

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

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Research article

Keywords: family, caregiver, hematopoietic cell transplant (HCT), blood and marrow transplant (BMT), design, mHealth, mobile technology, intervention

Posted Date: January 14th, 2020

DOI: <https://doi.org/10.21203/rs.2.20826/v1>

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Version of Record: A version of this preprint was published on December 5th, 2020. See the published version at <https://doi.org/10.1093/jamiaopen/ooaa053>.

Abstract

BACKGROUND 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 caregiver burden. This study sought to examine the support needs of family caregivers in their lived experiences of outpatient care in an effort to inform the development of a future mHealth intervention.

METHODS The current study is a part of a larger study in a population of family caregivers to patients undergoing blood and marrow transplant (BMT), consisting of three phases: i) tablet-based caregiver-facing intervention design (Phase I); ii) usability testing in an inpatient healthcare setting (Phase II); and iii) randomized trial to expand the user group to an outpatient setting (Phase III). In an earlier pilot study (Phases I and II), a tablet-based caregiver-facing application was developed and tested for supporting inpatient care. As part of Phase III, we conducted 20 semi-structured interviews in two outpatient BMT clinics at a large academic medical center in the Midwestern United States. A thematic analysis was performed to define emerging themes.

RESULTS Our data analysis identified five primary themes that BMT caregivers faced: I. lifestyle restrictions due to the patient's immunocompromised state; II. unfamiliar medical tasks required on behalf of patients; III. unmet needs based on existing resources; IV. adopting strategies due to the new roles; and V. reformation of social relationships with family and friends. Based on these findings, we observed three design considerations to guide the development of a future mHealth intervention: i) connecting caregivers with other caregivers through Chat Forums; ii) enabling video conferencing with healthcare providers; and iii) using readily accessible activities (e.g., journaling) to help express emotions.

CONCLUSION 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.

Background

Increased needs of family caregiving

As cancer survivorship has steadily improved, the need for family caregivers providing extended periods of care in a long-term outpatient setting has increased (1,2). Thus, family caregiving is an important public health issue. Typically, family caregivers (e.g., spouses, siblings, parents, relatives, and friends) provide unpaid care (3). Increased attention has been placed on self-management and coping strategies in cancer care delivery. Living with life-threatening illness, such as cancer, causes extreme stress for many patients, which extends to family caregivers (4–6). Cancer patients are significantly immunocompromised, which highlights the critical role that family caregivers play in disease

management. Their work often involves performing intensive medical tasks (e.g., central line care, dressing changes, intravenous infusions), managing multiple medications, and conforming to daily restrictions. However, the current healthcare model does not actively address caregiver needs, as the focus is primarily placed on patient care. Indeed, caregiver coping efforts may have an important impact on patient health-related quality of life (HRQOL) (2,7,8). The literature suggests that caregiver characteristics, such as perceived lack of support and understanding, may correlate with depression and anxiety (9), as well as decreased HRQOL (10). Health information technology, such as mobile health (mHealth) applications, has the potential to provide scalable caregiver support (11).

Long-term outpatient BMT management

Blood and marrow transplant (BMT) is an intensive medical procedure for patients with life-threatening cancers and other blood diseases (12,13). The trajectory of care often extends well-beyond 5-years post-transplant. Accordingly, caregivers must be actively involved in the transplant journey, including the pre-transplant, transplant, and post-transplant phases. However, BMT caregivers are suddenly thrust into this new role and are left feeling unprepared. Thus, it is not surprising that BMT caregivers experience significant levels of anxiety and distress, especially during the peri-transplant period (14). Although patients are allowed to go back home if there are no serious complications observed within the first 100-days post-transplant, the risk of transplant-related morbidity and mortality continues for much longer. This requires patients and caregivers to live with numerous restrictions in the home environment, including limited social contact and modifications in nutrition and physical activity.

