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Mobile Health Technology Is Here—But Are Hospice Informal Caregivers Receptive?

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Abstract

Background: Mobile health applications (mHealth apps) represent a rapidly emerging technology that is being used to improve health-care delivery. In home hospice, informal caregivers play an essential role in attending to the day-to-day needs of their terminally ill loved ones. Using mHealth apps by caregivers in this setting could potentially improve the support provided to both patients and caregivers at the end of life (EoL).

Objectives: To explore informal caregivers' receptivity and concerns in using mHealth apps along with app features, caregivers perceived to be most useful in home hospice care.

Design: Eighty semistructured phone interviews were conducted with informal caregivers who received care from a nonprofit hospice organization. Study data were analyzed using content analysis, coding for themes of receptivity and interest.

Results: Sixty-two (78%) participants were receptive to using an mHealth app in home hospice care. Informal caregivers were interested in features that addressed: (1) communication to improve patient care (n = 44, 70%), (2) access to patient care information (n 30 = 48%), (3) education (n = 24, 39%), and (4) updates from health-care personnel and scheduling services (n = 10, 16%).

Conclusions: A substantial majority of informal caregivers voiced receptivity to using mHealth apps and expressed interest in features that enhance communication and provide information to improve patient care. Although more research is needed to examine how to incorporate this technology into existing home hospice care, our study suggests that informal caregivers are likely to use this technology they feel will help enhance home-based EoL care delivery.

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Keywords

hospice; end of life; caregiving; technology; mHealth; telemedicine

Introduction

Mobile health applications (mHealth apps) are becoming an increasingly important tool used by health-care professionals, patients, and informal caregivers (ie, unpaid) to deliver and receive care. With over 75% of Americans owning a smart-phone, these apps have the ability to connect patients and caregivers with health-care professionals to improve care delivery.[1] The benefits are promising, with research showing better symptom management, decreased visits to the emergency room, and enhanced support for families caring for their loved ones.[2–13]

One setting in which mHealth apps can have a positive impact is on hospice care delivered at home. At the end of life (EoL), hospice provides comprehensive medical, psychosocial, and spiritual care and support to terminally ill patients and their families.[14] Over 1.3 million patients enroll annually, of which, approximately two-thirds receive care at home.[15] This consists of visits from providers (eg, physicians, nurses, social workers, spiritual care counselors, and volunteers); however, informal caregivers also play an essential role in attending to patients' day-to-day needs (eg, cleaning, feeding, coordinating care, and administering medications for comfort).[14,15] Communication between home hospice care providers and informal caregivers is critical, and mHealth apps have the potential to enhance information exchange in this setting to reduce patient suffering, caregiver distress, and burdensome care transitions.

Research examining mHealth apps in hospice and palliative care has been limited. However, an increasing number of studies are being conducted. A systematic review of clinician-based apps revealed that many of these apps focused on providing guidelines and information (eg, opiate conversion, advance care planning).[16] In Scotland, researchers have established the feasibility of using mobile phones to monitor symptoms remotely in palliative care patients.[17] Still, there is limited information examining how informal caregivers view this technology.[18] Given the role in caring for their loved ones and communicating issues to hospice providers, they are a critical group of stakeholders to consider when developing mHealth apps.

Accordingly, the objective of this study was to examine informal caregivers' receptivity and interest in using mHealth apps along with which app features caregivers perceived to be most useful in home hospice care. We hypothesized that many participants would be receptive to using these tools as a way to communicate EoL issues to hospice providers. Exploring these issues in this group could help inform future design and implementation of mHealth technology to meet the needs and demands of caregivers in the home hospice setting.

Methods

Design

This qualitative study used content analysis to synthesize data collected in phone interviews with informal home hospice care-givers.[19] Content analysis is an accepted qualitative method aimed at interpreting meaning from content of data (eg, text, audio, and video).[20] The institutional review board committees at Weill Cornell Medicine and the Visiting Nurse Service of New York approved the study.

