# “Tough things you’re going to have to go through”: A dyadic interview study of patients and their caregivers post-hematopoietic cell transplant (HCT)

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Submitted to: Journal of Participatory Medicine
on: September 02, 2025

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## *Abstract*

**Background:** Patients undergoing hematopoietic cell transplant (HCT) and their caregivers are under a significant amount of stress throughout the HCT process with fear of disease recurrence, graft failure, and many other HCT-related complications. However, the experiences and perspectives of HCT patients and their caregivers as dyadic units have not been well-published to date.

**Objective:** To better understand patient and caregiver perspectives throughout the HCT course, patients undergoing HCT and their caregivers were able to opt-in to interviews at multiple time points post-HCT as part of a larger study, Roadmap 2.0 (an app intervention trial to support HCT caregivers).

**Methods:** Semi-structured, dyadic (patient and caregiver) interviews took place around hospital discharge, day +30, +60, +90 and +120 post-HCT. Patient and caregiver discussions at each interview centered around a variety of topics including desired post-HCT information, coping, and additional resources for patients and their caregivers with the goal of gathering feedback to better inform future studies after Roadmap 2.0. Interviews were transcribed and double coded with inductive and deductive content analysis utilizing the Framework Method to identify key findings.

**Results:** Multiple findings emerged out of these rich discussions including the progression from immediately post-discharge to when HCT patients and their caregivers were further out from HCT. The progression was as follows: “Desire for data and tracking” to “Need for specific restrictions and outline on forward progress,” to “Need for additional directed information as progressing forward,” to “Bigger picture and getting back to life,” and concluding with “Reflection and fear.” Most patients and caregivers felt they were provided sufficient general anticipatory guidance throughout the HCT process but called for more specific expectations and guidance on a variety of issues. Many patients and caregivers employed multiple coping strategies during HCT with their coping strategies largely staying consistent over time. The most common coping strategy used by patients and caregivers was “Coping through social networks.” Additionally, the need for further acknowledgement and focus on the stress HCT places on caregivers was frequently discussed. Feedback on the Roadmap 2.0 app and app design for this population were also gathered.

**Conclusions:** Patients undergoing HCT and their caregivers were largely satisfied with the information and anticipatory guidance they were given but stressed a desire for more specific information throughout their HCT course. A variety of coping strategies are utilized by patients and their caregivers post-HCT and these were consistently utilized over time. However, increased awareness and acknowledgement of the strain HCT places on caregivers is needed within the healthcare setting and in

the general population. Future directions include continued incorporation of qualitative interviews with patients and caregivers as HCT-related interventions and apps are designed, beta tested and used in larger studies. Clinical Trial: Health Information Technology System (“Roadmap 2.0”) in the Context of Hematopoietic Cell Transplantation (ClinicalTrials.gov NCT04094844, https://clinicaltrials.gov/study/NCT04094844).

(JMIR Preprints 02/09/2025:81971)
DOI: https://doi.org/10.2196/preprints.81971

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# Original Manuscript

Amanda K. Johnson, MD, MPH
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September 1, 2025

Dear Dr. Amy Price and Editorial Board,

We wish to submit an original research article entitled "'Tough things you're going to have to go through': A dyadic interview study of patients and their caregivers post-hematopoietic cell transplant (HCT)" for consideration for publication in the *Journal of Participatory Medicine* as an original paper. We confirm this work is original and has not been published elsewhere, nor is it currently under consideration for publication elsewhere.
In this paper, we describe findings from patient and caregiver dyadic interviews in the post-hematopoietic cell transplant (HCT) period. This qualitative study was part of a larger study, Roadmap 2.0 (https://clinicaltrials.gov/study/NCT04094844), whose results have recently been published (doi: 10.1186/s44247-025-00165-5). In this study, we show that patients and their caregivers have dynamic needs throughout the post-HCT course, but their coping strategies are consistent during the post-HCT period, with *"Coping through Social Networks"* being the most common strategy to make it through the stress and challenges post-HCT. The results of this study are significant in that the study scope and methodology are novel compared to available literature on this topic as our group interviewed dyads over several time points in the post-HCT period. These results are also significant for shaping future studies involving patients and their caregivers, whether designing HCT-related apps or generally supporting patients and their caregivers more fully throughout the HCT course.

We believe that this manuscript is appropriate for publication by *Journal of Participatory Medicine* as our study helps promote participatory design in research and healthcare, developing technology for patient and caregiver self-care, as well as improving patient and caregiver experiences.