During the inpatient transplant procedure, patients and caregivers are surrounded by their healthcare team. However, once discharged, they are required to carry out all medical tasks and daily activities of living on their own (15). Patients and caregivers are expected to rapidly develop new skills and routines. Caregiving work is often multi-faceted, such as symptom management, arranging transportation, and managing the new living environment for patients (16). Many caregivers report difficulties during this phase due to the unfamiliarity of their new routine (13), leading to physical, emotional, social, and financial burden. Despite the reported burden, caregivers are not provided with the confidence or adequate knowledge to perform unfamiliar medical and non-medical tasks. Without an appropriate support system, caregivers are faced with challenges to navigate the long-term BMT journey virtually alone. Building strategies that improve caregiver wellness may positively influence patient health recovery (17). Recognizing that caregiving roles and responsibilities change over time, depending on the patient's recovery, the required coping strategies may also change across time.

Technology-mediated interventions for caregivers (BMT Roadmap)

Technology-mediated interventions have widely been studied in the context of health, with the aim of sharing health information and delivering patient-centered care more efficiently. Recent research in cancer care delivery has shown that most caregivers easily use technology, and a majority of caregivers want technology-supported intervention for caregiving efforts (18). To improve care delivery and outcomes, researchers have started to investigate the needs of supporting caregivers of patients with chronic illness

with technology-mediated interventions (11). Studies have examined how caregivers effectively manage health information with a variety of tools, such as handling applications for reviewing test results (19), tracking patient health information (20–23), or managing pain using smartphone-based diaries on behalf of the patients (24).

To alleviate caregiving burden, we have previously developed a mobile health app (BMT Roadmap) to support caregivers of patients undergoing BMT, or commonly referred to as hematopoietic cell transplant (HCT) (Phases I and II). On an Apple iPad, caregivers navigated information related to their hospital stay during the inpatient transplant procedure. Information displayed on the app integrated with the MiChart (Epic®; Verona, WI) electronic health record, which included real-time laboratory results and medications, clinical-trial enrollment, healthcare team directory, and discharge checklist (Fig. 1). At the time of hospital admission, each caregiver was given her/his own Apple® iPad and was provided with instructions to comfortably use the app throughout the inpatient, hospital stay. BMT Roadmap was associated with reduced caregiving burden and was easy-to-use and well-liked by caregivers who participated in the study (14). However, the app was targeted a priori for the inpatient setting, and to primarily serve as a source of patient-related information. User experience interviews highlighted the ongoing caregiving journey beyond the hospital, and the need for caregiver support in the outpatient setting, such as emphasis on caregiver-specific resources to promote caregiver health and well-being (25). The current study aimed to explore the lived experiences of BMT caregivers in the outpatient context. Based on the data analysis, we synthesized the feedback to come up with design considerations and content for an outpatient version of the BMT Roadmap app in an effort to develop a future mHealth intervention.

Methods

Data collection

The study team conducted semi-structured qualitative interviews in two outpatient clinics (Pediatric and Adult BMT Units), at a large academic medical center in the Midwestern United States (Figure 2). Participants were recruited during routine outpatient clinic visits by a clinical research coordinator. The eligibility criteria included: i) ability to provide informed consent; ii) comfort in speaking English; and iii) willingness to engage in face-to-face interviews. All participants confirmed that they were primary caregivers of patients who underwent BMT (i.e., provided $\geq 50\%$ caregiving duties). The semi-structured interviews explored: i) general caregiving experiences during the patient's BMT procedure; ii) barriers that interfered with post-transplant transitions to home; iii) adopting strategies of living with a new rhythm and restrictions; and iv) design implications for an outpatient version of mHealth app. During the interviews, we focused on the most common emerging challenges that caregivers faced and their support needs and coping strategies. Each interview lasted approximately 30 minutes and the participants were compensated for their time (\$10 gift card). Ethical approval was obtained from the University Health System Institutional Review Board.

Demographic information

We recruited 20 caregivers of patients undergoing first-time allogeneic transplant in the outpatient Pediatric and Adult BMT clinics (Table 1). The median age of the caregivers was 52 years (range, 21 – 82 years). Most caregivers were directly related to the patient, such as a parent (53%), spouse (13%) or child (13%), and female (80%). Transplants were all allogeneic (e.g., related donor, unrelated donor). The diagnoses were heterogeneous, and included acute myelogenous leukemia (n = 7), acute lymphoblastic leukemia (n = 5), myelodysplastic syndrome (n= 3), lymphoma (n=1), hemophagocytic lymphohistiocytosis (HLH) (n=1), severe aplastic anemia (n=1), Shwachman-diamond syndrome (n=1), and GATA2 haploinsufficiency (n=1). The median number of post-transplant days was 100.5 (range, 34 to 1380 days). The median age of the patient was 51 years (range, 4 to 72 years). During the study, four patients died and one did not have a recurring appointment; thus, their caregiver demographics were not obtained.

