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Harnessing mobile health technology to support long-term chronic illness management: exploring family caregiver support needs in the outpatient setting

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ABSTRACT

Objective: Family caregiving is an important public health issue, particularly with the aging population. In recent years, mobile health (mHealth) technology has emerged as a potential low-cost, scalable platform to address caregiver support needs, and thereby alleviate the burden on caregivers. This study sought to examine the support needs of family caregivers in their lived experiences of outpatient care to inform the development of a future mHealth intervention.

Materails and Methods: We conducted 20 semi-structured interviews in 2 outpatient hematopoietic cell transplant (HCT) clinics at a large academic medical center in the Midwestern United States. A thematic analysis was performed to define emerging themes.

Results: Qualitative data analysis identified 5 primary themes that HCT caregivers faced: (I) lifestyle restrictions due to the patient's immunocompromised state; (II) Unmet needs due to limitations in the current resources, including unfamiliar medical tasks without necessary trainings; and (III) caregivers' adaptive strategies, including reformation of social relationships with family and friends. Based on these findings, we suggest 3 design considerations to guide the development of a future mHealth intervention.

Conclusions: The findings herein captured the family caregiver's lived experiences during outpatient care. There was broad agreement that caregiving was challenging and stressful. Thus, effective and scalable interventions to support caregivers are needed. This study provided data to guide the content and design of a future mHealth intervention in the outpatient setting.

Key words: family caregiver, hematopoietic cell transplantation, bone marrow transplantation, mHealth

LAY ABSTRACT

Family caregiving is an important public health issue that affects millions of individuals. Recently, digital health platforms (eg, mobile phones, tablet devices) have become important tools in delivering care and supporting caregivers. This study examined the needs of family caregivers who are caring for individuals undergoing a hematopoietic cell transplantation (HCT) in order to design a future intervention using mobile phones. Following 20 interviews in 2 outpatient clinics at a large academic medical center in the Midwestern United States, we identified 5 primary themes that family caregivers faced: (I) lifestyle restrictions due to the patient's immunocompromised state; (II) unmet needs due to limitations in the current resources, including unfamiliar medical tasks without necessary trainings; and (III) caregiver's adaptive strategies, including reformation of social relationships with family and friends. Based on these findings, we suggested 3 design considerations to guide the development of a future mHealth intervention. Our findings captured the family caregiver's experiences during outpatient care. There was broad agreement that caregiving was challenging and stressful. Thus, effective and scalable interventions to support caregivers are needed. This study provided data to guide the content and design of a future mobile phone intervention.

INTRODUCTION

Family caregivers are individuals who provide unpaid care for their family or friends.[1] As human lifespans are steadily increasing, the need for family caregivers providing chronic care is also growing, particularly in the chronic care environment.[2,3] Yet, family caregivers often do not have formal medical training, and they must learn and acquire medical knowledge and coping strategies while carrying out new responsibilities. These may include performing activities, such as dressing and line changes, managing medications, coordinating clinic visits, providing transportation, and planning daily schedules (eg, dressing, cooking, activity, bathing, sleeping). Due to these demanding tasks without appropriate training, caregivers often experience stress or feel burdened, which may lead to depression and anxiety,[4,5] as well as a diminished health-related quality of life (HRQOL).[6] In turn, this may negatively impact patients' HRQOL and clinical outcomes.[2,7,8]

Caregiver burden has been defined as the "negative reaction to the impact of providing care on the caregiver's social, occupational, and personal roles."[9] Much focus has been placed on the wide range of *negative* implications associated with caregiving[10] (eg, depression, anxiety).[11] Despite this, a majority of caregivers have recognized the benefits of caregiving.[12,13] The imbalance of focusing primarily on negative aspects may limit our ability to develop new assessment and intervention methods.[14] Thus, a "corrective focus" is needed in caregiving research to expand our knowledge on the *positive* aspects of caregiving.[15,16] Research on self-management suggests that self-efficacy, a positive aspect, can promote caregiver health, well-being, and positive health behaviors (ie, improved sleep and physical activity).[17,18] Carbonneau's evidence-based conceptual framework on the positive aspects of caregiving suggests that self-efficacy may be correlated with a caregiver's ability to positively perceive the caregiving role.[19]

