



Published in final edited form as:

Transplant Cell Ther. 2022 July ; 28(7): 400.e1–400.e6. doi:10.1016/j.jtct.2022.05.007.

It Takes a Village: The Importance of Social Support after Hematopoietic Stem Cell Transplantation, A Qualitative Study

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Abstract

Background/Objective: Social support is essential to the recovery of patients who have undergone hematopoietic stem cell transplants (HSCT). We undertook a qualitative study to explore the specific sources and benefits of social support as experienced by HSCT recipients, as well as their unmet social support needs.

Methods: We conducted semi-structured interviews with 25 patients who had undergone HSCT and were recruited from the Dana Farber Cancer Institute's HSCT database. The interviews explored the sources of support patients receive, the type of assistance social support networks provide to patients, and unmet needs of social support. Interviews were audio-recorded, transcribed, and coded using the Dedoose software.

Results: The median (range) age of participants was 63 (22–73) years, and 13 (52%) were female, 20 (80%) were White, and 9 (36%) were diagnosed with acute myeloid leukemia. Participants reported receiving a majority of support from immediate family and close friends, with the primary benefits of social support including help with essential daily tasks, household chores, and receipt of emotional support. Participants reported occasional support from other

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patients but highlighted a desire for increased connection with patients who have undergone the same treatment. Participants also communicated a desire to have more guidance on how to optimize the support they do receive and the need for more educational resources for caregivers and supporters to enhance understanding of the HSCT process and lessen patient burden.

Conclusion: Participants rely on support from their family, friends, and other social connections for essential aspects of their recovery and daily living following HSCT. While there are many benefits to these relationships, patients emphasized the need for more guidance and resources to facilitate the aid and support they receive post-transplant.

Keywords

Social support; quality of life; distress; psychological health; hematopoietic stem cell transplantation; HSCT; social wellbeing; caregivers; supportive oncology

Introduction

Social support, the emotional and material resources provided by a social network to assist individuals in times of need or distress,¹ is critical in every aspect of the treatment and recovery from hematopoietic stem cell transplantation (HSCT). Although HSCT is potentially curative for malignant and non-malignant hematologic disorders, the treatment is intensive, and the recovery is prolonged.^{2, 3} Accordingly, HSCT recipients have significant physical and emotional needs that necessitate a reliable and robust social support network throughout the transplantation and recovery period.⁴⁻⁶ As the immune system rebuilds following transplantation, HSCT recipients must maintain a lifestyle of isolation to minimize their risk of contracting infections, contributing to significant limitations in everyday life (e.g., going grocery shopping, eating in a restaurant). Hence, HSCT recipients must rely on their caregivers and social support networks for practical/tangible support such as cleaning their living environment, picking up prescriptions from a pharmacy, and grocery shopping, as well as for emotional support.

Several studies have shown that social support may buffer against the negative effects of distress and is associated with improvement in key patient outcomes such as psychological wellbeing, quality of life (QOL), and survival in patients with serious illnesses.^{7, 8} Studies in the HSCT population have demonstrated that social support and self-efficacy can independently buffer against stressors related to chronic graft-versus-host disease (cGVHD) and other comorbid conditions, even after controlling for major sociodemographic and clinical covariates.⁹ In our prior work in the HSCT population, we also showed that greater perceived social support was associated with fewer symptoms of distress, post-traumatic stress disorder (PTSD) symptoms, and better QOL.¹⁰ Although social support has been associated with better clinical outcomes, understanding its nuances in the specialized HSCT context is critical but lacking.

Most studies that have characterized social support and examined its associations with clinical outcomes in patients with serious illnesses have used validated questionnaires.¹¹⁻¹³ However, social support is complex, and validated instruments may not capture every dimension of social support – especially in vulnerable populations such as HSCT recipients

who have unique needs over the extended duration of their treatment and recovery.^{14–16} Qualitative studies can inimitably help unpack and characterize the intricacies of social support in the HSCT population via the firsthand document of patient experiences. However, qualitative studies that characterize social support in the HSCT population are lacking. Hence, we conducted a qualitative study using semi-structured interviews to describe the nature of social support and its benefits following HSCT to inform efforts that identify and intervene upon the social support needs of HSCT recipients.