Data analysis

Seven study team members (JYS, DC, JK, RV, GC, AM, SWC) met at least once weekly and discussed findings and emerging themes from interviews. During team meetings, each investigator independently identified and shared significant findings from the interview. After the 20 interviews were conducted, a minimum of three study team members (JYS, DC, JK, RV, GC) performed a qualitative thematic analysis of the data and conducted the initial coding, as previously described (26). Content of the codebook was extensively discussed, reviewed, and refined to accommodate the most significant themes, until a consensus for the final codebook was achieved. All of the transcriptions were reviewed and coded, by a minimum of two investigators (JYS, DC, JK, RV, GC), using the developed codebook. The initial coding structure was refined as we went through the iterative cycles of coding, and newly emerging issues were also included as new codes. We entered and coded all the transcriptions into NVivo Pro 11 to compare, contrast, and define the most common emerging issues.

Results

Five primary themes faced by BMT caregivers emerged in our iterative cycles of data analyses: i) lifestyle restrictions due to the patient's immunocompromised state; ii) unfamiliar medical tasks required on behalf of patients; iii) unmet needs of existing resources; iv) adopting strategies due to the new roles; and v) reformation of social relationships with close friends and family members.

Our interviews highlighted challenges that caregivers encountered throughout the transplant journey. Caregivers were responsible for many duties, including managing the patient's health, performing medical tasks, arranging for transportation, scheduling and attending frequent clinic visits, and managing the patient's activities of daily life (ADLs). The ADLs included meal preparation, tracking patient fluid intake, and taking care of patient physical health and mental wellness (27). The five primary themes described below are supported by participant quotes, which highlight caregiver challenges as well as potential strategies that could be developed (Table 2).

I. Lifestyle restrictions 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. Even though patients were sent home, the first 6-12 months post-transplant were demanding due to numerous follow-up visits with BMT clinicians, other sub-specialists, multiple lab tests, imaging studies, treatments, and various infusions or transfusions. Some of the adjustments included administering numerous medications to the patient throughout the day, following defined nutrition requirements, arranging multiple transportations, and keeping the patient safe against infections (Figure 3). In particular, both caregiver and patient were restricted from crowded public places due to infection-risk, leading to limited contact with family and friends. Modified routines also impacted 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, 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 primary caregivers could share duties with others, they were able to put caregiving aside and do personal work for small periods of time. However, 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 (Figures 4 and 5). Indeed, patients remained vulnerable to life-threatening infections for up to one-year post-transplant. A caregiver reflected on her experience of keeping the home clean, similar to an inpatient 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, because I follow rules, which is the way I am. 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 the patients 24/7, causing significant financial strain. Even after discharge from the

hospital, patients and their caregivers were required to come in for frequent clinic visits. This obligation led to unstable employment with 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. Unfamiliar medical tasks required on behalf of patients

Caregivers reported having to perform multiple medical tasks on the patient's behalf. Most of the caregivers expressed confusion and difficulties, particularly as a non-medical professional, to learn and perform the tasks. Complex medical tasks often included medication administration, central line care, and dressing changes (Figure 6). Moreover, they also 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. From that point she came, maybe, I want to say three weeks until I got really comfortable. I was able to go from there. [CG2]

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

Probably 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 the caregiver's 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 uniformly felt ill-prepared for the post-discharge stage, suggesting the need for more intense instruction to better prepare caregivers with medical task-related training in the home environment.

III. Unmet needs of existing peer support resources

During interviews, caregivers stated that they did not actively engage or utilize existing resources. Even though the hospital provided accessible information and support services, including an information packet, face-to-face mental wellness sessions, or peer support groups, or were not sure how to access 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. Further, 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]

IV. Caregiver's own adaptation strategies in living with the new roles

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:

I think the first thing that I noticed is that 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 through 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.