The literature in the medical field and the human-computer interaction area have highlighted the urgent need to support family caregivers in the context of chronic illnesses (eg, cancer, dementia, diabetes), and suggested the important role of mobile health (mHealth) technologies.[20–24] The studies have largely examined how caregivers effectively manage health information, such as communicating with clinicians and reviewing test results,[25,26] tracking patient health information,[27–30] and managing pain with smartphone-based diaries on behalf of the patients.[31] Studies have also investigated how technology may be used to provide positive

psychological activities and promote caregiver HRQOL and resilience.[32,33] It is possible that enrichment events in caregiver daily life, such as positive activity exercises, will *positively* affect the: (1) quality of patient and caregiver relationship; (2) caregiver's feelings of accomplishment; (3) and meaning of caregiver's role in daily life. Ultimately, this will *positively* impact both the caregiver's and patient's well-being and health outcomes.[19]

Hematopoietic cell transplantation (HCT) is a potentially curative therapy for treatment of life-threatening cancers as well as noncancer blood diseases. However, patients undergoing HCT may develop life-threatening complications, including death from the procedure itself. Thus, family caregivers of HCT patients are at risk for significant mental and physical burden, and the expected caregiving tasks may be intense and prolonged.[34] Recent studies have examined how mHealth technologies may alleviate the mental health burden and social isolation,[35] while increasing HRQOL in the HCT caregiving population.[36]

Previous studies have examined the support needs of family caregivers, but they have often focused on caregiving through isolated inpatient settings or outpatient settings, rather than across the entire trajectory of care.[36–40] In order to examine challenges experienced by family caregivers of HCT patients as they engaged in outpatient care, we conducted semi-structured qualitative interviews with 20 family caregivers of HCT patients. The interviews focused on how caregivers navigated everyday life with newly imposed changes and responsibilities. Family caregivers were also probed about their attitudes and perceptions of any positive aspects of caregiving and of using mHealth technology to support their HRQOL. We examined their experiences and identified themes that emerged from the interviews. Based on these findings, we also described how new strategies were developed to help them carry out their caregiving responsibilities. In the following sections, we first present study methods followed by findings and design implications.