We have no conflicts of interest to disclose. Thank you for your consideration of this manuscript. We acknowledge the payment required should our manuscript be accepted. Should your team find our article more appropriate for a sister journal, we are open to potential automatic transfer.

Sincerely,
Amanda K. Johnson, MD, MPH

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# "Tough things you're going to have to go through": A dyadic interview study of patients and their caregivers post-hematopoietic cell transplant (HCT)

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*Abstract*
*Background:* Patients undergoing hematopoietic cell transplant (HCT) and their caregivers are under

a significant amount of stress throughout the HCT process with fear of disease recurrence, graft failure, and many other HCT-related complications. However, the experiences and perspectives of HCT patients and their caregivers as dyadic units have not been well-published to date.
*Objective:* To better understand patient and caregiver perspectives throughout the HCT course, patients undergoing HCT and their caregivers were able to opt-in to interviews at multiple time points post-HCT as part of a larger study, Roadmap 2.0 (an app intervention trial to support HCT caregivers).
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*Conclusions:* Patients undergoing HCT and their caregivers were largely satisfied with the information and anticipatory guidance they were given but stressed a desire for more specific information throughout their HCT course. A variety of coping strategies are utilized by patients and their caregivers post-HCT and these were consistently utilized over time. However, increased awareness and acknowledgement of the strain HCT places on caregivers is needed within the healthcare setting and in the general population. Future directions include continued incorporation of qualitative interviews with patients and caregivers as HCT-related interventions and apps are designed, beta tested and used in larger studies.
*Trial Registration:* Health Information Technology System ("Roadmap 2.0") in the Context of Hematopoietic Cell Transplantation (ClinicalTrials.gov NCT04094844, https://clinicaltrials.gov/study/NCT04094844).
*Keywords: Hematopoietic cell transplant (HCT); Bone marrow transplant (BMT); Application (App); Mobile health; mHealth; Caregivers*

*Introduction*
Hematopoietic cell transplant (HCT) is utilized to treat both malignant and non-malignant conditions, utilizing cells from self (autologous) for treatment of solid tumors and some lymphomas or donor (allogeneic) for hematologic malignancies and a wide range of other conditions (1). In both cases, high-dose chemotherapy is used, putting patients at high risk for infections and other complications (2,3). While HCT and supportive care for HCT complications have greatly improved over the recent decades, there remains a relatively high risk of morbidity and mortality related to HCT (2-5). Whether receiving an autologous or allogeneic HCT, a full-time caregiver is typically needed for an extended period (up to multiple months or even longer). Only recently has more public acknowledgement and research been published, acknowledging and focusing on the stress experienced by caregivers of patients undergoing HCT, with caregivers reporting psychosocial

distress and diminished quality of life (1,6-8).

Over recent years, a variety of studies have aimed to help providers and researchers better understand the challenges of individuals undergoing HCT and their caregivers as well as determine how best to reach and support them (9-13). The app, BMT Roadmap, was created by Choi et al. at the University of Michigan over a decade ago with the goal to provide information and support for caregivers of HCT patients (9). BMT Roadmap has been developed iteratively, incorporating feedback from rigorous user testing, to create its most recent version, Roadmap 2.0. Roadmap 2.0 incorporates positive, resilience-building activities and was designed for the outpatient setting (10). In 2020, a mobile randomized controlled trial of Roadmap 2.0 was started (NCT04094844; 14).

In the Roadmap 2.0 study, the randomization was at the caregiver level, with an intervention arm of caregivers receiving a menu of positive activities, access to caregiver forums within the app, and a variety of informational guides for caregivers (Figure 1). Caregivers in the control arm received no positive activities, caregiver forums, or informational guides. Caregivers in both arms received a Fitbit© that tracked steps and sleep and displayed these results in graphical form in the Roadmap 2.0 app (Figure 1). Caregivers in both arms were asked to record their mood score (scale 0 to 10) in the Roadmap 2.0 app, which was also displayed in graphical form (Figure 1). The study's primary endpoint was caregiver quality of life at Day +120 as measured by the PROMIS© Global Health Scale, hypothesizing that caregivers in the intervention arm will have better quality of life when compared to caregivers in the control arm (14). After 2020, the Roadmap 2.0 study was expanded to include other centers outside of the University of Michigan, extending to Oregon Health & Science University in 2021. The manuscript of the outcomes of the Roadmap 2.0 was recently published (15).

