

ARTICLE



Peer support in patients with hematologic malignancies undergoing hematopoietic stem cell transplantation (HSCT): a qualitative study

Hermioni L. Amonoo^{1,2,3}✉, Lauren E. Harnedy⁴, Emma C. Deary², Lara Traeger^{3,4,5}, Lydia A. Brown^{6,7}, Elizabeth P. Daskalakis², Corey Cutler^{3,8}, Amar H. Kelkar^{3,8}, Rachael Rosales^{2,3}, Lauren Goldschen^{2,3}, William F. Pirl^{1,3}, Emily H. Feig^{3,4}, Anna Revette⁹, Stephanie J. Lee¹⁰, Jeff C. Huffman^{3,4} and Areej El-Jawahri^{3,5}

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Peer support, a distinctive form of social support in which patients share emotional, social, and practical help based on their own lived experience of illness and treatment, positively impacts patient-reported outcomes in cancer populations. However, data on peer support experiences among hematopoietic stem cell transplant (HSCT) recipients are limited. We conducted semi-structured qualitative interviews among 12 allogeneic HSCT recipients who were ≤6 months post transplant without any complications and 13 allogeneic HSCT recipients >6 months post transplant and living with chronic graft-versus-host disease. Interviews explored patients' experiences with peer support and their preferences for a peer support intervention tailored to the needs of HSCT recipients. While the majority (70%) of participants reported no formal experience with peer support, most (83%) articulated themes of potential benefits of peer support (e.g., managing expectations and uncertainty that accompany HSCT). Most participants (60%) reported a preference for a peer support intervention prior to the HSCT hospitalization. Despite the limited data on peer support interventions among HSCT recipients and lack of formal peer support experience in most of our cohort, our study shows that HSCT recipients clearly acknowledge the potential benefits of a peer support intervention, and they prefer that it start prior to transplantation.

Bone Marrow Transplantation (2022) 57:1277–1286; <https://doi.org/10.1038/s41409-022-01711-9>

INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) holds promise for curing many malignant and non-malignant hematologic diseases [1, 2]. However, the transplantation process is arduous and accompanied by extended hospitalizations, exhaustive follow-up care (e.g., frequent clinic visits), and potential therapy-related complications (e.g., sepsis) [3, 4]. For allogeneic HSCT recipients, several long-term comorbidities (e.g., chronic graft-versus-host disease (GVHD)) and a high risk of mortality are also prevalent [5, 6]. Consequently, HSCT recipients frequently report psychological distress (e.g., anxiety, adjustment reactions) [7], and quality of life (QOL) or functional concerns throughout their illness and recovery course [8–10]. Despite numerous ongoing efforts to establish supportive oncology resources to enhance psychological and functional wellbeing among HSCT recipients, data on the role of peer support and its associations with wellbeing and clinical outcomes in this population are limited.

Social support, the complex phenomenon characterized by relationships among individuals and/or the sense of belonging to

different social networks for emotional and material help, has been linked with various forms of morbidity and mortality [11–15]. Peer support is a form of social support that entails cancer survivors sharing emotional, informational, and practical help based on lived experience of their illness, treatment, and recovery [15, 16]. Peer support, either one-on-one or in groups, has been impactful at all stages of cancer care [17]. In light of ongoing unmet supportive care needs in patients with cancer secondary to limited access to supportive care services [18], peer support could diminish the impact of stressors that accompany the cancer care cycle [19, 20]. While peer support programs have gained increased prominence in patients with solid tumors—especially those with breast and prostate cancer [16, 21, 22]—they remain an underdeveloped and understudied resource for patients with hematologic malignancies or HSCT recipients despite reported benefits of social support (i.e., including support from caregivers) in these populations [23–25].

Considering their unique treatment and recovery trajectories, HSCT recipients can offer experiential empathy, reframe the threat

¹Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, MA, USA. ²Department of Psychiatry, Brigham and Women's Hospital, Boston, MA, USA. ³Harvard Medical School, Boston, MA, USA. ⁴Department of Psychiatry, Massachusetts General Hospital, Boston, MA, USA. ⁵Mass General Cancer Center, Massachusetts General Hospital, Boston, MA, USA. ⁶Academic Research Collaborative in Health, La Trobe University, Melbourne, VIC, Australia. ⁷Melbourne School of Psychological Services, University of Melbourne, Melbourne, VIC, Australia. ⁸Division of Transplantation and Cellular Therapy, Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA, USA. ⁹Survey and Data Management Core, Dana-Farber Cancer Institute, Boston, MA, USA. ¹⁰Clinical Research Division, Fred Hutchinson Cancer Research Center and Division of Medical Oncology, University of Washington, Seattle, WA, USA. ✉email: hermioni_amonoo@dfci.harvard.edu

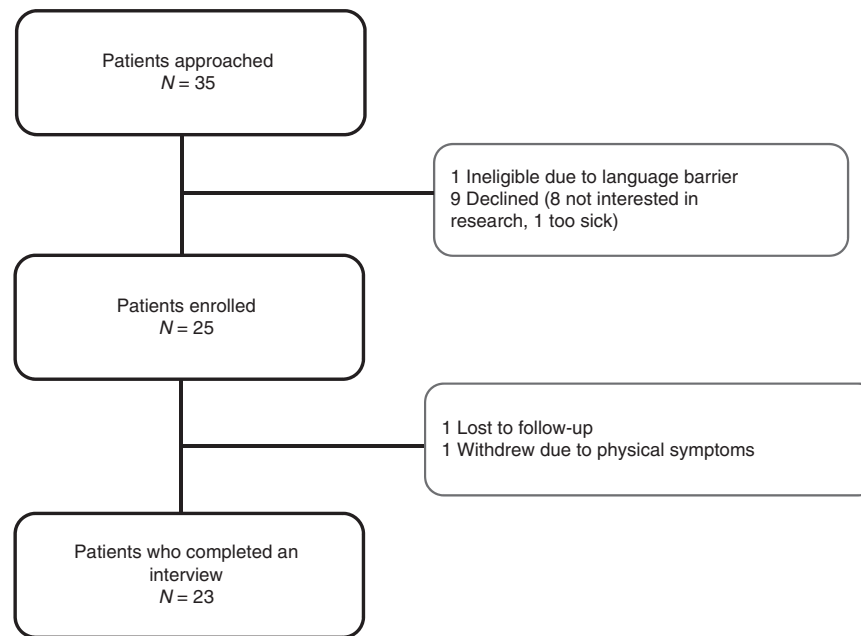


Fig. 1 **Consort diagram.** This figure is a CONSORT flow diagram showing participant flow through each stage of the qualitative study.