METHODS

Study design

The goal of our study was to examine the challenges of outpatient caregiving and identify implications for designing technologies to support family caregivers. To draw deeper insights from the caregiver's perspective, we conducted semi-structured interviews with 20 family caregivers. Using an interview guide, we initially probed
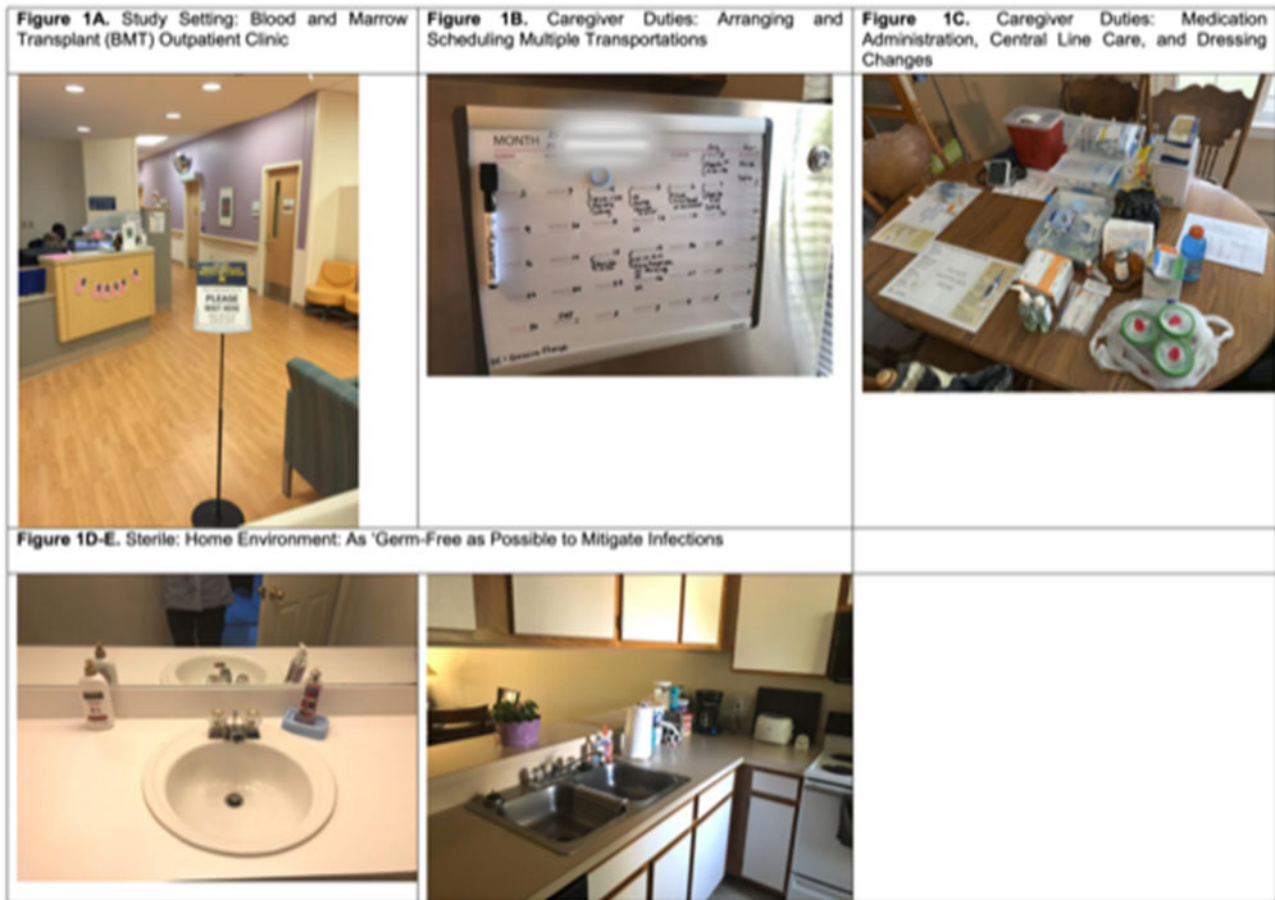
Figure 1. (A) Study setting: blood and marrow transplant (BMT) outpatient clinic; (B) caregiver duties: arranging and scheduling multiple transportations; (C) caregiver duties: medication administration, central line care, and dressing changes; (D and E) sterile: home environment: as "germ-free" as possible to mitigate infections.

interviewees about general caregiving experiences and also inquired about challenges specific to outpatient caregiving. Then, we asked about any positive aspects about their caregiving experience(s) (see Supplementary File—"Interview Guide"). Given the semi-structured nature of the qualitative interview, study participants had flexibility to spend more or less time on specific topics based on their responses. For example, while some participants wanted to share challenges related to understanding the medical information, others wanted to spend more time on social isolation.

Study settings and participants

The interviews were conducted in 2 outpatient clinics within the Pediatric and Adult HCT Units at a large academic medical center in the Midwestern United States (Figure 1A); interviews lasted approximately 30 min. Study participants were recruited during routine outpatient clinic visits. When patients had an outpatient appointment, patients often met with several clinical staff. Thus, family caregivers and patients were able to participate in the interview in between such visits. After we confirmed that they were primary caregivers of patients (ie, provided ≥50% caregiving duties), we asked their availability for the interview. The eligibility criteria included: (1) ability to provide informed consent; (2) English speaking; and (3) willingness to engage in face-to-face interviews. The participants were compensated for their time ($10 gift card). We obtained ethical approval from the Institutional Review Board.

Demographic information

We recruited 20 caregivers of patients undergoing first-time allogeneic HCT in the outpatient clinics (Table 1). Saturation is defined in qualitative research as a criterion for discontinuing data collection and/or analysis.[41] Herein, recruitment ended once it was determined that no additional data were being found whereby the investigators developed new thematic categories. In a manuscript by Guest et al,[42] it has been described that major themes are generally established after 12 interviews as long as the sample is a relatively homogeneous group (ie, herein, HCT caregivers only). The median age of the caregivers was 50.6 years (SD = 16.7, range, 21–82 years). Majority of the caregivers were female (80%) and related to the patient, such as a parent (53%), spouse (13%), or child (13%). Transplants were all allogeneic (eg, related donor, unrelated donor; see Supplementary File—Table S1: Patient Demographics). Of note, during the study, 4 patients died and one did not have a recurring appointment; accordingly, their caregiver demographics were not obtained.