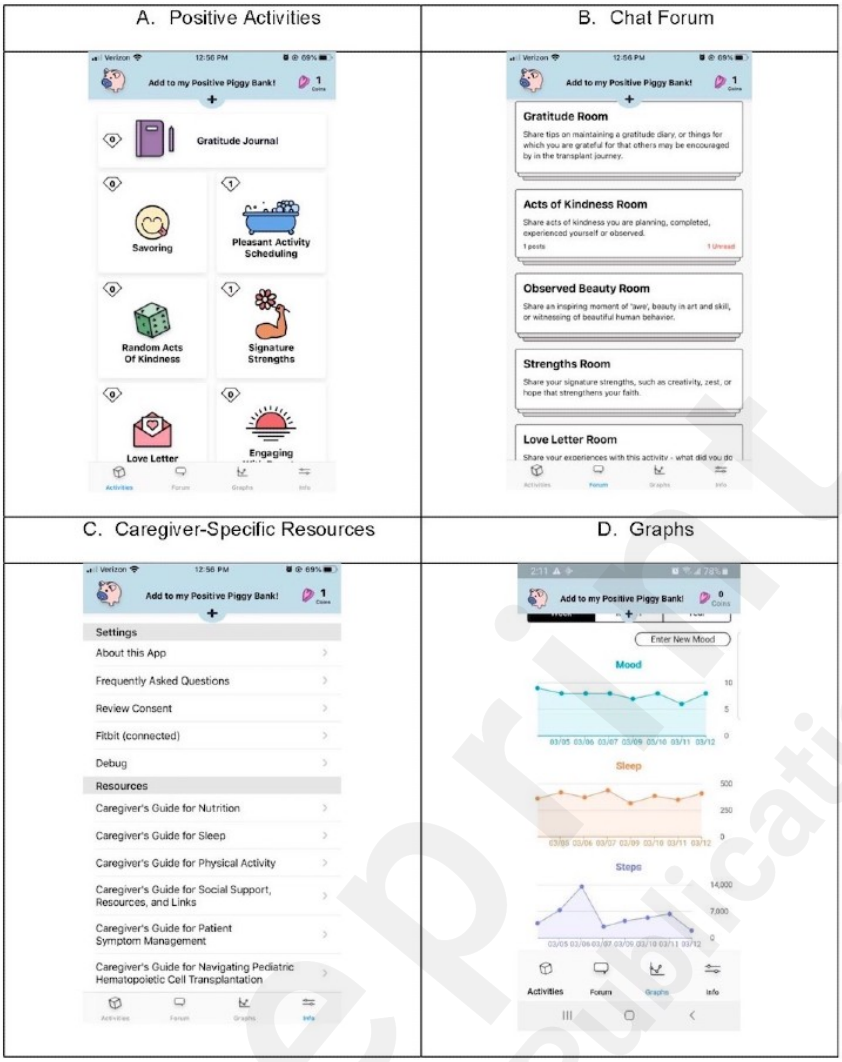


Figure 1. Screenshots from Roadmap caregiver user interface. ©Rozwadowski M, Dittakavi M, Mazzoli A, et al. Originally published in JMIR Research Protocols (https://www.researchprotocols.org/2020/9/e19288/), 18.09.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/).

As an opt-in addition to the Roadmap 2.0 study, patients and their caregivers were offered semi-structured, dyadic interviews at a variety of time points throughout the study (around hospital discharge, day +30, +60, +90 and +120 post-HCT). The inclusion of this optional portion of the study was to investigate the hypothesis that the support needed for patients and caregivers during the HCT process is both unique to each person and dyad as well as dynamic across the HCT course, which is commonly observed by clinicians throughout the post-HCT course. Additionally, we hoped to gain a better understanding of the support needed by patients and caregivers to further optimize future versions of BMT Roadmap and other mobile health and technology interventions for patients undergoing HCT and their caregivers. Herein, we summarize our findings of the semi-structured dyadic interviews as part of the Roadmap 2.0 study. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used as part of manuscript preparation (Supplementary File 1).

*Methods*

Institutional review board (IRB) approval was granted at Oregon Health & Science University and oversight approval granted at the University of Michigan, which served as the central or single IRB,

prior to conduction of optional interviews. Inclusion criteria for the opt-in interviews were the same as Roadmap 2.0 study inclusion criteria, which included patient age of at least 7 years, caregiver age of at least 18 years, patient and caregiver access to an iPad or cell phone, and patient and caregiver ability to read and understand English.