V. Reformation of social relationships with their family and friends

Caregivers indicated that their experience with chronic illness also had positive benefits in their life. These included strong bonds with significant others, benefit finding after they went through and overcame the adversity of the BMT process and gratitude for large and small things in their daily lives. For example, 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 that everyone pulled together to get through it. Because it was a long-term journey involving life-threatening complications, people relied on their 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 doctors have tried everything they could try, and finally 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 situation led them to become isolated and 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 that she lost a close mother-child relationship with the other two children at home after her first hospital stay with the patient. Two of her children expressed that they were feeling 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.

From our interviews, it was apparent that the illness experiences impacted caregivers' relationships with close others. The new relationships had both positive and negative impacts on caregivers' emotional status. These findings collectively gave rise to considerations of caregiver support interventions that could foster meaningful relationship bonds with significant others: i) connecting caregivers with other caregivers through Chat Forums; ii) enabling video conferencing with healthcare providers; and iii) using readily accessible activities (e.g., journaling) to help express emotions.

Discussion

In the current study, participants reported that caregiving in the BMT context was extremely challenging and stressful, especially at the beginning of their long-term outpatient care, immediately after hospital discharge. However, caregivers also found these experiences meaningful through the development of new coping strategies and closer relationships with significant others (e.g., siblings, relatives, friends) as they navigated the transplant journey. Although there were aspects of caregiving that caused significant stress and disappointment during the first several months' post-transplant, it 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 developed design suggestions for the future, outpatient BMT Roadmap app that could potentially contribute to their wellness (i.e., health and well-being).

Design consideration I: Connecting caregivers with other caregivers through Chat Forums

According to our study findings, caregivers were able to develop their own coping strategies based on information and knowledge they acquired over time. The majority of BMT caregivers faced numerous overwhelming challenges, particularly at the beginning of their long-term outpatient care. Gradually, caregivers accepted and internalized their situation and developed necessary strategies for the provision of care. In the BMT context, most of the caregivers learned and adapted practices based on their own experiences, and not from other caregivers who had gone through similar experiences, including support groups, or available community services. Even though accessible peer-to-peer support resources were provided by the healthcare system, caregivers still sought information from healthcare providers or developed individual coping strategies. However, these strategies, although they contained information that could be applicable and meaningful to others who were challenged by similar circumstances, were not shared or circulated. It is known that giving reinforcing networks and having increased social support positively impacts a group's ability to collectively solve problems with resources (28). For example, online support groups have been applied to various healthcare contexts, including caregiving support. Studies suggest that online support groups foster personal empowerment and provide emotional and information support that positively impact handling specific conditions, such as distress (29,30).

A possible solution in chronic illness management, including BMT, could be a team-based caregiver support activity through an mHealth app, such as a group activity; participants could be grouped according to specific caregiving characteristics, such as number of years in caregiving, patient population (e.g., children, adolescent, young adult, elderly), demographic characteristics (e.g., age, residential area, gender) or level of medical knowledge. Forming a team based on selected or targeted categories would suggest rich opportunities to have calibrated support specific to individual circumstances. Previous studies have shown that having mutual support groups with people who have already coped with the circumstance often result in high levels of reciprocity (28). Our study identified important components of BMT caregiver support groups and would be beneficial to apply these findings to the mobile application form. The app could allow caregivers to share (i.e., by posting) their concerns and experiences according to specific directed topics (e.g., nutrition, sleep, activity, emotions, well-being). With the app, caregivers could be paired with other peers or mentors and could work as a small team to achieve their daily goal (i.e., achieving daily sleep or steps goals). The interaction could provide one another support without imposing time constraints. For example, parents of children undergoing BMT could communicate with other parents to learn how their peers establish healthy eating or fluid intake patterns for their kids undergoing BMT. Wearable sensor devices (e.g., Fitbit) could potentially be connected with the app to track simple exercise or small activities to promote both caregiver and patient wellness.

Design consideration II: Enabling video conferencing

In this study, we identified a majority of participants who commented that home nurse visits were incredibly helpful to learn unfamiliar medical tasks, which relieved anxiety. Following hospital discharge,

caregivers were expected to automatically take over care duties on the patient's behalf. If they had questions, they were given instructions to call the outpatient BMT clinic or address any questions at their next outpatient appointment. Given that many caregivers felt frustrated with performing medical tasks, a video-assisted communication system with the healthcare team could be considered for the newly discharged patient and caregiver.