Data analysis

From the transcripts collected from the interview, we focused on the following areas: (1) challenges and opportunities of caregiving in the outpatient setting; and (2) strategies learned from these experiences. The team performed thematic analysis to identify selective themes that emerged from interviews. While the interviews took place, 7 study team members (J.Y.S., D.C., J.K., R.V., G.C., A.M., S.W.C.)

Table 1. Participant demographics

	M (SD)	Range
Age	50.6 (16.7)	21–82
	n	(%)
Education (highest level of schooling)		
4-year college graduate	6	(40)
Some college or 2-year degree	5	(33.3)
High school graduate or GED	3	(20)
More than 4-year college degree	1	(6.7)
Gender		
Female	12	(80)
Male	3	(20)
Race		
White	13	(86.7)
Other[a]	2	(13.3)
Ethnicity (Hispanic)		
Yes	1	(6.7)
No	14	(93.3)
Relationship to the patient		
Parent	8	(53.4)
Child	2	(13.3)
Spouse	2	(13.3)
Family friend	2	(13.3)
Grandmother	1	(6.7)
Marital status		
Married/partnership	11	(73.3)
Single	2	(13.3)
Widowed	1	(6.7)
Declined to answer	1	(6.7)
Current employment status		
Employed full-time (40 or more hours per week)	5	(33.3)
Employed part-time (up to 30 h per week)	1	(6.7)
Retired	4	(26.7)
Self-employed	3	(20)
Homemaker	1	(6.7)
Unable to work	1	(6.7)
Annual household income		
$0–$30,000	4	(26.7)
$30,001–$60,000	3	(20)
$60,001–$100,000	2	(13.3)
$100,001–$200,000	6	(40)

[a]By selecting "Other" the participant did not select American Indian/Alaska Native, Asian, Black of African American, Native Hawaiian or Other Pacific Islander, or White.

met weekly during the routine research team meeting, reviewed available transcriptions, and discussed emerging findings to have a common understanding as a team. After the 20 interviews were conducted, 3 team members (J.Y.S., D.C., J.K.) performed a collective affinity clustering[43,44] to build an initial coding structure of high-level themes that can represent the rest of the subthemes. We followed the open coding and affinity diagramming process: (1) each of the 3 researchers randomly selected 2 transcripts (6 in total) and conducted an initial open coding; (2) created codes from the open coding exercise were written on index cards (each code on an index card); (3) we placed each card into a diagram based on commonalities of the codes; and (4) all of the identified codes were reviewed to label representative themes. Any disagreement between 3 researchers was modified through iterative discussion. The team members then continued to conduct coding for the rest of the 14 transcripts using NVivo Pro 11. All of the transcriptions were reviewed and coded by a minimum pair of researchers from the team (J.Y.S., D.C., J.K., R.V., G.C.) with the developed codebook. Because each transcript was independently coded by a minimum of 2 researchers, we compared the coding results and discussed any disagreement to resolve it. Newly emerging codes were also discussed in a weekly team meeting and added into the existing coding structure. This iterative process enabled refining and regrouping of the subthemes according to the existing codes of high-level themes we had developed.

RESULTS

Family caregivers of HCT patients reported challenges as they engaged in outpatient care. They were responsible for many duties, including managing the patient's health, performing medical tasks, and managing the patient's activities of daily life. The overarching themes described below were supported by participant quotes, which highlighted caregiver challenges as well as strategies they developed from their experiences (see Supplementary File—Table S2: Participant Quotes). The major themes included: (I) lifestyle changes due to the patient's immunocompromised state; (II) unmet needs due to limitations in the current resources, including unfamiliar medical tasks without necessary; and (III) caregiver's adaptive strategies, including reformation of social relationships with family and friends.