During the consent/assent for Roadmap 2.0, patients and their caregivers were also offered participation in the opt-in interviews. As patients approached discharge, days +30, +60, +90 and +120 post-HCT, patients and/or their caregivers were contacted in person, via email and/or via telephone to arrange semi-structured dyadic interviews. Only dyadic interviews were conducted at each of these times with the hope that having both the patient and their caregiver discussing topics together would provide more insight and feedback compared to an individual (patient or caregiver) interview alone. Post-discharge interviews took place within seven days of discharge. Day +30, +60 and +90 interviews took place up to two weeks prior to or as late as two weeks following these timepoints. The day +120 interview took place up to one month prior to or as late as one month following this time point.

Interviews took place in person or via telephone aside from one interview where the caregiver was present on video call. Adult caregiver and patient interviews were conducted by AKJ (Pediatric Hematology/Oncology Fellow trained in qualitative methods) and two other research staff (trained in qualitative methods) conducted interviews for the pediatric patient and their caregiver (due to AKJ's potential to provide direct care to the patient). All interviewers were female and field notes were taken during the interview for reference following the interview. Interviews were audio recorded. Interview questions spanned a variety of topics including perspectives on important and missing information during the HCT process, coping, future intervention/app design ideas, and Roadmap 2.0 Feedback (Figure 2).

**General semi-structured interview questions (both caregiver and patient participants)**

1) In your opinion, what information is most important for you to have post-transplant?

2) Would an app with this information be beneficial to you?

3) If you could design an app or additional intervention post-transplant, what would it involve?

4) Do you think this additional app or intervention would be helpful, burdensome, or neutral?

5) What information do you feel was missing during your stay? For days +30, +60, +90, and +120: What do you wish you had been told between discharge and now?

6) Do you have an interest in tracking some of your symptoms post-transplant? Which ones would you want to track?

7) Are you interested in tracking your sleep, heart rate, temperature, etc. post-transplant?

8) What has helped you cope post-transplant?

**BMT Roadmap 2.0-directed questions (both caregiver and patient participants)**

1) What do you think of BMT Roadmap 2.0, wearable sensor, and positive activities (if applicable)?

- What do you find most helpful?
- What do you find least helpful?

2) Would you change anything about any of the above (add, change, take away)?

Figure 2. Interview Script.

Babbletype transcription (Babbletype Inc., Philadelphia, PA) was utilized to transcribe all interviews verbatim. Following transcription, interviews were double coded by two team members (ES, CR) using NVivo 12.0. Coding by content analysis was both inductive and deductive, utilizing the Framework Method (16). A codebook utilized in prior BMT Roadmap studies was initially modified to better reflect this study's interview script (15,17; Supplementary File 2). The Framework Method was utilized to give the research team the ability to analyze the data across the whole data set in addition to grouping by interview time point as well as grouping by dyad (16).

At multiple points during the coding process, team members (ES, CR) completing coding met with AKJ to discuss discrepancies, consensus was reached when discrepancies occurred, and the codebook was modified as needed. When approximately half of the interviews were completed, a preliminary analysis across all interviews was conducted. Following completion of all interviews, a subsequent analysis was conducted across all interviews, at each time point, and within each dyad over time.

*Results*

Interviews took place from November 2021 to July 2022. A total of 20 dyads were offered opt-in

interviews. Eight dyads declined and one dyad was lost to follow-up, leaving eleven patient-caregiver dyads who initially opted-in for the interview portion of the study. One caregiver withdrew from the study prior to the start of the interviews and the patient died prior to first hospital discharge, resulting in ten remaining dyads. Of the ten dyads, nine were adult patient-caregiver dyads and one was a pediatric patient-caregiver dyad. Seven dyads were patients and their caregivers from Oregon Health and Science University and three dyads were from University of Michigan. Seven of the caregivers were part of the positive activities intervention arm. Additional demographics of patients and their caregivers are listed in Table 1.