appraisal that could accompany HSCT, and provide suggestions for coping strategies beyond the scope of what HSCT clinicians can offer [26]. Hence, supportive oncology interventions that utilize peer support may be of substantial value for HSCT recipients. Qualitative studies that aim to explore HSCT recipients' experiences with peer support during transplantation and recovery are an essential first step in rigorous psychosocial intervention development [27]. Hence, we used semi-structured interviews to explore the experiences and preferences for peer support among patients with hematologic malignancies undergoing allogeneic HSCT.

METHODS

Study design

We used purposive sampling to identify allogeneic HSCT recipients who were either in acute recovery and ≤ 6 months post-HSCT or > 6 months post-HSCT living with chronic GVHD. We chose to sample transplant recipients early and late in their post-HSCT course to explore the potential value of peer support across the continuum of the HSCT process. We used semi-structured interviews to explore patient experiences with peer support during their recovery from HSCT. We followed the consolidated criteria for conducting and reporting qualitative research (COREQ) guidelines [28]. The study was approved by the Dana-Farber/Harvard Cancer Center institutional review board.

Participants

Participants were adults (age ≥ 18 years) with hematologic malignancies who had undergone HSCT at the Dana-Farber Cancer Institute (D.F.C.I.) between November 2019 and September 2020. Using the DFCI HSCT clinic database, we identified and approached potentially eligible patients via phone. Patients were eligible to participate if they could speak and respond in English and had access to a phone. We excluded patients with a major psychiatric or cognitive condition precluding their adherence to study procedures, as determined by their treating oncologist. All participants provided verbal consent prior to enrollment.

Sociodemographic data

All participants self-reported sociodemographic data at enrollment, including age, sex, race, ethnicity, education, and relationship status. We used the electronic health record to obtain clinical, disease, and treatment-specific information.

Qualitative interview development and data collection

Informed by a comprehensive literature review and in consultation with qualitative research experts, we developed a semi-structured interview guide which covered several domains, including: (1) patient overall experience and knowledge of peer support; (2) peer support resources used during HSCT and in recovery; (3) peer support intervention preferences (i.e., delivery, timing, duration, structure, length) and intended benefits; and (4) considerations and barriers to becoming a peer mentor. All participants completed phone-based interviews that lasted approximately 60 min. All interviews were completed by HLA, a psychiatrist and psycho-oncologist researcher with qualitative research expertise with no prior clinical relationships with participants. For data management and analysis, the interviews were audio-recorded, transcribed verbatim, and uploaded to the Dedoose 8.0.35 software (SocioCultural Research Consultants, L.L.C.: Los Angeles, CA).

Data analysis

We used directed content analysis for data analysis [29]. Widely used to examine the breadth and scope of patient experiences, directed content analysis derives themes from qualitative patient data and feedback from coders [30–32]. We used the Dedoose software for qualitative coding and data analysis. Two coders (HLA and LEH [clinical research coordinator]) read all the transcripts, developed, and revised the codebook using inductive and deductive methods. With codes informed by our interview guide and data, HLA and LEH coded interviews between April 2021 and July 2021 using complete sentences as the unit of coding. The coding framework, which followed the COREQ guidelines [33], was revised after reading five transcripts to validate the codes. The two coders met weekly to resolve discrepancies while reviewing the transcripts and discussing emerging themes. The two coders used transcript review, discussion, and consensus to resolve discrepancies, and meaning saturation was achieved after reviewing transcripts from 23 patients [34]. An evidence trail of all discussions was documented.

RESULTS

Participant characteristics

Of the 35 eligible patients, 25 (71%) enrolled, and ultimately 23 (66%) completed semi-structured interviews. Figure 1 provides further details about participant recruitment and enrollment. Of the 10 approached participants who did not enroll, one was ineligible due to language barriers, and nine declined for reasons including lack of interest in research studies.

Table 1. Participant characteristics.