I. Lifestyle changes due to the patient's immunocompromised state

Caregivers were required to adjust their routines after hospital discharge, which included new restrictions due to the patient's underlying immunocompromised state. The first 6–12 months post-transplant were demanding due to numerous follow-up visits with HCT clinicians and subspecialists, lab tests, imaging studies, treatments, and infusions or transfusions. Some of the adjustments included administering numerous medications to the patient throughout the day, following defined nutrition requirements, arranging transportation, and keeping the patient safe against infections (Figure 1B–E). Both caregiver and patient were restricted from crowded public places due to infection-risk, leading to social isolation. Modified routines also impacted caregiver employment status, which led to financial stress. During interviews, caregivers reflected on all of the radical changes following hospital discharge. Participants expressed feelings of being trapped or cooped up and were impatiently waiting for the doctor's approval to leave the house:

> We are basically trapped in our apartment. Now it's a little better than the first two months because in the first two months she had to have someone with her 24/7, which makes sense to a certain degree but now they made the rules a little bit more relaxed for us so that I can leave for two hours, go grocery shopping or something. She still needs help. [CG5]

The impact of social isolation was even more difficult when there was only one designated primary caregiver. If the caregiving responsibility fell solely on the primary caregiver, she/he was required to stay with the patient 24/7, and it was tough to maintain the balance between their own lives and the caregiving role:

> Sundays are my biggest source of stress. The other thing is you just don't realize when they want 24/7 care, it's around the clock. When we had our daughter home visiting that was great because she could run to the store for things, things that you just don't

stop and think about you need. It's like, "I can't leave." Hopefully, as we get further into this I have a little bit more freedom to leave him alone for little stretches of time. It can be stressful if there's no one else in the household to help. [CG17]

In addition to the prolonged duration of time spent together, the home environment had to be as "germ-free" as possible to mitigate infections in light of the patient's immunocompromised state (Figure 1D and E). Indeed, patients remained vulnerable to life-threatening infections for up to 1-year post-transplant. A caregiver reflected on her experience of keeping the home clean, similar to an inpatient High-efficiency particulate air (HEPA)-filtered room:

I prepared our house at an extremely clean level, because that's what the social worker said, "Get your house as clean as you can get it." I've done everything within my power to follow every direction. I think that you have to be very prepared and it's very scary and it's very overwhelming…It took probably a month for me to get into the groove, and now it's just simple as pie. [CG4]

The imposed restrictions caused employment challenges for caregivers. Caregivers had to leave their jobs to take care of their patients 24/7, causing significant financial strain. Even after discharge from the hospital, caregivers and their patients were required to come in for frequent clinic visits. This obligation led to unstable employment with a worsening financial burden. Similarly, caregivers needed to re-align work schedules and responsibilities due to frequent outpatient follow-ups:

It would be very difficult if my employer wouldn't be that understanding that I'm able to work at night, then I can't work right now, or try to work in parallel while I'm sitting here. If you have to go once or twice a week to the clinic because she can't drive, then how do you do that? It's difficult. [CG5]

Being a caregiver was an enormous responsibility—consistently providing *safe* physical, mental, and emotional support—at times, at the expense of their own personal health and well-being. Caregivers often put aside their own needs to focus on the patient's health.

II. Unmet needs due to limitations in the current resources, including unfamiliar medical tasks without necessary trainings

Caregivers reported having to perform multiple medical tasks on patients' behalf. Most of the caregivers expressed confusion and difficulty in learning and performing the tasks, particularly as nonmedical professionals. Complex medical tasks often included medication administration, central line care, and dressing changes (Figure 1C). Moreover, they monitored patient symptoms, physical activity, nutrition, and sleep based on recommendations provided by the clinicians. In order to be discharged from the hospital, caregivers had to demonstrate their competency in performing all of the required medical tasks, including symptom management, to the healthcare team:

The first day that we were discharged to come home, I forgot everything. Everything went out the window and I panicked. So, I had to call the 1-800 number that they gave and the doctor's number and they pretty much walked me through. They assigned us a nurse, she came out to help assist, so that was perfect. Then as she did that, then I remembered everything. Maybe, I want to say three weeks until I got really comfortable. [CG2]

Caregivers often expressed fear and discomfort due to uncertainty in performing medical tasks and the potential for negative consequences:

Just changing the dressing has been a source of angst for me. That's really difficult. I keep laughing saying, "Nurses go to school for four plus years to learn how to do all this stuff, and they're giving us a crash course in a half hour and say, 'Here, go do it," You can't leave him high and dry. That's been very stressful from that standpoint. [CG17]

As described above, despite caregivers' unfamiliarity and lack of confidence in performing medical tasks, they expressed a lack of support to assist in these activities. They relied on basic skills they learned prior to discharge, or home healthcare nurses who visited to guide them through the medical tasks. Participants commonly felt that they were not prepared for the postdischarge stage, and this suggested the need for more intense instruction to better prepare caregivers with medical task-related training in the home environment.