| | **Patients** | **Caregivers** | **Combined** |
|---|---|---|---|
| **Median age** | 54.5 | 58 | 56 |
| **Gender** | | | |
| Female | 2 | 9 | 11 |
| Male | 7 | 1 | 8 |
| Unknown | 1 | 0 | 1 |
| **Race** | | | |
| White | 9 | 9 | 18 |
| Unknown | 1 | 1 | 2 |
| **Ethnicity** | | | |
| Non-Hispanic | 9 | 10 | 19 |
| Hispanic | 1 | 0 | 1 |
| **Disease** | | | |
| Leukemia | 2 | N/A | 2 |
| Lymphoma | 1 | N/A | 1 |
| Multiple Myeloma | 4 | N/A | 4 |
| MDS | 2 | N/A | 2 |
| Aplastic anemia | 1 | N/A | 1 |
| **Caregiver Relationship** | | | |
| Mother/Parent | N/A | 3 | 3 |
| Spouse | N/A | 5 | 5 |
| Sibling | N/A | 1 | 1 |
| Daughter-in-law | N/A | 1 | 1 |

Abbreviations: MDS=myelodysplastic syndrome; N/A=not applicable
Table 1. Patient and caregiver demographics.

Interviews lasted approximately 15 minutes to 45 minutes. A total of 48 interviews were completed (one patient died prior to completion of all interviews). Two interviews were unable to be transcribed due to technological reasons, resulting in 46 interviews that were double coded and analyzed. While the interview script was consistent throughout the study, overall findings emerged at earlier and later timepoints looking across all dyadic interviews as they progressed through the post-HCT course. Over time, dyads moved from *"Desire for data and tracking"* and *"Need for specific restrictions and outline on forward progress"* to *"Need for additional directed information as progressing forward"* to *"Bigger picture and getting back to life"* to *"Reflection and fear."* Additionally, the

importance of coping strategies was highlighted with *"Coping through social networks"* being very common among both patients and caregivers.

*"Desire for data and tracking"*
Earlier in the post-HCT course, patients and their caregivers discussed tracking vital signs and movement via the wearable, recording signs and symptoms, and wanting more data (vitals and labs from clinic visits) more often when compared to later time points. Some caregivers also mentioned finding comfort in knowing and tracking data to assess how the patient was doing.

*"Yes, just tracking the recovery and like she [caregiver] said, everything is on track and we're headed in the right direction. That's the big thing, is just keeping track of how everything is and how well I'm doing and how she's doing herself." (Patient, Day +30)*

*"For me, I'm mostly looking at the vitals." (Patient, Day +30)*

*"…like between his last appointment the other day and today's, one of the numbers went down just a little bit, that would be a great thing to know, because we have three or four days between…" (Caregiver, Post-discharge)*

*"Need for specific restrictions and outline on forward progress"*
While the majority of patients and caregivers did not feel information was missing in their anticipatory guidance, most patients and caregivers wanted to know specifics on what the patient could or could not do based on their recovering immune system. Additionally, most patients and caregivers called for an explanation from their providers earlier in the post-HCT course of how to move forward and heal rather than the general recommendations they were provided.

*"It would be helpful to know what to do going forward, and for how long. Restrictions and what I have to do to keep safe and things like that." (Patient, Post-discharge)*

*"It's hard because you're in no man's land because you've never experienced this before. You just are trying to go through that puzzle, figure it all out. Even from now, where is he going to be like in six months from now? What are we looking for long-term? It's just a thousand things go through your mind that you want to have answers to but nobody really has answers to." (Caregiver, Post-discharge)*

*"…when we asked certain questions of the nurses and that sort of stuff, we got a lot of generalities. It's understandable generalities. Every patient is different. Part of my recovery in the hospital, some of the caretakers there, 'Wow, you're doing far better than most do.' What could I lag at? Again, something informational…It depends upon the patient, everybody is different, but I'd like a little more information than just that." (Patient, Day +30)*

*"Need for additional directed information as progressing forward"*
As patients and caregivers progressed through the first weeks and month after discharge, they continued to express a desire for information specific to restrictions and limitations as the patients continued to improve.

*"…It's just a lot easier now than it was when we first got released, I'll say that. It's a little overwhelming when you first get discharged. At this point we're home now, and it's almost back to normal, besides knowing what he can and can't eat and the meds he's got to take every day, which is even less than when we got discharged." (Caregiver, Day +60)*

*"What can or can't be done? I still feel like I have a lot of questions about that. What's appropriate for me to do and not appropriate?" (Patient, Day +60)*

*"I'd want to know what you are shooting for in regards to numbers because I didn't know that those low, low numbers that weren't even in the normal range got me concerned because of how low – Is something wrong? I'd like to know that that's okay to be in lower numbers. I guess I just need to have a comfort feeling that – I don't know how you would do this, but I need to have comfort that everything is okay, this is what you're looking at, this is what you can do, this is how you progress. I guess an explanation of what to expect…" (Caregiver, Day +60)*

*"Bigger picture and getting back to life"*
While patients and caregivers discussed the desire for a longer-term plan and outlook earlier in the post-HCT course, a strong need for this information came through during the interviews at later points post-HCT. Additionally, patients and caregivers both mentioned the challenges of transitioning out of the immediate post-HCT stage.

