: This study demonstrates feasibility and development of an evidence-based and theory-driven mhealth resource to support caregiver communication about cancer. This is the first theory-driven mhealth application created to support the communication burden experienced by cancer caregivers. A larger study is needed to establish the efficacy of the app as an intervention for caregivers.

KEYWORDS

cancer, caregiver, mHealth, oncology

1 | BACKGROUND

Despite their pivotal role in providing patient support, decades of caregiving research illustrate that cancer caregivers experience distress and anxiety as a result of poor communication with family, friends, and providers.[1-4] Distress can be caused by the perceived inability to communicate about cancer,[5] and difficult communication circumstances can create caregiver communication burden, defined as real or perceived communication challenges that impact caregiver quality of life.[6] For example, caregivers are often tasked with sharing diagnosis news with others, a complex role that involves deciding what information should be shared, when to share it, who should share the news, and how news should be shared.[7] Poor caregiver mental and physical health also impacts the ability to communicate effectively and contributes to communication burden.[8]

Cancer caregivers are a unique caregiving population, and there are three distinctive reasons why cancer care influences communication burden.[9] First, multimodal therapies and different stages of disease contribute to the intensity of care[10] which can cause cancer information overload for the caregiver, leaving them confused and overwhelmed by the amount of new information to process.[11] Second, the trajectory of cancer care may also include survivorship, which

creates a more fluid caregiving role. During this time, caregivers are no longer actively caregiving yet may engage in communication avoidance in order to evade discussing changes as a result of cancer.[12] Third, as outpatient cancer care becomes routine, cancer caregivers must engage in complex decision making and communication with multiple interdisciplinary providers. These distinguishing features of the cancer context warrant the need for cancer-specific caregiver resources and support.

Mobile health (mhealth) resources, such as smartphone apps, offer a viable support option for caregivers who face a steep learning curve when engaging information about cancer and need supportive tools for managing stress and developing coping skills.[13] Technology-supported resources for caregiving have the potential to meet the demand for flexible interventions and a range of informational and instructional topics.[14,15] Smartphone apps, in particular, are easily accessible and often low or no cost.[16] National reports on caregivers and technology show that half of family caregivers are under age 50 and already online and connected, with 97% reporting feeling comfortable with computers and 80% feeling comfortable with smartphones and tablets.[17] Caregivers searching for smartphone apps are looking for caregiving resources,[17] and these resources focus primarily on providing a platform for staying connected with families, friends, and professional care providers, facilitating an organized approached to care and providing information to support decision making.[18]

However, current technologies for caregivers are either ineffectively distributed or do not meet the needs of caregivers.[19] To date, the development of most mhealth apps does not include planning with the targeted user group, and acceptability testing remains one of the weakest aspects of app design.[16,20] In order to improve utility and likeliness of mHealth adoption,[21] feedback from caregivers and providers needs to be incorporated into the development of such tools. This paper describes the development and preliminary feasibility of a mhealth resource, *Caregiver Communication about Cancer* (app), designed to provide communication support to cancer caregivers.

2 | METHODS—DEVELOPMENT AND ACCEPTABILITY TESTING

An eight-step process was conducted in the development and acceptability testing of the mhealth resource.

2.1 | Steps 1, 2, and 3

A description of the first three steps of the development process has been published elsewhere.[22] Briefly, awareness of the need for caregiver resources aimed at providing communication support arose from the COMFORT SM Communication Curriculum, a national health communication curriculum designed to improve patient-centered communication. After a thorough review of the literature and integration of communication theory, Module F of the COMFORT Curriculum was developed based on the Family Caregiver Communication Typology,[23] and content was developed for each family caregiver health literacy skill as outlined by the Health Literacy for Cancer Caregivers model.[24] Based on Module F from the COMFORT

Curriculum, a new caregiver communication resource, *A Communication Guide for Caregivers©* was developed with content written at the sixth-grade level, designed in accord with suggested visual literacy guidelines, and pilot tested with cancer caregivers and providers.[22]