During the interviews, caregivers stated that they did not actively engage or utilize existing resources developed by the hospital for supporting their own wellness. The hospital often provided information and peer support services, including an information packet, face-to-face mental wellness sessions, counseling with social workers, or peer group interaction opportunities, for caregivers throughout the treatment processes. However, caregivers had limited engagement with the currently available resources and did not feel motivated to participate in the services or use available resources. One of the biggest reasons they were unable to engage in such services was the limited time they had coupled with the patient's unpredictable medical course. Furthermore, if caregivers lived far away from the healthcare system, they were unable to attend in-person sessions. Many participants also expressed time constraints in utilizing the current services:

I have not followed up on any of it [support group]. Part of it is we don't live close here. We're in a small city. It's usually an hour and 15 away so it's not something I would do outside of the visits. We come, and then once we're here by the time you do what you need to do you're ready to get out of here. And he needs to get home to get his magnesium IV going, so we don't usually have time to do too much else. [CG16]

III. Caregiver's adaptive strategies, including reformation of social relationships with their family and friends

Caregivers expressed undesirable emotions accompanied with caregiving tasks, such as frustration, anger, uncertainty, and depression. To reduce these negative emotions, some caregivers sought out more patient-related health information, while others identified interpersonal support or engaged in religious or spiritual activities. Surprisingly, many caregivers found the most effective way to cope with their circumstances was to take each day one-at-a-time:

It is a very long, slow journey and progress is in very small increments. Sometimes it's hard to see day-to-day progress, ups or down. You have to really take the long view of things to see that. On the other hand, we move through each day a step at a time, just not focus too much on the long term. [CG7]

Some caregivers developed a positive mindset by keeping a journal or mental notes, crafting, or engaging in small daily routines, like exercise:

Stress relief. I work out. We have a treadmill and a bike, so I've been working on that about every other day. I love to read and watch movies. Things like that help. [CG17]

Other caregivers expressed that even though such activities were not time-intensive, having small activities made them feel refreshed and enabled them to focus on positive feelings rather than any negative emotions. Accordingly, under the available resources, caregivers acquired, developed, and adopted their own strategies over time. For example, caregivers indicated that their experience with chronic illness also had positive benefits in their life. These included developing strong bonds with significant others and focusing on gratitude for large and small things in their daily lives after they went through and overcame the adversity of the HCT process. Caregivers and patients were required to spend a long time together, which allowed them to develop stronger relationships. During interviews, many caregivers described their illness experience as a traumatic life-event, but they also reflected on how everyone pulled together to get through it. Because it was an intense journey involving life-threatening complications, people relied on the personal connections around them to navigate the caregiving experience. These close connections included relationships with their family and friends and social connection with their community, such as religious organizations:

> The one option available left was bone marrow transplant, which was a huge step to take and that's life changing for him, for me, for the whole family. But everyone has pulled together and been very helpful. We have good friends support and it's all working out fine. You need a lot of family support and friends support to be able to have this be successful. [CG4]

On the other hand, some caregivers reported that their circumstances led them to become isolated and to lose close relationships with friends or family. For example, when parent caregivers of pediatric patients stayed in the hospital for the transplant, young siblings had to live with other family members. One of the participants described how she lost a close mother-child relationship with the other 2 children at home after her first hospital stay with the patient. Two of her children expressed that they felt like their parents abandoned them. She regretted that she did not maintain close connections with other family members while she was staying in the hospital with the patient. The new relationships that caregivers developed through the care journey had both positive and negative impacts on their emotional status. These findings collectively gave rise to considerations for caregiver support interventions that could foster meaningful relationship bonds with significant others.

DISCUSSION

In the current study, participants reported that providing care for patients throughout the HCT procedure was extremely challenging and stressful, especially at the beginning of their outpatient care immediately after hospital discharge. However, we found that caregivers gained insights through the development of new coping strategies and closer relationships with significant others (eg, siblings, relatives, friends). Although there were aspects of caregiving that caused significant stress and disappointment during the first several months post-transplant, such challenges also provided opportunities for introspection, self-reflection, and the development of strategies to navigate challenging events related to the patient's illness. By analyzing emerging themes from the caregiver's perspective, we provide design implication suggestions for future mHealth interventions that could potentially contribute to caregivers' health and well-being.