Patient characteristics	Without GVHD (N = 12)	With GVHD (N = 13)	Total (N = 25)
Age, median (range)	58.5 (25–73)	61 (22–73)	63 (22–73)
Female sex, n (%)	7 (58.33%)	6 (46.15%)	13 (52.0%)
Race, n (%)			
White	10 (83.33%)	10 (76.92%)	20 (80%)
Black	1 (8.33%)	2 (15.38%)	3 (12%)
American Indian	0 (0%)	1 (7.69%)	1 (4%)
Asian	0 (0%)	0 (0%)	0 (0%)
Other	1 (8.33%)	0 (0%)	1 (4%)
Hispanic, n (%)	2 (16.67%)	0 (0%)	2 (8.0%)
Hematology malignancy type, n (%)			
AML	6 (50%)	3 (23.08%)	9 (36%)
ALL	2 (16.67%)	4 (30.77%)	6 (24%)
MDS	1 (8.33%)	3 (23.08%)	4 (16%)
NHL	1 (8.33%)	1 (7.69%)	2 (8%)
Other	2 (16.67%)	2 (15.38%)	4 (16%)
Relationship status, n (%)			
Married/relationship	8 (66.67%)	10 (76.92%)	18 (72%)
Divorced	1 (8.33%)	0 (0%)	1 (4%)
Single	2 (16.67%)	3 (23.08%)	5 (20%)
Widowed	1 (8.33%)	0 (0%)	1 (4%)
Religion, n (%)			
Catholic	6 (50%)	3 (23.08%)	9 (36%)
Non-Catholic Christian	3 (25%)	1 (7.69%)	4 (16%)
None	1 (8.33%)	2 (23.08%)	4 (16%)
Jewish	1 (8.33%)	2 (23.08%)	4 (16%)
Muslim	0 (0%)	2 (23.08%)	3 (12%)
Missing	1 (8.33%)	0 (0%)	1 (4%)
Education, n (%)			
High school graduate or GED	2 (16.67%)	1 (7.69%)	3 (12%)
Some college/associate's degree	3 (25%)	2 (15.38%)	5 (20%)
College graduate	4 (33.33%)	5 (38.46%)	9 (36%)
Graduate degree	3 (25%)	5 (38.46%)	8 (32%)
Income, n (%)			
<\$250,000	1 (8.33%)	1 (8.33%)	2 (8.33%)
\$25,000–\$49,999	4 (33.33%)	1 (8.33%)	5 (20.83%)
\$50,000–\$99,999	4 (33.33%)	2 (16.67%)	6 (25%)
\$100,000–\$150,000	2 (16.67%)	2 (16.67%)	4 (16.7%)
>\$150,000	1 (8.33%)	6 (50%)	7 (29.17%)

This table provides a detailed summary of participants' sociodemographic characteristics grouped by the presence or absence of graft versus host disease (GVHD).

Table 1 summarizes participants' characteristics. While 12 (52%) \leq 6 months post transplant without chronic GVHD, 13 (57%) were >6 months post transplant with a diagnosis of chronic GVHD. Participants were half female ($n = 13$; 52%), mostly White ($n = 20$; 80%) and married ($n = 18$; 72%), with a median (range) age of 63 (22–73) years. Acute myeloid leukemia ($n = 9$; 36%) was the most common diagnosis. Nine participants (39%) reported that both the pre-transplant phase and the period between discharge from the transplant hospitalization and the first 100 days post HSCT were the most challenging phases of their HSCT trajectory.

Peer support experiences

Participants were open to sharing various dimensions of their experiences with peer support, including the potential benefits of peer support. However, few (30%) participants reported prior experience with peer support during HSCT. Table 2 provides details of all themes and quotes.

Definition of peer support. All participants endorsed understanding of peer support and defined it as a connection with others who had undergone HSCT to share experiences of their treatment and recovery. While some participants referenced a

Table 2. Qualitative interview results: themes, description, and quotes.

Themes	Subthemes	Description	Quotes
Definition of peer support		Participants provided definitions that entailed a connection with others who had undergone HSCT to share experiences of their treatment and recovery.	<ul style="list-style-type: none"> • "It means people who are going through the same thing that I'm going through and how it's hit them and how they're dealing with different aspects of the cure... in this sense a peer would be somebody that's experiencing the same thing or has experienced the same thing." (ID 24) • "...Peer support is like some kind of group or community of people that you have access to them or contact information on a regular kind of schedule... just chat with and ask questions, too, about, 'Hey, has anyone ever had this experience? Or has anyone ever figured out the best way to do X, Y or Z?' That's what I think of when it comes to peer support." (ID 20)
Potential benefits of peer support	Emotional support	Participants reported peer support could help with the emotional distress that typically accompanied the HSCT and recovery.	<ul style="list-style-type: none"> • "So, for me, it would be someone who is available to talk to most times ... the emotional stress and how to cope with that." (ID 16) • "Having somebody else that's going through the same thing, like another transplant patient, so that you're able to commiserate, you're able to talk about the process and what's it's like for you emotionally..." (ID 4)
	Validation	Participants reported engaging with a peer about their triumphs and challenges with the HSCT would be valuable, especially because the transplant is something family and friends could not directly relate to because most have not undergone HSCT.	<ul style="list-style-type: none"> • "I knew significant life changes were coming. I just didn't really understand to what extent it could be. So, in retrospect, I do think peer support kind of on both ends, kind of education for friends and family, some kind of group for them, as well as something for the transplant patients, I think is beneficial..." (ID 23) • "You know that somebody went through what I went through and survived it and he's living a normal life or a semi-normal life. I think that would be really helpful. And to know what he did to alleviate the pain and fear of this phase... would be very helpful to see other success stories..." (ID 11)
	Expectations and uncertainty management	Participants reported that peer support could help them manage numerous uncertainties that accompany all aspects of HSCT.	<ul style="list-style-type: none"> • "The bottom line, what you must know about people that get this potentially fatal diagnosis is that it creates like an earthquake in their lives. And I know very few people that can handle this amount of anxiety and the unknown without having a lot of... anxiety. And because of that, they're going to need extra handholding, repeating the information. I don't know how many times." (ID 15) • "Everything's still going to be different for the rest of my life, so I'm sure being in contact with other patients, people that have gone through it, I'm sure would be helpful to know what to expect and I know everyone's different. But just to get a feel for it from other people." (ID 2)
	Social support	Participants emphasized the importance of connecting with individuals who have experiential knowledge of HSCT, even those who had a strong sense of support from their caregivers (i.e., family and friends).	<ul style="list-style-type: none"> • "It just is unbelievable. But then again, I've never been part of the cancer world. I've never been part of the transplant world, so everything was new. Nobody in my world has ever had these challenges. And so, for me, everything was new, and I needed and was gasping for support. And I don't believe that my doctors understand the level of support that's necessary for somebody who's just gotten this diagnosis. I don't think they were negligent by any stretch, but they