Methods

Study Design

The full details about study design and criteria have been reported previously.¹⁷ Briefly, we used a qualitative study design characterized by semi-structured interviews that explored the nature of social support in a purposive sample of HSCT recipients. We recruited patients from our institutional HSCT database who were either within 6-months of transplantation and without graft-versus-host-disease (GVHD) or 6-months post-transplantation with GVHD. We observed the consolidated criteria for conducting and reporting qualitative (COREQ) research guidelines.¹⁸ The study was approved by the Dana-Farber/Harvard Cancer Center institutional review board.

Recruitment

Eligible participants were adult patients who received allogeneic stem cell transplantations and were < 6-months post-HSCT without GVHD or 6-months post-HSCT with GVHD. We sampled HSCT recipients early and late in their post-HSCT trajectory to explore social support experiences across the post-transplant continuum. We approached all eligible participants via phone between November 2019 and September 2020 and enrolled those interested in participating in the study after obtaining their verbal consent. We excluded all patients who had a cognitive or major psychiatric disorder that precluded their ability to complete study procedures at the discretion of their transplant oncologist.

Participant Characteristics

All participants self-reported the following demographic data: sex, race, ethnicity, age, education, and relationship status. We obtained clinical, disease, and treatment information from the electronic health record.

Qualitative Interviews

H.A., a psychosocial oncologist with expertise in conducting semi-structured interviews and no direct involvement in the care of study participants, completed all interviews via phone. Interviews lasted approximately 60 minutes. The semi-structured interview guide covered several domains, including: 1) sources of social support, 2) what social support entailed, 3) potential benefits of social support, and 4) unmet social support needs. We audio-recorded all interviews.

Data Analysis

We used descriptive statistics (e.g., mean, standard deviation) for participant demographic and disease characteristics.

Qualitative Data Analysis

For qualitative coding and data analysis, we used the Dedoose 8.0.35 software (SocioCultural Research Consultants, LLC: Los Angeles, CA). We transcribed verbatim audio-recorded interviews and used content analysis to derive themes from patient data.¹⁹ To create the codebook, two team members with expertise in coding qualitative data (H.A. and L.H.) read five transcripts independently to derive themes. Guided by the semi-structured interview guide and discussion, we revised the codebook using a blend of inductive and deductive methods to validate the codebook. Two team members coded all transcripts between April and July 2021 using complete sentences as the unit of coding, incorporating refinements to the codebook as needed. To resolve disagreements, the two coders met weekly to review the transcripts for emerging themes and to discuss discrepancies in coding. We documented all discussions and decisions pertaining to data analysis. We achieved meaning saturation after reviewing 23 transcripts.

Results

Patient Characteristics

We enrolled 25 (71%) of the 35 eligible patients, and 23 (66%) completed qualitative interviews. For the 10 approached participants who did not join the study, nine provided various explanations (e.g., no interest in research studies) for refusal to participate and one could not participate due to language barriers. Two enrolled participants did not complete interviews. We lost one to follow-up, and the other withdrew from the study due to worsening physical symptoms. Of the 25 participants who enrolled, the median (range) age was 63 (22–73) years, 13 (52%) were female, 20 (80%) were White, and 9 (36%) were diagnosed with acute myeloid leukemia. Table 1 provides full details of participants' characteristics.

Sources of social support:

Participants identified family and friends as their primary sources of support throughout the HSCT and recovery. Participants also reported receiving sporadic support from other patients they encountered while receiving care, such as in waiting areas of clinician offices. Other sources of support came from clinicians, including transplant oncologists, nurses, therapists, and social workers.