Design consideration I: Connecting caregivers with other caregivers though group-based activities

According to our study findings, caregivers were able to develop their own coping strategies based on the life experiences and knowledge they acquired over time. The majority of HCT caregivers faced overwhelming challenges, particularly at the beginning of their outpatient care. Gradually, caregivers accepted and internalized their situation and developed necessary strategies for the provision of care. In our findings, most of the caregivers learned and adapted practices based on their own experiences rather than from other caregivers who had gone through similar experiences, including support groups or available community-based services. Even though accessible peer-to-peer support resources were provided by the healthcare system, including the clinics, they were not useful resources that helped caregivers to navigate their challenges. In our findings, caregivers' constrained time and physical limitations were the biggest challenges that interfered with engagement with current support services. Caregivers developed strategies over time rather than learned from others. For example, while some strategies could be applicable and meaningful to others who faced similar circumstances, they were not easily shared or circulated among other caregivers. This led us to consider a virtual, small group, activity-based peer support group as a possible mHealth solution. As online support groups foster personal empowerment and provide emotional and information support, having mutual support groups with people who have already coped with the same circumstance often results in high levels of reciprocity.[45–47] Although previous studies suggested the critical role of technology in peer support, a majority of existing literature on online peer support were focused on online forums that allow a large group of caregivers to post their thoughts and acquire feedback from others. However, the lack of tailored support resulted in low adoption, discontinued use, and abandonment of peer support tools.[48]

Recent studies have shown the usefulness of technology that assists individuals in choosing peers depending on their tailored needs and dispositions at a specific timepoint in the context of mental illness.[48] Similarly, in seeking information on pregnancy, women received meaningful support from their peers' experiences.[49] By leveraging peers' experiential knowledge, as well as passing along medical information acquired throughout their healthcare experiences, they developed useful resources for others who may seek similar support. From these examples, we suggest forming a small support group according to specific caregiving characteristics, including number of years in caregiving, patient population (eg, children, adolescent, young adult, elderly), demographic characteristics (eg, age, residential area, gender), or level of medical knowledge. Small group support is particularly useful to provide practical verbal probing, invitation, and rich suggestions for interactions for participants.[50] Using targeted categories, such as characteristics over diagnosis, would suggest rich opportunities to generate tailored resources specific to individual circumstances and provide a sense of belonging for participants in a small group.

Group-based support also has the possibility to be expanded to a variety of shared activities, including shared nutrition, sleep, emotions, or well-being tracing. With this approach, caregivers could work as a small team to achieve their daily goals (ie, achieving sleep or steps goals). By participating in an activity, caregivers can naturally share their concerns and experiences according to specific directed topics. The interaction could provide one another with support without imposing time constraints.

Design consideration II: Enabling video conferencing for real-time education

Complex medical procedures that caregivers must perform on behalf of their loved ones were the most distinct features of HCT caregivers. Following hospital discharge, caregivers were expected to automatically take over care duties on the patient's behalf. Caregivers had to quickly learn how to perform central line care and dressing changes as they became a primary caregiver. From our findings, we identified that home nurse visits were incredibly helpful for caregivers to learn unfamiliar medical tasks, which relieved anxiety. However, nurses visited the caregivers' homes 3 times on average, and caregivers had to learn everything within the limited time.

To alleviate the burdens of learning complex medical procedures within a short period of time, we suggest a video-assisted communication system with the healthcare team for the newly discharged patient and caregiver. Previous literature suggests that healthcare providers perceive home telehealth as just as beneficial as an in-person interaction.[51,52] Video conferencing interventions have emerged to increase health knowledge, insights, and skills,[53] and they are actively being used to support caregivers in other medical contexts, including dementia,[54] brain injury,[55] and other oncology populations,[56] but not actively among HCT caregivers. Unlike these other disease populations, HCT caregivers experience an intensive recovery period of up to 100 days after the transplantation due to the patient's immunocompromised status. To minimize further complexities, close monitoring by caregivers is essential. Providing frequent and stepwise support through video conferencing could capture caregiver needs and provide appropriate real-time support. Caregivers who report low health literacy and skills could particularly benefit from this resource. With telemedicine, this could potentially offer unique solutions for caregivers who often struggle with complex medical tasks.