2.2 | Step 4—review of existing mHealth resources for caregivers

We conducted background research to review available caregiver mhealth resources. First, the iTunes store and Google Play were searched using the following combination of words: "cancer and caregiver app," "caregiver mhealth," "cancer caregiver mhealth," "mhealth for cancer caregivers," and "cancer caregiver app." Second, an Internet Google search was conducted using the same combination of words described above. Third, all National Cancer Institute–designated cancer centers (n = 69) were searched for materials in four ways: (1) Internet search using the name of the cancer center and "cancer mhealth," (2) Internet search using the name of the cancer center and "cancer app," (3) searching the cancer center's website under "resources" or "patient and family" and search for "cancer app" and "cancer caregiver app," and (4) using the cancer center's internal search function on its website for "app" and "mhealth." Finally, the top 16 rated nonprofit cancer organizations were searched using this same algorithm.[25]

The search for existing resources for cancer caregivers produced 200 smartphone apps. After removing the duplicates (n = 23) and the non-English apps (n = 2), the majority of remaining apps either did not relate to family caregiving for an adult patient (n = 89), were monitoring tools (n = 42) and games (n = 15), or appealed generally to seniors (n = 17). Of the 12 apps that remained, 11 were for diseases other than cancer [dementia (n = 6), Alzheimer's disease (n = 4), and autism (n = 1)]. Given that there were no resources available that focused on cancer caregiver communication, we decided to develop one.

2.3 | Step 5—prototype development of Caregiver Communication About Cancer (app)

Contents from the print version of *A Communication Guide for Caregivers©* were used to establish the structure of an mhealth resource, while the six domains of family caregiver health literacy were integrated to become interactive resources within the app. In accord with plain language standards that increase access to information for a range of backgrounds, and informed by the cultural awareness concepts integrated throughout the COMFORT curriculum, app content was designed to be sensitive to a range of cultural needs united by the shared experience of cancer.

The following objectives guided the development of the interactive app: (1) improve caregiver communication skills related to caregiving, (2) facilitate information and resource sharing with other family members, (3) provide resources for caregiver self-care, and (4) increase knowledge about the disease and its management. The design plan included communication talking tips and resources for communication with the patient, family, far away family, and health care providers in addition to a feature for caregivers to record questions for health care providers and manage a "to do" list. A mhealth

designer executed the planned contents in the form of a free iOS application currently available on the iTunes store. Table 1 illustrates the structure and content of the app.

2.4 | Step 6—assessing acceptability of prototype

To explore whether the app design was potentially easy to use and valuable to caregivers, we recruited a convenience sample of cancer caregivers from an outpatient cancer clinic and asked them to review the app while waiting for a clinical appointment. Caregivers were provided an iPad by a research nurse unknown to the caregivers and asked to interact with the app. The research nurse asked each caregiver a series of five open-ended questions examining ease of use for self and others, appropriate print size, and likeliness of using talking tips and took notes on their responses. Caregivers then responded to four items on the Mobile App Rating Scale[26] assessing ease of use, navigation, design, and layout, and the nurse recorded these responses. Family caregiver demographic information was not collected, as analysis based on this information was not included in the study design.

2.5 | Step 7—provider assessment of quality and perceived impact

Next, we assessed demand for the app from cancer providers. Interprofessional health care providers who participated in a communication training course in the last 2 years were sent an email invitation to download and review the app using the Mobile App Rating Scale (MARS).[26] The MARS tool is used to assess the quality of app engagement, functionality, esthetics, and information as well as the perceived impact of the app on the user's knowledge and attitudes. Finally, providers were also asked if they would recommend the app to family caregivers. This research activity was considered exempt under City of Hope Institutional Review Board (#14153), with a waiver of written informed consent.