The literature suggests that healthcare providers perceive home telehealth (i.e., audio or video quality) just as beneficial as an in-person interaction (31,32). Video conferencing interventions have emerged to increase health knowledge, insights, and skills (33), and they are actively being used to support caregivers in other medical context, including dementia (34), brain injury (35), and other oncology populations (36), but not actively in BMT caregivers. Unlike these other disease populations, BMT caregivers experience an intensive recovery period 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

Our findings indicated that caregivers undergo a reformation of their social relationships during the long-term care trajectory. The prolonged hospital course and uncertain outcomes led to social isolation. On the other hand, stressful experiences led to closeness with their significant others, and a sense of personal growth was also felt. 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 (37–39). This positive reformation of close relationships, we argue, should be highlighted and turned into a useful coping strategy. From our study, not all caregivers had effective strategies to maintain connections with their social circle. Due to physical distance or time constraints, including long-term hospitalization or frequent clinic visits, 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, in which there is not enough support for caregivers (40), they developed their own solutions. Previous studies found that interventions that applied positive psychology improve psychological well-being and reduce depressive symptoms in a cost-effective manners (41–43). Studies also suggested that positive psychology interventions have been actively implemented in other populations, such as chronic pain medicine and diabetes and the effect of positive activities can be maximized with other caregiver supporting interventions (41,44–46). To assist with identified barriers from our field study, we suggest including these readily accessible activities that promote positive emotions, as well as connection with close others. 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 (e.g., 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 and friends. As a next step, we are currently working on an outpatient version of the BMT Roadmap app, *Roadmap 2.0* (Figure 7). We hope that future work will include a refined design informed by data collected in caregivers who participated in this current study, followed by a randomized, controlled trial of the intervention.

Limitations

Despite the rigorous qualitative work performed herein, we recognize the limitations of the study. First, the collected and analyzed data came from 20 caregivers recruited from a single health institution with limited range of demographics (i.e., almost all White). Although an iterative data analysis was performed to remove bias, a relatively small number of participants from a single institution may not cover or represent the general caregiving population. Additionally, face-to-face interviews, conducted in the outpatient clinics, might have influenced the participant responses. Even though we encouraged participants to discuss their responses openly, the presence of the interviewer and the environment of the outpatient clinic, may have limited their responses. Lastly, caregivers were selected based on heterogeneous patient disease criteria (e.g., age of patient, type of transplant, type of donor, disease complications) that may have influenced the caregiving experiences. We attempted to focus the outpatient interviews on the daily routine and self-management activities of caregivers after the patient was recently discharged from the hospital setting. Based on the findings herein, our qualitative research work was extended into the caregivers' home environment (data forthcoming). Collectively, the qualitative findings informed the content of a large-scale national survey in efforts to collect quantitative data from more diverse populations, including from different BMT centers and different socioeconomic backgrounds (data forthcoming).

Conclusion

The main goal of this study was to unpack existing barriers from caregivers' perspectives that could be relieved by caregiver support interventions. We highlight caregivers' support needs and examine opportunities that can be applied to Roadmap 2.0. The current study suggests that caregivers experience many barriers, including social isolation and having to perform complex medical tasks based on limited training. At the same time, caregivers actively developed coping strategies to navigate the patient illness journey. Indeed, some caregivers reported meaningful experiences and acquired lessons after their first several months post-transplant. Herein, we introduce design considerations for BMT caregivers, a model caregiving population of chronic illness management. Our overarching goal is to better prepare caregivers for long-term, outpatient self-management care. As more caregiving activities are being directed into the outpatient space, our study supports the urgent need of calibrated interventions across the caregiving trajectory. With advances in technology and data analytics, there are increasing opportunities to provide

meaningful solutions for caregivers who are not well-equipped under the existing healthcare structure. Therefore, establishing rigorous assessment processes that can inform system designers and healthcare researchers is critical to design and develop evidence-based solutions to both the caregiver and patient. We hope that future studies, enhanced with larger representative samples, will add further to the data herein.