Table 2. continued

Themes	Subthemes	Description	Quotes
			were kind, and they were helpful, but I wouldn't call supportive in that." (ID 15) • "So ideally to me, it would mean, like I said before, someone who has been in your situation, who is roughly the same age and has come through the other side and who can provide you with support that is specific to your particular disease and your particular treatment. It doesn't obviously have to be exact, but it would be nice to be sort of in that area. I think that's something that I lacked." (ID 16)
	Informational Support	Participants reported the need to learn from other patients and get advice on various aspects of the recovery from HSCT which clinicians and their caregivers could not provide.	• "Well, yeah. I mean, it's really all the nonmedical questions that you can only ask your doctor and your medical team so much. They can't help you with everything. So, there's the personal aspect. There's the family life and the kids. So yeah, there's that aspect of life that you'd like some advice on, that you have questions on." (ID 17)
	Communication	Participants expressed the desire to talk with survivors about how to communicate their experiences with family especially children.	• "I think of it now, I have problems with my two-year-old...so I must think and rephrase how I'm saying the message I'm trying to convey in a way that she'll be able to take it without having a nervous breakdown or start crying or getting angry." (ID23)
	Caregiver support	Participants advocated that peer support should incorporate caregivers since there are limited avenues for caregivers to get support from other caregivers.	• "I wanted to know as little as possible about what was going on... But I think it's important that for those people around you that they get the education and understanding of what's going on, because it can be tumultuous at times and it's been very, very hard and it's been stressful on the family dynamic and all these other things..." (ID 23)
Currently used peer support resources		Few participants reported previous peer support experiences pertaining to their treatment, and often found it difficult to connect through third-party organizations.	• "I'm looking at the person that they teamed me up with through the Leukemia Society, and she had been 10 years post-transplant and I didn't find it helpful at all talking to her because it was something that was so far beyond for her, and she was going on with her life and she couldn't remember a lot of the different things." (ID 4)
Connection as Mentees and Mentors	When to receive support	Participants indicated their desire to establish a peer support connection prior to the transplant, so they can better understand what to expect and have someone who has been through it to answer their questions.	• "Trying to think, prior to transplant, like I said, there's so much...it might be good to have somebody who's already been through it describe to you a little bit more about the hospital stay and stuff, so maybe one or two contacts before." (ID 1) • "So having somebody right away, right when you're diagnosed that you can ask all the questions to would be so helpful." (ID 15)
	When to become a mentor	Participants reported they were willing to be mentors, but often not until later in their treatment when they are able to balance more responsibilities outside of maintaining their own health.	• "I'd have to answer that question further down the road, how I felt at five months or a year and go from that. I think one of the key questions in answering is: I need more support than I can give right now. When the facilitator needs more support, then it tells you that they're not ready yet." (ID 4)
Duration of peer support intervention		Participants reported that during the transplant hospitalization and in acute recovery a peer support connection should be a few months long, and several participants also expressed an interest in a connection that could last for at least a year to several years post-HSCT.	• "... When life becomes more and more normal, you're going to need less and less support from the outside world..." (ID 6) • "I think you would make friends forever. I think you would end up being friends with one or two of them probably forever, for the rest of your life." (ID 10)

Table 2. continued

Themes	Subthemes	Description	Quotes
Format and delivery of peer support intervention	Platform	Participants shared that in-person sessions could facilitate rapport with peers. However, virtual connections via a video platform like a Zoom meeting would be easier to schedule.	<ul style="list-style-type: none"> • “I would recommend video chats, as those are the most personable. It’s always friendliest to be able to see someone else’s face as opposed to simple voice or simple text communications... It’s far easier to get in contact someone digitally than travel to meet them in person... Also, since the individual is getting a stem cell transplant, their immune system is extremely vulnerable. Traveling to a location or meeting other people is dangerous, as they could become sick. Out of concern for safety and out of convenience, I would recommend [virtual] communication.” (ID 08)
	Number of people	While a group provided opportunities to learn from several individuals with diverse perspectives and experiences, one-on-one peer support allows for more intimate connection between individuals – especially for those who may not be comfortable speaking up in a group setting.	<ul style="list-style-type: none"> • “If you hook up with one person who happens to be a little bit on the negative side... [vs] if you have like five or six people together talking... You’d have that continuum where you may have someone who’s a little negative, and everything was horrible, but then you have somebody that will counteract it and say, “It really wasn’t that bad...so I think that it balances out if you have several different people.” (ID 4)
Reservations/Concerns about peer support intervention		Few participants expressed their own fears of misrepresenting or providing a skewed perspective of the transplant experience to others based on their own challenges with treatment.	<ul style="list-style-type: none"> • “And I just prefer to talk to the professionals, to my doctor, to people who knew exactly what was going on with me and who had seen many, many examples of people going through this. To me, that was better support at the time beforehand than to talk to people who had been through it who might have a variety of different experiences that I have to decide whose experience was mine going to be like and whose wasn’t going to be like.” (ID 12) • “Now, obviously, we don’t want to have a situation where the peer group feedback misrepresents what they may be going to experience or scare anybody or provide erroneous information somehowBut I don’t want to scare them. Right now, for me to meet with someone, and let them know, ‘No, it didn’t work out for me. My cancer came back...’ (ID 20) • “And then I also feel guilty because I’m doing better. I have 100% engraftment, and I’ve had that now for a while, and he’s just working on 75% right now, and he’s so excited that he finally hit 75%, so anyway, I look at him, and I don’t want to talk too much about how things are going well for me because I feel bad for him, and then on the other hand, I hear his story, and I think, “Are things going to fall apart for me?” so I think that’s one concern when you’re talking to somebody else that has had a transplant.” (ID 4)

This table provides details of all themes that emerged from qualitative data analyses and their corresponding participants’ quotes.

one-on-one interaction, others alluded to group peer support as follows:

“It means people who are going through the same thing that I’m going through, how [it] affects them and how they’re dealing with different aspects...a peer would be somebody that’s experiencing the same thing or has experienced the same thing...” (ID 24)

Potential benefits of peer support. Participants also articulated potential benefits (e.g., distress management, management of expectations, and uncertainty that could accompany HSCT) of peer support throughout their HSCT trajectory.