Participant Recruitment

Informal caregivers were recruited through the use of a weekly list provided by the Visiting Nurse Service of New York Hospice and Palliative Care (VNSNYHPC), a nonprofit community organization that provides hospice care for over 1000 patients daily in the New York City area. The VNSNYHPC staff generated a list each week that contained patients who were discharged from their home hospice service in the prior week. The information included patient demographic data as well as the contact information (ie, name, address, and phone number) of the informal caregiver. Informal caregivers received a letter introducing the study and informing them to expect a call in 2 to 3 weeks from a member of the research team. A research assistant called potential participants, described the study, and obtained verbal consent from those interested. Caregivers had to be 18 years or older, English-speaking, and provided care to a patient who had received VNSNYHPC home hospice care.

Phone Interview Methodology

A trained research assistant interviewed participants who were willing and interested, using a semistructured interview guide. The guide included a set of questions with follow-up probes based on participants' responses. Information was collected regarding the caregiver's age, gender, race/ethnicity, relationship with the patient, and education level. Demographic data and relevant caregiver responses were entered into Research Electronic Data Capture (REDCap), a secure web application for building and managing databases.

Participants were then asked a series of questions developed by a group of geriatrics/palliative care physicians (R.A., V.P., and C.R.) based on clinical experience and a literature review on EoL care, caregiving, telemedicine, and mHealth apps.[17,18,21–23] These questions included: (1) do you own a smartphone?; (2) would you have been receptive to using a mobile application to care for your loved one during your home hospice experience?; (3) if a mobile application was offered by hospice, would you have any concerns about using it?; and (4) if a mobile application was offered by hospice, what features would be most beneficial for you to help care for the patient? Participants who were receptive to using an app but could not think of any specific features that were beneficial (question 4) were provided with a list of features by the interviewer. Features mentioned included video chat, medication/symptom tracking, and educational materials. Participants were allowed to provide multiple responses to the question if desired. Interviews were conducted between April 2017 and August 2017 and telephone conversations lasted between 1 and 10 minutes.

Analysis

Audiotaped interviews were analyzed using content analysis.[19] A pair of investigators trained in content analysis independently reviewed phone interview recordings and systematically organized data into a structured format. Codes were developed to label responses that were relevant and subsequently organized into larger themes. This was continually revised and reformulated after reviewing each new transcript.[16] No themes were predetermined beforehand. The investigators then met to compare and discuss findings and reconciled any differing codes or themes until there was an agreement on a framework of themes and their definition. Thematic saturation was achieved after 70 interviews. NVivo 11 software was used.[24]

Results

Of the 671 caregivers contacted, 365 (54%) were unreachable despite 3 phone call attempts, 226 (34%) declined participation, whereas 80 (12%) completed the interview. Caregiver and patient demographic information are presented in Tables 1 and 2, respectively.

Receptivity and Concerns

Sixty-two (78%) participants were receptive to the idea of an mHealth app. Differences in receptivity based on caregiver demographic data were seen, with those <65 years old (n = 46/54, 85%) more likely to be receptive compared to those ≥65 years old (n = 16/26, 62%). Of participants who were unreceptive, 1 caregiver <65 years old did not own a smart-phone, while 3 caregivers ≥65 years old did not own a smart-phone. No obvious trends in receptivity were seen as a function of race or gender. Of the 80 participants, 31 (39%) expressed concerns about using an app, with security (n = 11, 35%) and usability (n = 13, 42%) being commonly mentioned. Despite caregivers expressing security concerns, most individuals (n = 10, 91%) expressing security concerns stated they would use an app regardless. As 1 participant said, “You always have [security] concerns when using apps… [but that wouldn’t keep me] from using it.” Those who expressed usability concerns felt they were not technologically literate enough to use an app. One caregiver mentioned, “I wouldn’t only because [buying a smartphone and learning to use the app] would be more work.”

App Features

Participants (n = 62) who were receptive to using an app were asked about features that they would find useful in caring for the patient. Features mentioned were coded into 4 themes: communication (n = 44, 70%), access to patient care information (n = 30, 48%), education (n = 24, 39%), and updates from health-care personnel and scheduling services (n = 10, 16%).

Communication

Video chat.—Thirty-two (52%) participants expressed interest in an mHealth app feature that could allow them to video chat with the hospice team. Caregivers mentioned the usefulness of this feature when a provider was unable to make a home visit. Many remarked on the importance of sharing real-time visual information with the hospice team. As 1 participant stated, "[video chat] is instantaneous… if you were in a position to be anxious, I would think you want to talk to somebody [right away] … then the other side can see what you are going through or what the patient is going through."