*"…you get to this point and you're starting to think, 'I'm going to go back to the real world. Can I handle that, or is it really this good? Are things going to be okay?' It's just a lot of different feelings that come out that you haven't really even had to deal with before." (Patient, Day +60)*

*"It's hard to transition them to live. You've got to light a fire under them." (Caregiver, Day +90)*

*"…that's what I'm looking at. It's, 'Here's how to resume your life'…(Patient, Day +90)*

*"Reflection and fear"*
Following contemplation of the *"Bigger picture and getting back to life,"* patients and caregivers continued to reflect on what they had just been through with the weight of their underlying diagnosis and fear of rejection, relapse, or other complications despite how far they had come post-HCT.

*"I think about the future now…I want to be able to know what to look for if it is coming back." (Caregiver, Day +120)*

*"…It's probably been more of the emotional part of it, for me. I don't know what [he] is experiencing…it's been a lot of crisis to crisis to crisis. Now it's like, 'Oh! There's no crisis.' I think dealing with that has been more of a challenge for me. I didn't know it would be quite that hard…I think that surprised me." (Caregiver, Day +120)*

*"…The recovery can occur to me in many different ways…In my case, I have persistent MDS* [myelodysplastic syndrome] *and it seemed to be done in the hospital, but now after the biopsy, it's still there. It's not a relapse, it's not a remission, it's not a recurrence.…It would have been much more helpful had we been aware of the possibilities of what we could be facing." (Patient, Day +120)*

*"I think the biggest thing since day 100 when we left is just not really knowing…what the status of him is. That's just coming down off of the last three months, I'm sure." (Caregiver, Day +120)*

Another key finding, relevant across time periods, was that many patients and caregivers described

social networks as critical to their coping (*"Coping through social networks")*. Many caregivers also commented on the stress of caregiving for a patient undergoing HCT places on them.

*"Coping through social networks"*
While there was significant variety in coping strategies utilized by patients and their caregivers throughout the HCT course, most patients and caregivers had some social network component to their coping. Additionally, most patients and the caregivers utilized the same or similar coping strategies throughout the study period. One patient, when asked about how he coped post-HCT, answered *"my wife,"* at nearly every interview. Nearly all patients and caregivers mentioned coping through interactions with caregivers, family, friends, or other groups of people who supported them post-HCT.

*"At the darkest time, I called my sister when he was in the hospital. It was so bad and I don't think I was prepared for how bad it was going to be. I just called her and poured my heart out into her. She really helped me." (Caregiver, Day +30)*

*"…I tell you, where I work, I have a lot of ladies there, golfers, and they've been really awesome… I've been blessed." (Caregiver, Day +120)*

Both a pediatric and young adult patient mentioned the importance of communicating with their friends via social media and/or gaming platforms throughout their post-HCT course, providing them with a sense of belonging during a time of isolation.

*"Talking to people and playing video games…" (Patient, Day +30)*

*"For me, I think it's really just been hanging out with my friends online. I actually just checked right now, checked Discord to see if anyone was on. Not yet, it's early in the day and they're probably still at work or at school, but just hopping in. There's a group server that we have, so there's just a general chat that people will sit in while they play games or do whatever on their computer. You just pop in…Just sit there and talk about whatever." (Patient, Day +90)*

*HCT Caregiver Challenges*
In addition to the above findings, which were common across caregivers and patients, caregivers reiterated the challenges and stress they face when caring for a patient going through HCT. While healthcare systems and society at large are continuing to work on supporting caregivers, the caregivers in this study provided a call to continue to improve their support, particularly as they face a variety of new stressors during HCT.