Emotional support: Participants reported peer support could help with the emotional distress that typically accompanied the HSCT and recovery.

"Having somebody else that's going through the same thing, ... so that you're able to commiserate, you're able to talk about the process and what it's like for you emotionally..." (ID 4)

Management of expectations and uncertainty that could accompany HSCT: Participants reported that peer support could help them manage numerous uncertainties that could accompany all aspects of HSCT and recovery.

"The bottom line, what you must know about people that get this potentially fatal diagnosis is that it creates like an earthquake in their lives. And because of that, they're going to need extra handholding, repeating the information. I don't know how many times." (ID 15)

Social support: Even participants who had a strong sense of support from their caregivers (e.g., family and friends) emphasized the importance of connecting with individuals who have experiential knowledge of HSCT.

"It just is unbelievable...I've never been part of the cancer world. I've never been part of the transplant world, so everything was new. Nobody in my world has ever had these challenges. And I needed and was gasping for support. And I don't believe that my doctors understand the level of support that's necessary for somebody who's just gotten this diagnosis. I don't think they were negligent by any stretch, and they were kind, and they were helpful, but I wouldn't call supportive in that." (ID 15)

Prior utilization of peer support resources. Most participants reported they were not aware of existing peer support resources internal or external to their transplant centers. Two participants reported a one-time connection with peers via the Leukemia and Lymphoma Society [35] or Blood and Marrow Transplant Information Network (B.M.T. Infonet) [36]. One other participant reported an informal connection via a neighbor who had a friend who had undergone HSCT. Participants reported difficulty connecting with peer mentors from these organizations because their matches were too far along (e.g., 10 years post-transplant) in their recovery from HSCT.

Peer support intervention preferences

The majority of participants (83%; $n = 19$) expressed an interest in engaging in peer support. Although participants reported limited prior peer support utilization, they articulated several preferences and considerations for peer support interventions. For example, meeting virtually either one-on-one or in groups, bi-weekly meetings with peers, and structured conversations with an agenda that covered several topics during meetings.

Connection as mentees or mentors. When asked about best timing of a peer support intervention, 14 (61%) participants reported they would prefer to initiate peer support prior to the transplant hospitalization. The myriad reasons for engaging with peers early in the transplant process included learning from peers about what to expect from the HSCT to calibrate expectations going into transplant.

"So having somebody right away, right when you're diagnosed that you can ask all the questions would be so helpful..." (ID 15)

Duration of peer support intervention. While some participants reported that a peer support intervention should be provided for a few months, specifically during the transplant hospitalization and

in acute recovery, several participants expressed an interest in an intervention that could last for at least a year to several years post-HSCT.

"I think you would make friends forever. I think you would end up being friends with one or two of them probably forever, for the rest of your life." (ID 10)

Format and delivery of peer support intervention. Several participants shared that in-person meetings could facilitate rapport with peers. However, a virtual intervention via a video platform like a Zoom Video Communications Inc., San Jose, CA application (zoom.us) [37] would be easier to schedule. Although phone-based interventions would also be convenient logistically especially in the context of the coronavirus disease-2019 (COVID-19) safety concerns, they lacked the advantage of seeing individuals.

"I would recommend video chats, as those are the most personable. It's always friendliest to be able to see someone else's face as opposed to simple voice or simple text communications... Well, firstly, you might be connecting people from great distances away. It's far easier to get in contact someone digitally than travel to meet them in person. Out of concern for safety and out of convenience, I would recommend [virtual] communication." (ID 08)

Participants articulated the benefits of both group vs. one-on-one peer support intervention. While group peer support provides opportunities to learn from several individuals with diverse perspectives and experiences, one-on-one peer support allows for more intimate connection between individuals—especially for those who may not be comfortable speaking up in a group setting.

"If you hook up with one person that happens to be a little bit on the negative side, versus if you have five people together talking, you'd have a mixture. You'd have that continuum where you may have someone who's a little negative, and everything was horrible, but then you have somebody that will counteract it and say, "It really wasn't that bad...so I think that it balances out if you have several different people." (ID 4)

Reservations/concerns about peer support intervention. In exploring potential concerns and reservations about a peer support intervention, a couple of participants expressed their fears of misrepresenting or providing a skewed perspective of the transplant experience to others based on their challenges with treatment. One participant also reported guilt about responding well to treatment and the worry that not experiencing difficult side effects would be a potential barrier to being an effective peer mentor.

"I don't want to talk too much about how things are going well for me because I feel bad for him, and then on the other hand, I hear his story, and I think, "Are things going to fall apart for me?" so I think that's one concern when you're talking to somebody else that has had a transplant." (ID 4)

DISCUSSION

For this study, we conducted semi-structured interviews in 23 patients with hematologic malignancies who have undergone allogeneic HSCT to explore their experiences and preferences with peer support. Despite limited access to peer support experiences for the majority of patients in our study, most (83%) participants

were interested in both receiving and providing peer support. Participants also reported various potential benefits of peer support, including emotional support, management of expectations and uncertainty, and overall social support. Most participants reported a strong preference to initiate peer support in the pre-transplant phase.

Our findings expand current knowledge of peer support and its potential benefits in patients with solid tumors to patients with hematologic malignancies who have undergone allogeneic HSCT. In a heterogeneous group of patients with solid tumors (mostly breast cancer), peer support has enhanced knowledge, patient satisfaction with care [38, 39], improved mood and coping strategies [40, 41], instilled a sense of hope [39], expanded social support [42], decreased isolation, fostered a sense of belonging, and created validation for patient experiences with their diagnosis and treatment [40, 43]. Since our cohort reported peer support could enhance psychological and social wellbeing during HSCT and in recovery, we emphasize that peer support could also be an important resource in the care of allogeneic HSCT recipients. Further research is needed to understand the full potential and role of peer support in supportive oncology interventions for this population.