Abbreviations

ADLs

Activities of daily life

BMT

Blood and marrow transplant;

CG

Caregiver

HCT

Hematopoietic cell transplant;

HRQOL

Health-related quality of life

IV

Intravenous therapy

mHealth

Mobile health

Declarations

Acknowledgements

The authors wish to thank the caregivers, patients, and clinicians who participated in this study.

DECLARATIONS

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.

Consent for publication

Not applicable.

Availability of data materials

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

Competing interests

The authors declare that they have no competing interests.

Funding

This work was supported by an American Society of Hematology Bridge Grant and NIH/NHBLI grant (1R01HL146354) and the Edith S. Briskin and Shirley K Schlafer Foundation (Sung Won Choi).

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Tables

Table 1. Participant Demographics

ID	Age	Race	Hispanic (yes/no)	Marital Status	Highest level of Schooling	Current Employment Status	Annual Household Income
1	44	White	No	Married or in domestic partnership	4-year college graduate	Unable to work	\$100,001-\$200,000
2	31	White	No	Married or in domestic partnership	More than 4-year college degree	Employed full-time (40 or more hours per week)	\$100,001-\$200,000
3	52	Other	No	*declined to answer	Some college or 2-year degree	Self-employed	\$0-\$30,000
4	62	White	No	Married or in domestic partnership	4-year college graduate	Retired	\$100,001-\$200,000
5	54	White	No	Married or in domestic partnership	4-year college graduate	Employed full-time (40 or more hours per week)	\$100,001-\$200,000
6	21	Other	Yes	Single, never married	Some college or 2-year degree	Employed full-time (40 or more hours per week)	\$0-\$30,000
7	30	White	No	Single, never married	4-year college graduate	Employed part time (up to 39 hours per week)	\$0-\$30,000
8	59	White	No	Married or in domestic partnership	4-year college graduate	Retired	\$0-\$30,000
9	35	White	No	Married or in domestic partnership	Some college or 2-year degree	Self-employed (full time)	\$60,001-\$100,000
10	44	White	No	Married or in domestic partnership	Some college or 2-year degree	Homemaker	\$100,001-\$200,000
11	46	White	No	Married or in domestic partnership	High School Graduate or GED	Employed full-time (40 or more hours per week)	\$30,001-\$60,000
12	62	White	No	Married or in domestic partnership	4-year college graduate	Retired	\$30,001-\$60,000
13	82	White	No	Widowed	High School Graduate or GED	Retired	\$30,001-\$60,000
14	59	White	No	Married or in domestic partnership	High School Graduate or GED	Employed full-time (40 or more hours per week)	\$60,001-\$100,000
15	78	White	No	Married or in	Some college or 2-	Self-employed	\$100,001-\$200,000

				domestic partnership	year degree		
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Table 2. Representative interview quotes categorized by theme

Restrictions due to the patient's immunocompromised state

We're pretty much homebound. I have a membership to a workout place, I can't go. Very mindful of any germs I'm at, like at school, I'm staying away from kids where I work in my office. I don't go to the workout places because very easily could bring something home. You're feeling like you're held prisoner, and we're at day 40. We have 60 to go. It can be stressful. [CG17]

He's fairly isolated. Physically, he has a chat thing that he does with friends who live in other countries that are ahead of us in time zone. They get home from school and they're online talking and stuff. It's a normal day for him, except he doesn't go anywhere, because there's nowhere to go and everybody else is in school. [CG21]

Unfamiliar medical tasks required on behalf of patients

I would say for me it was just learning how to hook up an IV. I'm not a nurse by background, and I've never had any desire to do anything like that. Getting comfortable with doing all of that. Being nervous about hurting him, doing something wrong. [CG16]

Unmet needs of existing resources designed for caregivers

Support system. I'm looking for a support system for people with the same disease, because it's one thing for us. But we're not going through this, she is. It's nice if she can have someone to talk to on a regular basis, or as a group so they can support each other, right now I'm not finding that. I'm sure it exists, it's just not readily available. [CG08]

Caregiver's own adaptation strategies to live with new roles

I think the first thing that I noticed is that 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. [CG07]

Reformation of social relationships with their close others

It's been a long road from seven or eight years ago when he was first diagnosed. The doctors have tried everything they could try, and finally 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. [CG04]