Family: *“My support primarily comes from my family.”*

(ID05)

“The short and sweet of it is I have had family members who have provided me with transport, food, and emotional support during these trying times.”

(ID08)

Friends: *“I felt lucky that I have plenty of friends that call me and text me”*

(ID02)

Acquaintances: *“Well, I have a neighbor too that had cancer, not leukemia ... And sometimes she’s out gardening, and we just talk, and she gives me her support. And she’s not what I would consider a close friend of the family or anything, but she has been so supportive and caring and compassionate, and it has meant a lot to me.”*

(ID07)

Benefits of Social Support in HSCT

All participants (23) articulated a benefit of social support in their recovery following HSCT. Participants reiterated that there were many physical limitations, as well as the risk of a weakened immune system after receiving a stem cell transplant. So, the most helpful support often manifested in completing daily and mundane yet necessary activities (e.g., cleaning, meal preparation) that patients were unable to complete for themselves. Additionally, participants also identified emotional support as a major type of support received from others.

Assistance with activities of daily living: *“I can’t even put socks on because I can’t reach my feet... We’ll just leave it at that. In the beginning, even helping with bathing, driving me to appointments, just listening when I want to bitch, all that kind of stuff.”*

(ID23)

Assistance with chores: *“Yeah, and I have a core group of friends who took care of my house ... they would mow the lawn, clean the pool, do landscape, whatever needs to be done, they would help with. Now they come over and they shovel and that sort of thing...”*

(ID23)

Emotional support: *“My wife has been fantastic in terms of just making a home environment as pleasant as possible and being there for me every step of the way. That’s been the biggest thing. Without her, if I wasn’t happily married, I think this would be a lot more difficult to deal with.”*

(ID24)

Unmet social support needs in the context of recovery from HSCT

While most participants reported satisfaction with the level of support they received during transplant and recovery, 74% of participants also described ways they felt their support was lacking. For example, participants articulated the need for guidance on optimizing their sources of support (i.e., from family, friends, social networks). Second, participants expressed the need for more resources for their caregivers to support their loved ones better while navigating the different aspects of recovery. Third, participants expressed a desire to connect with others who had gone through and recovered from HSCT.

Optimizing support: *“... But it seems like everyone is like, “Let me know what I can do to help, blah, blah, blah,” everyone asks a million questions. But a lot of it is*

they don't know what to do, so that's what they're saying. But we found that even though a lot of people were offering to help, there was just a few core people that actually follow through with it. And a lot of it is just people don't really know what to do."

(ID 23)

Caregiver resources and support: *"... 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 pretty tumultuous at times and it's been very, very hard and it's been stressful on the family dynamic and all these other things..."*

(ID23)

Connecting with other patients: *"Oh, certainly having somebody to talk to who's already been through it would be very helpful. Then it kind of gives you a sounding board or somebody to ask, and then they can repeat things like, don't worry, you're going through cancer treatments... So there's a lot more hope, there's a lot more-- so somebody can actually tell you and just reiterate"*

(ID15)

Discussion

In this study of 23 patients with hematologic malignancies who had undergone HSCT, we used semi-structured interviews to examine social support and its benefits following HSCT. Although we used a purposive sample of patients who were either early or late in their post-HSCT trajectory, the reported themes of social support experiences were similar across the post-transplant continuum. Patients reported that a variety of individuals, including family, friends, and clinicians, constitute their support network and often provide different types of support. Patients also reported that while their immune system rebuilds in required isolation, their social support networks were beneficial with necessary daily tasks they could not complete themselves (e.g., cleaning, picking up prescriptions, grocery shopping). Nevertheless, patients also described ongoing needs, including guidance on optimizing support, resources for caregivers, and opportunities to connect with other patients who had undergone HSCT.