With limited data on the most efficacious template for a peer support intervention in oncology, our participants provided useful insights for tailored peer support interventions in our population with unique treatment and recovery needs [17]. Participants' recommendations for a peer support intervention included either one-on-one or group-based intervention with less than five individuals, bi-weekly sessions that lasted several months to a year, and structured sessions with an agenda that covered several topics such as resources for managing physical symptoms. Participants also suggested a virtually-delivered intervention which was easier to schedule and more commonplace, especially during the COVID-19 pandemic. Virtual meetings may also be more suitable for patients in the acute post-transplant period when patients are mostly confined to their homes. While most peer support interventions for oncology populations have been either one-on-one or group-based [41], our cohort clearly articulated the strengths of both delivery models. Hence, a peer support intervention that incorporates both a one-on-one and a group component (i.e., a hybrid model peer support intervention) for this population could be optimal. With no prior work on hybrid model peer support interventions in oncology populations, evidence from other medical populations such as patients with alcohol use disorders (i.e., alcoholics anonymous) provides insights (e.g., manualized intervention with topics to be covered during group meetings, group members connecting with a "sponsor" who serves as a one-on-one resource outside meetings) for an intervention organization to be considered for our population [44].

The prolonged transplant hospitalization accompanied by significant side effects is psychologically taxing for all patients undergoing HSCT [7, 45]. For patients who develop chronic GVHD, coping with the challenges associated with GVHD in the first year of recovery is also stressful and jeopardizes psychological wellbeing [46]. However, regardless of GVHD status, our cohort reported the pre-transplant phase was the most challenging, suggesting that initiation of peer support as people prepare for the transplantation would be most beneficial. This finding supports evidence that distress in the pre-HSCT phase is often underestimated [47]. Further, a pre-transplant peer support program could be instrumental in helping patients manage expectations for treatment outcomes and potential variability in clinical outcomes post-HSCT. As such, peer support in the pre-transplant period could help address unmet psychological and support needs among HSCT recipients, highlighting the need for supportive oncology interventions to be more proactive and delivered earlier in the illness and treatment course than is currently offered.

The unique recovery process following HSCT is characterized by a high burden of morbidity and mortality [3, 6, 48], which must be seriously considered in the development of a peer support intervention. Although participants reported a desire to receive peer support pre-HSCT, participants also reported they may not have the physical and psychological energy required to be effective peer mentors until later in their recovery. For example, participants suggested waiting to become a peer mentor until one-year post-HSCT. Another concern is that both peer mentors and peer support receivers could encounter abrupt changes and/or setbacks in their recovery such as transplant failure, cancer recurrence, or imminent death [3, 6, 49]. Hence, a peer support connection could lead to unintended consequences and heightened distress for all participants involved. Compared to many supportive oncology interventions in this population that are delivered by trained professionals [45, 50], a peer support intervention for this vulnerable population must incorporate resources to support participants during unique and abrupt changes throughout the recovery process following HSCT.

Our study has several notable limitations. First, our sample mainly included non-Latino White, married, and educated participants who received transplants at a tertiary academic medical center. Hence, our findings may not reflect the perspectives of patients from ethnic minorities or lower socioeconomic backgrounds. For example, the suggestion for a virtual peer support intervention via Zoom may not be feasible for patients without access to smart devices or broadband internet services [51]. Second, since our transplant center has an extensive national and international referral base, patients may receive less pre-transplant support compared to smaller transplant centers that care for mostly local patients. Third, since most of our participants were married and patients with less familial or spousal support may express different needs and preferences for a peer support intervention. Fourth, patients enrolled in this study may have been more likely to want peer support than those who declined. Fifth, our sample included only patients who have undergone allogeneic HSCT, one of many different cellular therapies with a unique treatment and recovery course. Hence, patients who have received other cellular therapies (e.g., chimeric antigen receptor T-cell therapies) may report different peer support needs.

In conclusion, our qualitative study, which explores peer support experiences and preferences of patients with hematologic malignancies who have undergone HSCT, underscores numerous potential benefits of peer support in this population. Since a majority of our cohort expressed interest in engaging in peer support, both as recipients or providers of peer support, we highlight that peer support may be an underutilized resource in bolstering the psychological and social wellbeing needs of patients with hematologic malignancies or those who have undergone HSCT. Finally, although our findings provide formative information for the development of a potential peer support intervention for patients undergoing HSCT, more data is needed on the nature and role of peer support in supportive oncology interventions for HSCT recipients.

DATA AVAILABILITY

Data that support findings in this manuscript cannot be shared for ethical reasons because it must remain protected due to the Health Insurance Portability and Accountability Act per our consent process.

REFERENCES

1. Bhatia S, Francisco L, Carter A, Sun CL, Baker KS, Gurney JG, et al. Late mortality after allogeneic hematopoietic cell transplantation and functional status of long-term survivors: report from the Bone Marrow Transplant Survivor Study. *Blood*. 2007;110:3784–92. <https://doi.org/10.1182/blood-2007-03-082933>