*"It's just hard to think sometimes as a caregiver. I just really have been a lot more aware of how it takes – Even to go exercise or do things for yourself at all, when your person that you're taking care of isn't at their best or you're really concerned, it's just you lose part of your brain too. Energy, willpower, and stuff. That's been really an eye-opener for me, even though I've been a mom for years." (Caregiver, Day +90)*

*"I would like something specifically, a program for the caregiver. I get nothing. They don't even ask me how I'm doing when we go to these appointments. That's disappointing." (Caregiver, Day +60)*

*"…there's a higher level of understanding and resources and outrage and support for a patient than there are for the caregiver. Their* [care]*givers are expected to be everything…there are not a whole lot of resources on that. Then there's, I think, an assumption from friends, family, and peers. 'If*

*you're a spouse, that's your job.' I don't think there's an understanding of how it changes* [going through HCT]*." (Caregiver, Day +90)*

*Roadmap 2.0 and General App Feedback*

During the interviews, we also asked for structured feedback from both patients and caregivers on Roadmap 2.0 and apps in general. Prior studies by our group and a portion of the larger Roadmap 2.0 study focus on feedback related to the intervention specifically as a way to continuously improving technology interventions going forward.

Outside of some technical issues, patients and caregivers were overall satisfied with the study and the Roadmap 2.0 app.

*"I liked the Gratitude Journal, reminding me to stay positive and grateful for the good things. The Engaging with Beauty, I always think that's important too, just find the beauty in everything even if you're at the hospital…Pleasant Activity Scheduling I like, and the Savoring. It's just all reminders just to do things that are pleasant or positive." (Caregiver, Day +30)*

*"I actually like the whole thing. Just to be able to go in, just be able to jot down something in different areas that I was thinking about. I like the Fitbit, it makes sure I'm moving. Overall, I'm pretty satisfied with the whole program-type thing." (Caregiver, Day +60)*

Some patients and caregivers, however, mentioned that they prefer other apps and wearable devices (e.g., newer version of Fitbit with additional features). Additionally, some patients and caregivers had coping and intervention strategies for stress that they preferred to use instead of Roadmap 2.0 (e.g., reading their Bible, journaling).

*"I tried wearing the Fitbit so that it's pulling in the data but I'm not really an app person. I'm not playing with those Roadmaps or Fitbits or whatever." (Patient, Day +60)*

In addition to specific feedback on Roadmap 2.0, patients and caregivers were asked about app design for the post-HCT setting more generally. The majority of responses centered around an "all-in-one"-type of app, where they could access their appointments, test results, and have additional resources (informational related to medications, HCT complications, or coping strategies). Many patients and caregivers suggested a more interactive user interface (particularly on the patient-facing app) with exercise plans, activity and mental health suggestions based on wearable or other input data (e.g., heart rate, sleep, mood), as well as sharing information between the patient and caregiver.

*Discussion*

*Principle Findings*

In this study, patients actively undergoing HCT and their caregivers engaged in semi-structured interviews on their perspectives related to important and missing HCT information, app/intervention design, coping, and specific feedback on Roadmap 2.0 as an opt-in portion to the larger Roadmap 2.0 study. These interviews, as highlighted in the quotes above, led to multiple rich comments and ideas for improving their care broadly as well as specifically, with hope to apply these findings to future interventions and apps for patient-caregiver dyads, including future versions of the BMT Roadmap app.

As patients and their caregivers transition from the hospital to the outpatient environment, where vital signs and labs are checked much less frequently, participants' *"Desire for data and tracking"* resonating in earlier time points post-HCT is not surprising. Similarly, participants' *"Need for*

*specific restrictions and outline on forward progress"* is also fitting for earlier in the post-HCT course when one of the primary goals is to discharge from the hospital and it is impossible to give directed guidance on every potential exposure situation the patient and their caregiver is going to face outside of the hospital. Additionally, about 12% of adult autologous transplant patients and 24% of adult allogeneic transplant patients experience unplanned re-admission to the hospital within 30 days of discharge for a variety of complications that span from minor, short hospital stays to life-threatening illnesses, making outlines of the future difficult to outline early in the post-HCT course (18).

As patients and caregivers spend more time outside of the hospital after discharge, additional anticipatory guidance is certainly needed in keeping with participants' *"Need for additional directed information as progressing forward."* During the second and third months after HCT, patients are likely beginning to regain strength and overall feel better, making it more difficult to remember that their immune system is still immature, and they are at continued high risk for infections.