2.6 | Step 8—acceptability testing

Consistent with the majority of mhealth app research, we gathered a convenience sample.[27] The research team utilized the university's research match online system of individuals interested in participating in research and distributed a study announcement. Through this approach, 34 individuals agreed to be contacted. Caregivers had to be 18 years of age, English speaking, and have access to an Apple device (eg, iPad or iPhone). Caregivers volunteering for the project received an email from the research team providing a written information sheet about the study and a sheet requesting caregiver contact information. Caregiver participation was dependent upon return of initial contact email which decreased study enrollment rates.

Two research team members (EW and JX) contacted caregivers via email and asked them to download the app onto their personal device and use the app for 1 week as part of their routine caregiving. A telephone interview was scheduled for the following week. Using a preset guide based on the Unified Theory of Acceptance and Use of Technology (UTAT), caregivers were asked to provide reactions to the app, report use of the app, give recommendations for improvement, and provide responses on two subscales of the UTAT scale.[28] Interviews were audiorecorded. This research activity was considered exempt under the Purdue University Institutional Review Board (#1711019861), with a waiver of written informed consent.

2.7 | Data analysis

Demographics and survey items for steps 7 and 8 were summarized using the Statistical Package for the Social Sciences (SPSS) to produce descriptive statistics. Qualitative responses generated in steps 6 and 8 were reviewed by three members of the research team (EW, JG, YM). Open-ended responses were analyzed using an iterative process of thematizing.[29] First, each researcher studied the data independently and used open coding to identify responses that suggested a possible theme. Second, the researchers then met to identify, sort, and integrate themes that had been independently identified. A process of constant comparison allowed for the integration and collapsing of themes into broader associated categories. Third, researchers rereviewed the interview transcripts, and key categories were refined. At this point, we collectively clarified the interpretive claims about the categories identified.

3 | RESULTS

3.1 | Step 6—assessing acceptability of prototype

The prototype was presented for feedback to five family caregivers, ranging from 19 to 55 years old. All five family caregivers found the app easy to use, the size of the print in the app accessible, and that it was "very likely" that family caregivers could follow the talking tips in the app. Four of five caregivers reported that the app was logical, understandable, clear, and had an intuitive screen flow throughout the content. In terms of navigation and design, all five caregivers reported that the app was easy to navigate and intuitive across all screens. In terms of layout, three caregivers reported that the app was professional and simple, and two caregivers reported that it was mostly clear, and they were able to select and read items. One caregiver recommended using color-coded tabs at the bottom of the screen.

When asked how likely it would be for family caregivers to use the resources in the app, one caregiver shared that "It was easy for me." Another caregiver described: "I personally would use the app. It reminds me of a pumped-up version of 'Caring Bridge' (another app)," and another remarked: "This app would be perfectly fit and helpful for caregivers. It's very interesting." Two of the five caregivers shared that the app would not be useful as it needed "to include more links, more information," yet others in their family may benefit: "It's not something I would use but other family members might."

TABLE 1 Caregiver Communication About Cancer (app) structure and content

Family Caregiver Communication Component[a]	A Communication Guide for Caregivers		
	Section of App	Content Description	
		Talking Tips	Resources
● Relationship with the care recipient ○ Communication with the care recipient ○ Understanding the care recipient	❖ Patient	● How it feels to be a caregiver (eg, body mind time, heart) ● Considerations and examples for sharing information with the patient ● Difficulty of discussions ● How to handle disagreements	● Meditation/relaxation audio clip ● Patient heart, mind, and body wellness tracker
● Access to information ○ Proactivity and determination to seek information ○ Information presented in quality formats	❖ Caregiving	● Customizable question and to do lists ● Example questions (eg, How is chemotherapy different from radiation or hormonal treatment?)	● Customizable/shareable reminders, notes, and patient overview chart
● Managing the challenges of caregiving ○ Self-care ○ Role recognition and understanding caregiver rights ○ Attitudes, approaches, and emotional challenges ● Support systems ○ Financial and legal support ○ Practical support ○ Psychosocial support ○ Social support	❖ Family ❖ Far away	● Suggestions for those in the family who will not talk about cancer ● Options to help relay news ● Words to use to start conversations ● Suggestions for how to ask for help ● How to redirect an offer that is not helpful (saying no to help) ● Suggestions for far away family on how to help and ways to be involved ● Ideas for what to tell far away family	● 10 questions to help learn about individual family communication and suggestions for self-care ● Ways to share information ● Shareable web resources
● Relationship with health care providers Active engagement with health care providers Supported by health care providers to understand information ● Understanding information ○ Understanding the health care system ○ Understanding the disease, treatment, and potential outcomes ○ Understanding information for day-to-day care ○ Processing health information	❖ Health care	● Suggestions for communicating with health care providers	● List of common medical words in plain language ● Searchable plain language dictionary ● Questions to ask about chemotherapy