2. Copelan EA. Hematopoietic stem-cell transplantation. *N Engl J Med*. 2006;354:1813–26. <https://doi.org/10.1056/NEJMra052638>
3. Bhatia S. Long-term health impacts of hematopoietic stem cell transplantation inform recommendations for follow-up. *Expert Rev Hematol*. 2011;4:437–52. <https://doi.org/10.1586/ehm.11.39>.
4. Socie G, Salooja N, Cohen A, Rovelli A, Carreras E, Locasciulli A, et al. Non-malignant late effects after allogeneic stem cell transplantation. *Blood*. 2003;101:3373–85. <https://doi.org/10.1182/blood-2002-07-2231>
5. Kraft S, Bollinger N, Bodenmann B, Heim D, Bucher C, Lengerke C, et al. High mortality in hematopoietic stem cell transplant-associated thrombotic microangiopathy with and without concomitant acute graft-versus-host disease. *Bone Marrow Transplant*. 2019;54:540–8. <https://doi.org/10.1038/s41409-018-0293-3>
6. Styczynski J, Tridello G, Koster L, Iacobelli S, van Biezen A, van der Werf S, et al. Death after hematopoietic stem cell transplantation: changes over calendar year time, infections and associated factors. *Bone Marrow Transplant*. 2020;55:126–36. <https://doi.org/10.1038/s41409-019-0624-z>
7. Amonoo HL, Massey CN, Freedman ME, El-Jawahri A, Vitagliano HL, Pirl WF, et al. Psychological considerations in hematopoietic stem cell transplantation. *Psychosomatics*. 2019;60:331–42. <https://doi.org/10.1016/j.psyc.2019.02.004>
8. Bevans MF, Mitchell SA, Marden S. The symptom experience in the first 100 days following allogeneic hematopoietic stem cell transplantation (HSCT). *Support Care Cancer*. 2008;16:1243–54.
9. Fromm K, Andrykowski MA, Hunt J. Positive and negative psychosocial sequelae of bone marrow transplantation: implications for quality of life assessment. *J Behav Med*. 1996;19:221–40.
10. El-Jawahri A, LeBlanc T, VanDusen H, Traeger L, Greer JA, Pirl WF, et al. Effect of inpatient palliative care on quality of life 2 weeks after hematopoietic stem cell transplantation: a randomized clinical trial. *JAMA*. 2016;316:2094–103. <https://doi.org/10.1001/jama.2016.16786>
11. Holt-Lunstad J. Why social relationships are important for physical health: a systems approach to understanding and modifying risk and protection. *Annu Rev Psychol*. 2018;69:437–58. <https://doi.org/10.1146/annurev-psych-122216-011902>
12. House JS, Landis KR, Umberson D. Social relationships and health. *Science*. 1988;241:540–5. <https://doi.org/10.1126/science.3399889>
13. Reblin M, Uchino BN. Social and emotional support and its implication for health. *Curr Opin Psychiatry*. 2008;21:201–5. <https://doi.org/10.1097/YCO.0b013e3282f3ad89>
14. Tardy CH. Social support measurement. *Am J Community Psychol*. 1985;13:187–202. <https://doi.org/10.1007/BF00905728>
15. Veiel HO. Dimensions of social support: a conceptual framework for research. *Soc Psychiatry*. 1985;20:156–62. <https://doi.org/10.1007/BF00583293>
16. Hu J, Wang X, Guo S, Chen F, Wu YY, Ji FJ, et al. Peer support interventions for breast cancer patients: a systematic review. *Breast Cancer Res Treat*. 2019;174:325–41. <https://doi.org/10.1007/s10549-018-5033-2>
17. Campbell HS, Phaneuf MR, Deane K. Cancer peer support programs-do they work? *Patient Educ Couns*. 2004;55:3–15. <https://doi.org/10.1016/j.pec.2003.10.001>
18. Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future supply and demand for oncologists: challenges to assuring access to oncology services. *J Oncol Pract*. 2007;3:79–86. <https://doi.org/10.1200/JOP.0723601>
19. Schaefer C, Coyne JC, Lazarus RS. The health-related functions of social support. *J Behav Med*. 1981;4:381–406. <https://doi.org/10.1007/BF00846149>
20. Amonoo HL, Johnson PC, Dhawale TM, Traeger L, Rice J, Lavoie MW, et al. Sharing and caring: the impact of social support on quality of life and health outcomes in hematopoietic stem cell transplantation. *Cancer*. 2021;127:1260–5. <https://doi.org/10.1002/cncr.33455>
21. Power S, Hegarty J. Facilitated peer support in breast cancer: a pre- and post-program evaluation of women's expectations and experiences of a facilitated peer support program. *Cancer Nurs*. 2010;33:E9–16. <https://doi.org/10.1097/NCC.0b013e3181ba9296>
22. Steginga SK, Pinnock C, Gardner M, Gardiner RA, Dunn J. Evaluating peer support for prostate cancer: the Prostate Cancer Peer Support Inventory. *BJU Int*. 2005;95:46–50. <https://doi.org/10.1111/j.1464-410X.2005.05247.x>
23. Beattie S, Lebel S, Tay J. The influence of social support on hematopoietic stem cell transplantation survival: a systematic review of literature. *PLoS ONE*. 2013;8:e61586. <https://doi.org/10.1371/journal.pone.0061586>
24. Song Y, Chen S, Roseman J, Scigliano E, Redd WH, Stadler G. It takes a team to make it through: the role of social support for survival and self-care after allogeneic hematopoietic stem cell transplant. *Front Psychol*. 2021;12:624906. <https://doi.org/10.3389/fpsyg.2021.624906>
25. Margolis M, Austin J, Wu L, Valdimarsdottir H, Stanton AL, Rowley SD, et al. Effects of social support source and effectiveness on stress buffering after stem cell transplant. *Int J Behav Med*. 2019;26:391–400. <https://doi.org/10.1007/s12529-019-09787-2>
26. Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient Educ Couns*. 2008;70:315–37. <https://doi.org/10.1016/j.pec.2007.11.016>
27. Czajkowski SM, Powell LH, Adler N, Naar-King S, Reynolds KD, Hunter CM, et al. From ideas to efficacy: the ORBIT model for developing behavioral treatments for chronic diseases. *Health Psychol*. 2015;34:971–82. <https://doi.org/10.1037/hea0000161>
28. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349–57. <https://doi.org/10.1093/intqhc/mzm042>
29. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs Health Sci*. 2013;15:398–405. <https://doi.org/10.1111/nhs.12048>
30. Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs*. 2008;62:107–15. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
31. Feig EH, Harnedy LE, Golden J, Thorndike AN, Huffman JC, Psaros C. A qualitative examination of emotional experiences during physical activity post-metabolic/bariatric surgery. *Obes Surg*. 2022;32:660–70. <https://doi.org/10.1007/s11695-021-05807-x>
32. Carrillo A, Feig EH, Harnedy LE, Huffman JC, Park ER, Thorndike AN, et al. The role of positive psychological constructs in diet and eating behavior among people with metabolic syndrome: a qualitative study. *Health Psychol Open*. 2022;9:20551029211055264. <https://doi.org/10.1177/20551029211055264>
33. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349–57. <https://doi.org/10.1093/intqhc/mzm042>
34. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? *Qual Health Res*. 2017;27:591–608. <https://doi.org/10.1177/1049732316665344>
35. America LLSO. Leukemia & Lymphoma Society LLS. <https://www.lls.org>
36. InfoNet B. <https://www.bmtinfonet.org>
37. McRoy C, Patel L, Gaddam DS, Rothenberg S, Herring A, Hamm J, et al. Radiology education in the Time of COVID-19: a novel distance learning workstation experience for residents. *Acad Radiol*. 2020;27:1467–74. <https://doi.org/10.1016/j.acra.2020.08.001>
38. Usher J, Kirsten L, Butow P, Sandoval M. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Soc Sci Med*. 2006;62:2565–76. <https://doi.org/10.1016/j.socscimed.2005.10.034>
39. Gray R, Fitch M, Davis C, Phillips C. A qualitative study of breast cancer self-help groups. *Psychooncology*. 1997;6:279–89. [https://doi.org/10.1002/\(SICI\)1099-1611\(199712\)6:4<279::AID-PON280>3.0.CO;2-0](https://doi.org/10.1002/(SICI)1099-1611(199712)6:4<279::AID-PON280>3.0.CO;2-0)
40. Dennis CL. Peer support within a health care context: a concept analysis. *Int J Nurs Stud*. 2003;40:321–32. [https://doi.org/10.1016/s0020-7489\(02\)00092-5](https://doi.org/10.1016/s0020-7489(02)00092-5)
41. Allicock M, Carr C, Johnson LS, Smith R, Lawrence M, Kaye L, et al. Implementing a one-on-one peer support program for cancer survivors using a motivational interviewing approach: results and lessons learned. *J Cancer Educ*. 2014;29:91–8. <https://doi.org/10.1007/s13187-013-0552-3>
42. Barlow SH, Burlingame GM, Nebeker RS, Anderson E. Meta-analysis of medical self-help groups. *Int J Group Psychother*. 2000;50:53–69. <https://doi.org/10.1080/00207284.2000.11490981>
43. Ashbury FD, Cameron C, Mercer SL, Fitch M, Nielsen E. One-on-one peer support and quality of life for breast cancer patients. *Patient Educ Couns*. 1998;35:89–100. [https://doi.org/10.1016/s0738-3991\(98\)00035-4](https://doi.org/10.1016/s0738-3991(98)00035-4)
44. Kelly JF, Humphreys K, Ferri M. Alcoholics anonymous and other 12-step programs for alcohol use disorder. *Cochrane Database Syst Rev*. 2020;3:CD012880 <https://doi.org/10.1002/14651858.CD012880.pub2>
45. El-Jawahri A, Traeger L, Greer JA, VanDusen H, Fishman SR, LeBlanc TW, et al. Effect of inpatient palliative care during hematopoietic stem-cell transplant on psychological distress 6 months after transplant: results of a randomized clinical trial. *J Clin Oncol*. 2017;35:3714–21. <https://doi.org/10.1200/JCO.2017.73.2800>
46. Lee SJ, Onstad L, Chow EJ, Shaw BE, Jim HSL, Syrjala KL, et al. Patient-reported outcomes and health status associated with chronic graft-versus-host disease. *Haematologica*. 2018;103:1535–41. <https://doi.org/10.3324/haematol.2018.192930>
47. Lee SJ, Loberiza FR, Antin JH, Kirkpatrick T, Prokop L, Aleya EP, et al. Routine screening for psychosocial distress following hematopoietic stem cell transplantation. *Bone Marrow Transplant*. 2005;35:77–83. <https://doi.org/10.1038/sj.bmt.1704709>
48. Gratwohl A, Brand R, Frasson F, Rocha V, Niederwieser D, Reusser P, et al. Cause of death after allogeneic haematopoietic stem cell transplantation (HSCT) in early leukaemias: an EBMT analysis of lethal infectious complications and changes over calendar time. *Bone Marrow Transplant*. 2005;36:757–69. <https://doi.org/10.1038/sj.bmt.1705140>
49. Olsson R, Remberger M, Schaffer M, Berggren DM, Svahn BM, Mattsson J, et al. Graft failure in the modern era of allogeneic hematopoietic SCT. *Bone Marrow Transplant*. 2013;48:537–43. <https://doi.org/10.1038/bmt.2012.239>

50. Amonoo HL, El-Jawahri A, Celano CM, Brown LA, Harnedy LE, Longley RM, et al. A positive psychology intervention to promote health outcomes in hematopoietic stem cell transplantation: the PATH proof-of-concept trial. *Bone Marrow Transplant.* 2021;56:2276–9. <https://doi.org/10.1038/s41409-021-01296-9>
51. Nadkarni A, Hasler V, AhnAllen CG, Amonoo HL, Green DW, Levy-Carrick NC, et al. Telehealth during COVID-19—does everyone have equal access? *Am J Psychiatry.* 2020;177:1093–4. <https://doi.org/10.1176/appi.ajp.2020.20060867>

ACKNOWLEDGEMENTS

Time for data analysis and manuscript preparation was supported by the National Cancer Institute through grant K08CA251654 (to HLA) and the National Heart, Lung, and Blood Institute through grant R01HL113272 (to JCH). AE-J is a scholar in clinical research for the Leukemia & Lymphoma Society.

AUTHOR CONTRIBUTIONS

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data. All were involved in drafting the article or

revising it critically for important intellectual content. All provided final approval of the manuscript and agreed to be accountable for all aspects of the work.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

Correspondence and requests for materials should be addressed to Hermioni L. Amonoo.

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