Design consideration III: Using readily accessible activities for emotional expression

Caregivers undergo a reformation of their social relationships during the care trajectory. Our findings showed that the prolonged hospital course and uncertain outcomes led to social isolation for caregivers. However, we also found that stressful experiences led to closeness with their significant others and a sense of personal growth. Prior studies showed how emotional support from their close friends and family generated confidence in one's ability to cope with stressful experiences and manage negative feelings, enhancing their self-efficacy.[57–59] This positive reformation of close relationships that caregivers shared during the interview, we argue, should be highlighted and turned into a useful coping strategy. Because of physical distance or time constraints, including hospitalization, some caregivers failed to maintain good relationships with friends or family members, and thus, lost a critical means of social support. Under the existing healthcare system, where there is a lack of sufficient support for caregivers,[60] caregivers developed their own solutions. Recent studies found that interventions with positive psychology principles may improve psychological well-being and reduce depressive symptoms in cost-effective manners.[61–63] Such principles have been actively implemented in chronic pain medicine and diabetes, and the effects can be maximized with other caregiver-supporting interventions.[61,64–66] We suggest including these readily accessible activities that promote positive emotions, as well as connection with close others. By following instructions provided by the app, caregivers could express and enhance their emotions by conducting activities, such as writing in a journal, expressing gratitude, reinforcing a positive mindset, and engaging in stress relief activities (eg, engaging in pleasant activities like reading a book, doing crafts, or going for a walk). Outcomes of the activities could easily be shared with their family or other caregivers and make a positive impact by acting as guidance for others.

CONCLUSIONS

The goal of this study was to unpack existing barriers from a caregiver's perspective and to provide design implications for future mHealth interventions. We highlight that caregivers experience many barriers, including social isolation and having to perform complex medical tasks with limited training. At the same time, caregivers actively developed coping strategies to navigate the patient illness journey. Caregivers reported meaningful experiences and acquired lessons after their first several months post-transplant, including the positive aspects of caregiving. Nonetheless, we recognize key limitations of the current study, including single-center design, homogeneous participant population (eg, White, female, educated) with bias toward willingness to participate. As more caregiving activities are being directed into the outpatient space, our study supports the urgent need of calibrated interventions across the caregiving trajectory. Our team is making concerted efforts for recruiting more diverse, equitable, and inclusive participant populations onto our research studies to capture larger, more diverse populations. For example, we are currently designing studies with multisite collaboration as well as inclusion of caregivers of other disease populations other than cancer/HCT. Given the broad categories of design considerations provided: (I) connecting caregivers with other caregivers though group-based activities; (II) enabling video conferencing for real-time education; and (III) using readily accessible activities for emotional expression, we believe these could be applicable across caregiving populations. Future studies should include heterogenous caregiving populations to test the applications of novel interventions. With advances in technology and data analytics, there are increasing opportunities to provide meaningful solutions for family caregivers who are not well-equipped.

AUTHORS' CONTRIBUTIONS

J.Y.S.: Writing-original draft, data collection, data curation, data analysis, visualization; D.C.: Data collection, data curation, data interpretation, writing-review/editing; J.K.: Data collection, data curation, data analysis, visualization, writing-review/editing; R.V.: Data collection, data curation, data analysis, visualization, writing-review/editing; G.C.: Data curation, data analysis, writing-review/editing; A.M.: Data curation, data interpretation, writing-review/editing; A.L.H.: Data interpretation, writing-review/editing; D.A.H.: Data curation, visualization, writing-review/editing; S.Y.P.: Data interpretation; writing-review/editing; D.B.: Data interpretation, writing-review/editing; S.W.C.: Data curation, investigation, methodology, formal analysis, resources, supervision, validation, visualization, writing-original draft, writing-review/editing.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was obtained from the University Health System Institutional Review Board (HUM00115569). All the participants signed the consent form before participating in this study.

AVAILABILITY OF DATA MATERIALS

The data used and analyzed for the study are available from the corresponding author on reasonable request.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no competing interests.

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