[a]Reference: Yuen, E. Y., Dodson, S., Batterham, R. W., Knight, T., Chirgwin, J., & Livingston, P. M. (2015). Development of a conceptual model of cancer caregiver health literacy. *Eur J Cancer Care (Engl)*. doi: 10.1111/ecc.12284.

3.2 | Step 7—provider assessment of quality and perceived impact

Twenty-six cancer providers assessed the quality of the app. The majority of providers were nurses (69.2%) and had more than 16 years of clinical experience (53.8%) working with family caregivers. All but one provider could think of family caregivers who would benefit from the app, and would recommend the app to caregivers. Providers felt the app would be impactful in increasing the user's knowledge and improving attitudes toward family caregiving. On the five-point scale (5 = strongly agree), providers ranked the app very likely to increase awareness of family caregiver needs (4.12), increase knowledge about communication (4.19), change attitudes toward family centered care (4.12), increase motivation to address family caregiver concerns (4.15), and encourage family caregivers to look for help (4.15). Detailed supporting information on provider assessment can be accesed online.

In terms of app functionality, performance, and esthetics, the providers ranked the app very high in all three dimensions. See supplemental appendix which summarizes feedback from providers. Across all ratings, 92.3% (n = 24) of providers ranked the app high in design (consistency and intuitiveness across components), layout (arrangement and size of buttons), and information quality (correct, well-written content). Lower ratings were for app strategies to encourage repeat use, app customization for retaining user's setting preferences, and app interactivity for user to provide input and feedback.

3.3 | Step 8—acceptability testing

Acceptability testing was conducted with six cancer caregivers, four current caregivers, and two former caregivers who had provided care within the last 3 years. Caregivers provided care to patients with a variety of cancer types for an average of 1 to 2 years, and the majority of caregivers worked full time, were female, and Caucasian. On a seven-point scale (7 = likely), caregivers perceived the app to be useful (5.23) and had high perceived ease of use (6.00). The overall positive feedback about app acceptability was also reflected in the caregiver interviews. All of the caregivers who used the app reported a need for the app in cancer caregiving, sharing that they had experienced communication tension about discussing cancer. Caregivers agreed that they would be more likely to use the app if it were recommended by a member of the health care team. Table 2 summarizes caregiver recommendations for app modification.

TABLE 2 Caregiver recommendations based on step 8—acceptability testing

Topic	App Feature	Recommended Content
Finances/law	List with links to internet	Description of medical power of attorney, power of attorney, living will that can be shared with others
Local resources	Access user location	Desire for tailored online resources for local caregiving assistance based on location
Pharmacy	Link to internet	Assistance interpreting lab work so that caregiver can explain to others
Chemotherapy/ radiation	Button/tab	Definitions explaining medical words associated with cancer treatment
Food	Button/tab	A list of types of vitamins or food that compliment cancer treatments
"Chart the cancer journey" activity	Picture uploads	Ability to upload photos to this app feature
Communication with far away family	Interact through the app	Ability to send patient information to multiple family members