Figures

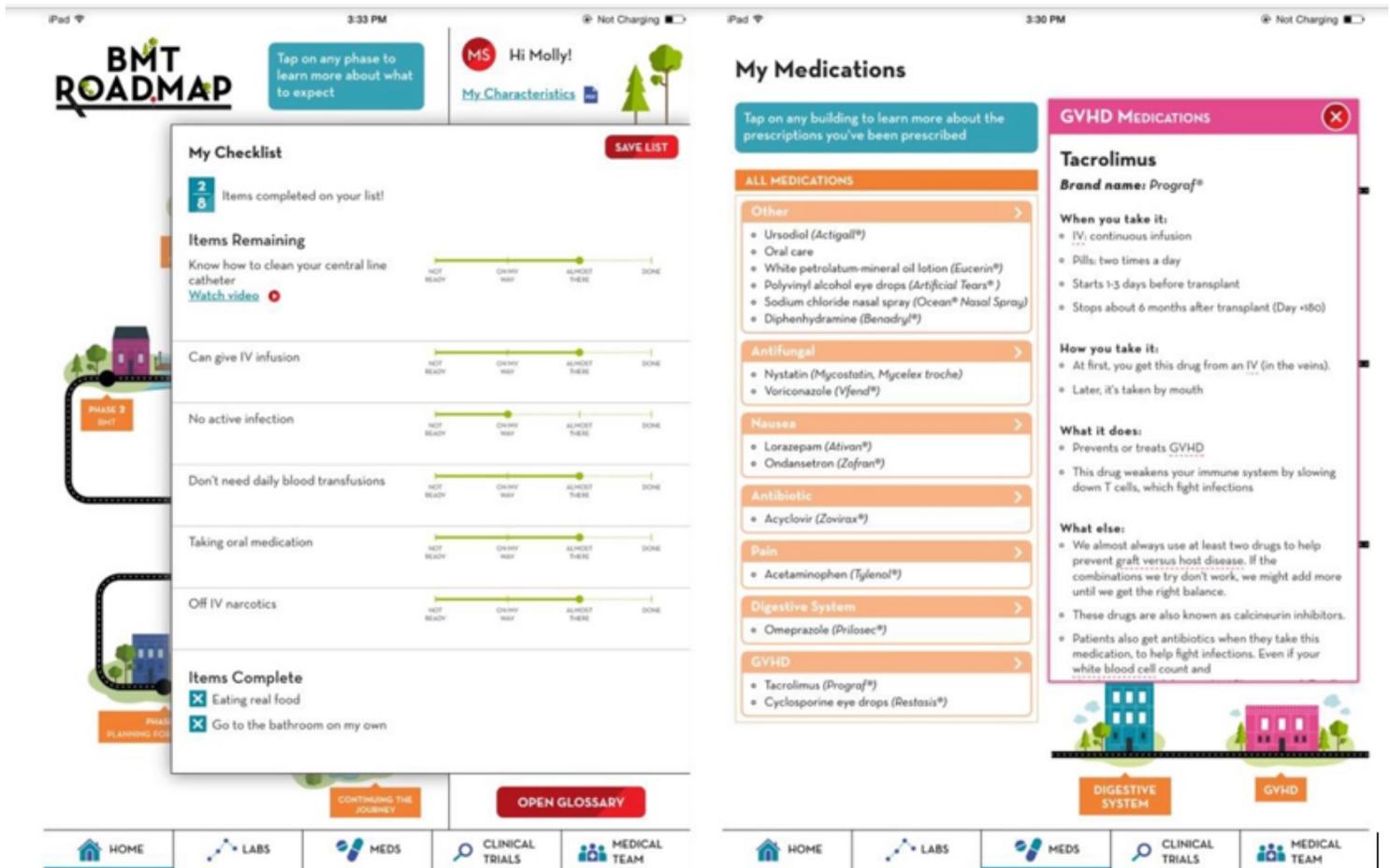


Figure 1

Mobile health app (BMT Roadmap)



Figure 2

Study setting: outpatient BMT clinic



Figure 3

Caregiver's duty included arranging multiple transportations*



Figure 4

Patient's home environment had to be as 'germ-free' as possible to mitigate infections*



Figure 5

Patient's home environment had to be as 'germ-free' as possible to mitigate infections*