Text messaging.—Ten (16%) caregivers expressed interest in a feature that would allow text messaging to their hospice team. Five (8%) specifically mentioned short messaging similar to an online conversation while 2 referred to more formal communication such as e-mail to convey concerns/issues.

Image/video sharing.—Seven participants (11%) thought it would be useful to have an app-based feature that allowed images and/or short videos about the patient's care to be shared with the hospice team. Caregivers expressed limitations in communicating the patient's health status as well as their corresponding concerns over the phone. Participants shared that being able to send visual information could better convey these issues and lead to more accurate assessments by providers so that appropriate care could be delivered. As 1 participant illustrated, "the [hospice nurse on the phone] would ask questions like 'what does it look like' … to be able to look at a picture, share information, look at videos, that … certainly would be helpful."

Access to Patient Care Information

Medication information.—Twenty (32%) participants wanted an app-based feature that would provide information on medications. Specifically, many were interested in having an upto-date list of medications the patient needed to take. One participant noted, "[a medication list] would be great because there are so many medications involved." Other participants expressed that having information on dosing and side effects would be useful when administering medications to their loved ones.

Symptom information.—Nineteen (31%) participants were interested in a feature that would allow them to track the patient's symptoms (eg, degrees of pain, nausea, anxiety) as well as relay this information to the hospice team.

Hospice contact information.—Four (6%) participants desired a feature that listed the contact information of their hospice providers and provide ways to contact them directly through the app. One participant described this feature as such, "it would be like your social workers name is [X] and this is her number, your nurse is [X] and this is her number … [and] you can send them a message … in the app."

Education

End-of-life information.—Seven (11%) participants expressed interest in having EoL/hospice-related resources that could be delivered by an app. More details about hospice care, what to expect at the EoL, and common symptoms were mentioned as information that would be particularly useful. One participant reflected on his experience and stated, "[it would be helpful to know] what sort of end stage [symptoms] to look for, the changes in breathing, the mottled skin, those type of things."

Information on caregiving.—Six (10%) participants wanted to have information on how to be a caregiver and what to expect when caring for a dying loved one. Specifically, information on caring for bed-bound patients, maintaining their cleanliness, and treating common EoL symptoms were mentioned. App-based explanatory guides and tutorial videos were brought up as ways that information could be accessed. As 1 patient shared, "a guide on how to care [would have been useful] …just teach us things that we didn't know. Changing sheets or diapers, just the overall medical care (as a caregiver)."

Updates From Health-Care Personnel and Scheduling Services

Scheduling features.—Six (10%) participants noted that scheduling phone calls and home visits could be streamlined via an app. One participant described having a feature that would allow her to learn when upcoming visits were planned and which providers would be visiting from the hospice team. Other participants expressed a desire to be able to schedule phone calls/visits through an app. As 1 participant noted, "[It would be great] if there was some part of the [app] interface where I could have said 'this is the problem, this is where you can reach me,' rather than staying on hold."

Patient updates.—Four (6%) participants, especially caregivers who worked and/or did not live with the patient, desired more updates on their loved ones' care, especially after a home visit or if a change was made in the care plan (eg, change in medications). As 1 participant said, "Sometimes they would visit but … I wouldn't know exactly what they did during the visit because I was working, so maybe a checklist or even a paragraph just stating what they noticed and [if there were] any recommendations."

Discussion

A significant majority of informal caregivers in this study voiced receptivity to using an mHealth app if offered the opportunity during the home hospice experience. Caregivers expressed interest in mobile app features that focused on communication, access to patient care information, educational materials, and updates from health-care personnel and scheduling services. As participants reflected on their hospice experience, many felt that these particular features would have been a useful addition to the care they and their loved one received. Having more ways to connect to the hospice team was viewed as important by caregivers and currently used methods to communicate issues, such as home visits and/or telephone calls, may not always be sufficient.