Between three and four months after HCT, patients and their caregivers are typically allowed to return home if they needed temporary local housing due to their home being outside of the immediate area of the HCT center and their appointments are spaced out further. Just prior to and around this time, patients and their caregivers begin wondering what returning home and the follow-up plan will look like and thus a desire for the *"Bigger picture and getting back to life,"* which is commonly observed clinically and confirmed in this study. Additionally, similar to the anxiety experienced around the time of discharge, *"Reflection and fear"* occur just prior to and just after day +100 and was discussed by multiple patients and caregivers during the day +120 interview.

Lastly, the stress HCT places on patients and their caregivers is significant and coping through a variety of mechanisms unique to each patient and their caregivers was observed. It is not surprising that similar coping strategies were utilized throughout the HCT process given many patients and caregivers experience a prior diagnosis (malignant or non-malignant) that later leads to recommendation for HCT. Thus, their coping skills are tested prior to proceeding to HCT. Despite having previously tested coping strategies, many caregivers drew attention to the challenges of caregiving for a patient undergoing HCT (1). Additional quantitative, qualitative, and mixed methods studies are needed as we gain further insight into these stressors and attempt to implement strategies to improve the HCT caregiver burden.

*Strengths and Limitations*

This study has multiple strengths including a geographically diverse sample and the use of repeated interviews over time, which allowed for building trust and a deep understanding of interviewees' experiences. Multiple dyadic interviews were conducted at a variety of time points, allowing for triangulation and increased trustworthiness of the data to enhance both the validity and reliability of our data. Additionally, having the majority of interviews conducted by AKJ allowed for increased consistency between interviews. Coding of the data by more than one researcher outside of the interviewers brought additional perspectives and provided reflexivity which guarded against bias in the interpretation. In terms of limitations, these interviews were optional and thus are more likely to involve individuals with more polarized views (either very positive or very negative). As the interview script consisted of semi-structured questions, responses may certainly be more limited in comparison to fully open-ended questions. While overall the dyadic interview method is felt to be a strength in terms of allowing the patient and caregiver to engage in a richer discussion together, it is possible that either the patient or the caregiver was not fully comfortable sharing some responses in front of the other during these interviews.

*Conclusions*
The field of mobile health and technology continues to expand, and apps are rapidly being developed. Health apps make up a smaller niche and are increasingly being used. Integration of these apps with the electronic health record is beginning to be done as well (19,20). With this in mind, engaging end users (e.g., patients, caregivers, providers) in the design process of these apps is extremely important for usability as well as improving these interventions. This study shows the strengths of mixed methods design for intervention design and improvement, highlighting where HCT patients and their caregivers need further information, guidance, and support during the HCT process. Results of the larger Roadmap 2.0 study have recently been published, focused primarily on quantitative findings (15). Based on our prior work and results of this study, we plan to continue to incorporate qualitative interviews in future Roadmap studies to further understand the patient and caregiver experience as well as determine additional patient and caregiver needs and resources post-HCT.

*Acknowledgements*
The authors would like to thank the research staff as well as the patients and their caregivers who made this study possible. The authors would also like to thank Anaïs Tuepker, PhD, MPH, and Cinzia Caparso, PhD, RN, for their thoughtful reviews of manuscript drafts.

*Funding*
Portions of this study were funded under the grant for the larger Roadmap 2.0 study (R01HL146354). This grant will not support funding of the article processing fee. The article processing fee will be provided by annual scholarly funds.

*Conflicts of Interest*
None declared.

*Data Availability*
Complete qualitative data (de-identified transcripts) will be made available upon request. Requests for data should be sent to the corresponding author.

*Authors' Contributions*
Johnson AK: Conceptualization, Methodology, Investigation, Formal analysis, Writing-original draft, Writing-review & editing
Smeallie E: Investigation, Validation, Writing-review & editing
Roslin C: Investigation, Validation, Writing-review & editing
Rozwadowski M: Project administration, Resources, Writing-review & editing
Shereck E: Conceptualization, Methodology, Supervision, Writing-review & editing
Choi SW: Conceptualization, Methodology, Funding acquisition, Supervision, Writing-review & editing

*Abbreviations*
HCT = hematopoietic cell transplant

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# Supplementary Files

# Multimedia Appendixes

Codebook.
URL: http://asset.jmir.pub/assets/714251d83ebc85b85f9a01ebc7d3ac81.docx

# CONSORT (or other) checklists

COREQ Checklist.
URL: http://asset.jmir.pub/assets/0b5a1527a1273e42c400b96962d8b31d.pdf