Figure 6

Caregiver's duty included medication administration, central line care, and dressing changes*

*Representative photos were provided with informed consent by caregivers in their home environment

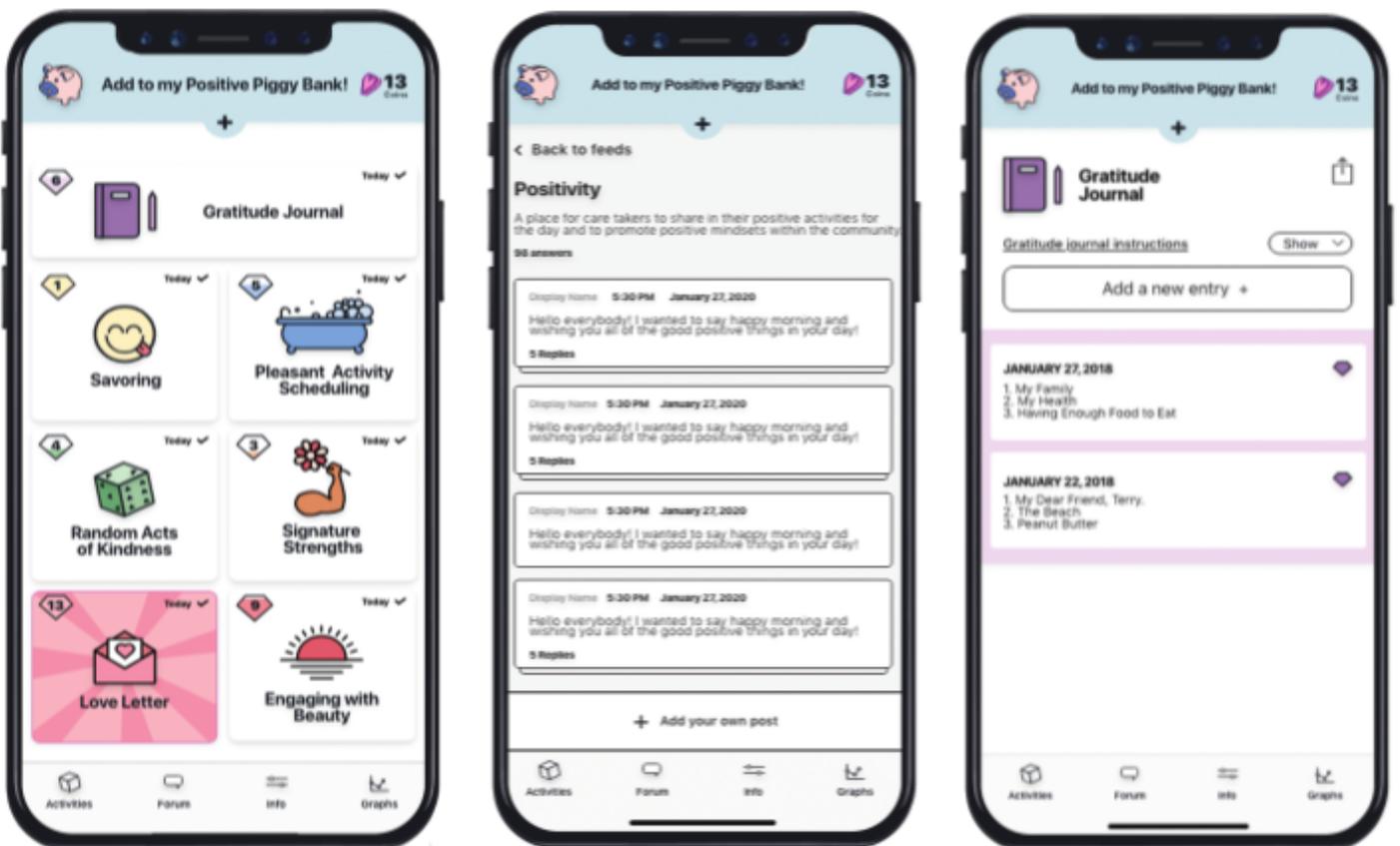


Figure 7

Prototype of an outpatient version of the BMT Roadmap app, Roadmap 2.0

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [5Checklist20190815.docx](#)
- [6InterviewScriptforCaregivers20190815.docx](#)