4 | DISCUSSION

While apps designed to assist clinicians with communication and advance care planning are current trends in mhealth apps,[30] the production of resources to support the communication of the caregiver lags behind significantly. Information seeking has been the primary goal of caregiver app users, and a common reason for technology use among caregivers.[31] Caregivers regularly express a need for more information to assist in keeping the care recipient safe at home, to manage stress and time for themselves, and to cope with the disease itself.[15] However, the capacity for mhealth tools to support the caregiver in their communication with others may yield benefits that far exceed information-only resources such as traditional print tools. Unlike any existing mhealth resource for cancer caregivers, this project tracks the design of a tool that addresses caregiver communication burden. Resources aimed at improving the caregiver's ability to communicate needs and concerns may influence access to supportive services that may influence patient outcomes and quality of life.

Providers felt strongly that informal caregivers would benefit from the app and indicated that they would recommend the resource to caregivers. This is an essential finding, as caregivers are not always aware of available resources and often do not feel like they have enough time to acquire and learn a new technology.[13] Providers also felt the app would increase caregiver communication knowledge, and positively impact family caregiver concerns and caregiver support seeking strategies. Esthetics, design, and performance were ranked very highly by providers, while the "interesting to use" and "app interactivity" elements were identified as areas to improve in future iterations/builds.

For caregivers, the app was rated least useful in terms of cancer caregiving tasks (cancer information–driven content), but the resource was found to be highly useful in the overall experience of caregiving,

easy to use and navigate, and very understandable. Aligning with current research about caregiver preferences, the app is easy to set up and use, and includes an accessible design, especially for older adult populations.[18] Overall, caregivers indicated that there was a need for such a resource in the caregiving experience.

4.1 | Clinical implications

The science of app development for cancer caregivers is in its infancy, and few studies have been published to illustrate a rigorous approach to development. Gaps in knowledge remain including caregiver preferences for platforms, need for technology in terms of caregiver support, whether mediated or face-to-face communication in conjunction with mhealth use is desired and under what circumstances, and what types of decisions and problems are best addressed via mediated platforms.[32] Learning more about how mhealth resources are used and how effective they are will require concerted research efforts like those exhibited in this multistep study.[33] Next steps include the implementation of the app across a larger population to determine the extent to which the app can be successfully integrated into care, and to test the use of the app in a proof-of-concept exploratory randomized controlled trial.

4.2 | Study limitations

This study is limited in that there were a small sample of caregiver testers, and we were testing a prototype instead of a finalized product. Although a small sample size for exploratory acceptability studies is standard, the material and its implementation in care need further examination. As noted in a recent systematic review of mhealth apps in health promotion, the small sample size limits generalizability.[27] Still, studies on new ideas that are aimed at innovative translational research typically involve a relatively small sample size.[34] This study is similar to other published research on app development and acceptability where 8 to 10 users are routine for feasibility and usability testing.[35,36]

The study required caregivers to have an iPhone or iPad as the prototype was developed for use on the iOS platform only. Given that a review of apps for caregivers[37] concluded that apps were most useful when they were available for multiple devices (eg, iPhone, Android, etc), recruitment efforts may have been stymied by prototype design on one platform.

5 | CONCLUSION

Promoting caregiver support in the patient's cancer journey is vital to ensuring quality cancer care. Although the number of mhealth resources, notably apps, continues to focus on tools to support patient care needs, app development is in its infancy and scant attention has been given to the needs of cancer caregivers. *Caregiver Communication About Cancer* is currently the only app that focuses on caregiver information needs and communication support, relies on evidence-based communication strategies, provides information and resources at an appropriate health literacy level compliant with

Plain Language legislation, and presents a range tools for communicating information with others. With more than 2.8 million Americans serving as a cancer caregiver,[9] it is vital to provide caregivers with resources and learning strategies to support their communication and caregiving needs.

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CONFLICT OF INTEREST

The authors report no conflict of interest.

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