Although studies using mHealth apps in home hospice care are limited, promising research examining these tools in the palliative care population is underway and echo some of the themes identified in this study. For example, the feasibility of using mobile phones to monitor patient symptoms remotely via the Advanced Symptom Management System in Palliative Care was successfully tested in Scotland.[25] In patients with cancer, the reporting of symptoms by patients through a web-based platform that would send an alert to a nurse was associated with an increase in median overall survival compared to those receiving usual care.[26] Lastly, a multicomponent psychosocial intervention delivered in home via videophone to care-givers of patients with dementia was shown to decrease burden scores and improve positive aspects of caregiving and satisfaction with social support.[27] These projects could provide insights into mHealth implementation efforts in the home hospice setting.

Many caregivers also shared a desire to have more information about the patient’s care and what to expect when caring for a terminally ill loved one. This is not an uncommon issue as many caregivers and patients have very little knowledge about hospice and EoL caregiving.[28] Studies have shown that educating caregivers can help improve outcomes.[29] Further research is needed to examine what knowledge would be useful for caregivers, whether there is a difference if information is provided through an app versus other delivery forms (ie, brochures, educational sessions), and whether it can enhance the care patients and informal caregivers receive.

Although there was an overall receptivity to using mobile apps, we found that older caregivers were less likely to be receptive to using a mobile app which may be due to older adults not adopting smartphones as rapidly as younger cohorts. Recent data from the Pew Research Center showed that although 80% of US adults aged 65 years and older owned a cellphone, only 42% owned a smartphone.[1] Examining whether this trend will continue requires investigation as future caregivers brought up using smartphones begin to care for their loved ones on home hospice. In addition, further exploration on how to design mobile apps that will adequately address security and usability concerns expressed by care-givers is needed in order to increase its receptivity and universal adoption among users.

There are limitations to our study that need to be considered. We had a small percentage (12%) of respondents and a high percentage (54%) of participants that were not reachable by phone. Given this response rate, we may not have captured the full spectrum of opinions held by informal caregivers regarding mHealth app use at the EoL. Although we called caregivers who were not reachable by phone at least 3 times, the calls were mainly conducted on weekday afternoons, a potentially inconvenient time. However, of those who were reachable by phone, 24% participated. This relatively low yield reveals the recruitment challenge faced by researchers who conduct EoL/hospice research.[30] Participants were also recruited from 1 hospice organization in an urban location, and these results may not translate to other populations, particularly those living in a rural setting. In addition, some caregivers were unable to answer open-ended questions regarding features they would want an app to have. Because of this, they were then prompted with possible options. Although this engaged them in thinking about what would be valuable, it could have influenced their responses. Lastly, the study was focused on informal care-givers’ receptivity toward and recommendations for use of mHealth apps; we did not conduct interviews with hospice patients themselves.

Conclusion

Given the many challenges informal caregivers face when their loved ones are enrolled in home hospice, new methods to improve outcomes need to be explored. Most participants in our study were receptive to using an mHealth app. Many expressed interest in features that improved communication and provided information to improve patient care. Although more research needs to be conducted to examine how to incorporate mobile devices into existing home hospice care, our study suggests that caregivers are a willing group of users.

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Table 1.

Caregiver Participant Demographic Data.

Characteristics	n = 80
Age, years	
Median	58
Mean (SD)	57.2(12.9)
Gender	
Female	59 (73.7%)
Male	21 (26.3%)
Relationship to patient	
Child	46 (57.5%)
Spouse	10(12.5%)
Other relative	19(23.7%)
Friend	5 (6.3%)
Race/ethnicity	
White	38 (47.5%)
Black	14(17.5%)
Hispanic	16(20%)
Asian	6 (7.5%)
Other	6 (7.5%)
Education level	
High school	21 (26.3%)
College	42 (52.5%)
Grad school	17(21.2%)

Abbreviation: SD, standard deviation.

Table 2.

Patient Demographic Data.

Characteristics	N = 80
Age, years	
Median	85
Mean (SD)	85.9(14.7)
Gender	
Female	53 (66.3%)
Male	27 (33.7%)
Race/ethnicity	
White	43 (53.7%)
Black	13 (16.3%)
Hispanic	17(21.3%)
Asian	5 (6.2%)
Other	2 (2.5%)
Hospice diagnosis	
Cancer	36 (45%)
Noncancer	44 (55%)
Length of stay, days	
Median	24.5
Mean	77.5

Abbreviation: SD, standard deviation.