Despite the ongoing coronavirus disease-2019 (COVID-19) pandemic which elevated loneliness and social isolation,^{20, 21} our cohort articulated social support provided by various individuals including family and clinicians. Participants also reported a myriad of benefits of social support during recovery, including help with essential tasks that they cannot complete due to the quarantine and isolation requirements post-transplant. Although our understanding of social support and social wellbeing needs in the HSCT population is growing, only a few studies have shown that social support is associated with better psychological wellbeing and QOL.^{9, 10, 13, 15} Interestingly, limited social support has also been associated with lower survival and a higher likelihood of death or readmission within 90 days of discharge for hospitalized patients with aggressive hematologic malignancies.²² Studies examining social relationships in other medical populations have also revealed an association between strong social relationships and clinical outcomes.^{8, 23, 24, 25} For

example, a meta-analytic review by Holt-Lunstad and colleagues found that there is a 50% increased likelihood of survival for patients with a variety of chronic diseases who reported stronger social relationships even after controlling for age, sex, health status, and cause of death.²³ Thus, prospective studies that robustly evaluate social support (i.e., including type and amount) and its impact on clinical and HSCT outcomes, including mood, QOL, mortality, and healthcare utilization, would augment our findings and be revolutionary in informing efforts to promote social support for this population.²³

A tangible finding from this study that potentially impacts clinical care is patients' clearly articulated desire for guidance on how to best optimize their social support. Limited patient knowledge on ways to utilize and organize support may result in undue burden on patients as they struggle to navigate their illness course. Currently, there are no published resources to assist HSCT recipients with delegation and optimization of post-transplant support consistent with our participants' reported need for more support for their caregivers. Evidenced-based interventions that equip patients with skills to mobilize and coordinate social support across the illness trajectory and effective ways of communicating their needs during different phases of the illness and recovery course are needed. Consequently, in addition to assessing the quality and quantity of social support following HSCT, more research is needed to establish resources that will assist HSCT recipients and caregivers to better utilize and anticipate the role of social support throughout the recovery process.

While numerous studies have highlighted the importance of reliable caregivers in the recovery experience of HSCT recipients,^{13, 26, 27} their focus has been on familial caregivers. However, our study cohort reported receiving significant support from a variety of sources beyond just family, including friends, non-familial relationships (e.g., neighbors), and clinicians. Therefore, social support resources should target patients' primary caregivers (i.e., usually family) and various other members involved in the care and support of the patient. A stronger understanding of how these individuals contribute to social wellbeing for patients will also help determine what barriers and deficits of social support exist for the HSCT population. Similarly, participants shared their need to connect with other individuals who have undergone HSCT. While peer support has been associated with a range of clinical outcomes in various cancer populations,²⁸⁻³⁰ there are limited data describing peer support experiences or their association with outcomes in HSCT. With a heightened risk for infection during the acute recovery phase, peer support delivery for HSCT recipients must consider innovative and virtual video platforms such as Zoom Video Communications Inc., San Jose, CA application (zoom.us).³¹ Our prior work characterized the potential benefits and unmet peer support needs among HSCT recipients and advocated for integrating peer support interventions for this population with unique treatment and recovery needs.¹⁷

Our findings highlight various dimensions of patients' experiences with social support which are not typically captured by existing validated instruments that assess social support among HSCT recipients and other oncology populations.¹¹⁻¹³ While we report that HSCT recipients receive support from individuals other than family, most social support measures focus primarily on support provided by family or spousal caregivers.¹¹⁻¹³ Further, although measures such as the Social Support Effectiveness-Questionnaire^{13, 32} comprehensively assess types of familiar support (e.g., emotional support), the extent to which quantity of

support addresses unmet support needs, and potential unintended negative consequences of support, there are no questions to assess patients' ability to optimize and seek support from diverse individuals. Hence, qualitative studies like ours provide complementary information to what could be obtained with validated social support measures.

This study has several notable limitations. First, while our sample size allowed for thematic saturation and allowed us to obtain a snapshot of the social support experiences of HSCT recipients, it is not a representative sample size for all HSCT recipients. Second, our participants were mostly White, non-Hispanic, educated, and married, and were recruited from an academic medical center with different social support resources than HSCT recipients from lower socioeconomic and/or ethnic minority populations. Third, since all our participants were in the first year of recovery following HSCT, their social support experiences and needs may not be translated to HSCT recipients who are farther along in their recovery. Fourth, since most of our participants were married, their social support needs likely vary from those who are single or reported limited familial supports. Fifth, since the COVID-19 pandemic has impacted social interactions, it is possible that the pandemic could have impacted participants' perception and experience of social support.

In summary, HSCT recipients receive social support from various individuals, and they can articulate the benefits of social support in their transplantation and recovery experiences. However, we highlight the need for resources and guidance for this population with complex needs to optimize their social support relationships. Further research that is prospective and describes how different individuals contribute to social support and the association between social relationships and clinical outcomes will further fuel efforts to incorporate social support in supportive care interventions in patients who undergo HSCT.

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Highlights

- Patients undergoing HSCT articulate many benefits of social support
- HSCT recipients receive social support from various sources including family
- HSCT recipients suggest the need for more resources to optimize social support

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Table 1.

Participant Characteristics

	Total (N=25)
Age, median (range)	63 (22–73)
Female sex, n (%)	13 (52.0%)
Race, n (%)	
White	20 (80%)
Black	3 (12%)
American Indian	1
Asian	(4%)
Other	0 (0%)
Hispanic, n (%)	1 (4%)
Hematology malignancy type, n (%)	2 (8.0%)
AML	9 (36%)
ALL	6 (24%)
MDS	4
NHL	(16%)
Other	2 (8%)
	4 (16%)
Relationship Status, n (%)	18 (72%)
Married/relationship	1 (4%)
Divorced	5
Single	(20%)
Widowed	1 (4%)
Religion, n (%)	9 (36%)
Catholic	4 (16%)
Non-Catholic	4
Christian	(16%)
None	4 (16%)
Jewish	3 (12%)
Muslim	1 (4%)
Missing	
Education, n (%)	3 (12%)
High school graduate or GED	5 (20%)
Some college/associate's degree	9
College graduate	(36%)
Graduate degree	8 (32%)
Income, n (%)	2 (8.33%)
< \$25,000	5 (20.83%)
\$25,000 - \$49,999	6
\$50,000 - \$99,999	(25%)
\$100,000 - \$150,000	4 (16.7%)
> \$150,000	7 (29.17%)

Table 2.

Patient Experiences of Social Support following HSCT: Themes, Description, and Quotes

Themes	Description	Subthemes	Quotes
Sources of Support	Patients reported receiving support from a variety of individuals including family, friends, and sporadic support from other patients they encountered while receiving care.	Family	<p>“My support primarily comes from my family...” (ID05)</p> <p>“The short and sweet of it is I have had family members who have provided me with transport, food, and emotional support during these trying times.” (ID08)</p>
		Non-Family	<p>“Well, I have a neighbor who had cancer, not leukemia, and I’m not really close with them but I have since become closer because this woman, in particular, told me what she went through...And she’s not what I would consider a close friend of the family or anything, but she has been so supportive and caring and compassionate and it has meant a lot to me.” (ID07)</p>
		Friends	<p>“I felt lucky that I have plenty of friends that call me and text me” (ID02)</p>
Benefits of Social Support	Patients reported that there were many physical limitations after receiving a stem cell transplant, so the most helpful support often came in the form of help to complete daily and mundane activities as well as receiving emotional support.	Daily Mundane Activities	<p>“I can’t even put socks on because I can’t reach my feet... We’ll just leave it at that. In the beginning, even helping with bathing, driving me to appointments, just listening when I want to bitch, all that kind of stuff.” (ID23)</p> <p>“So not being able to clean my house, and not being able to do the yard work, and do the shopping and all that stuff, and having my husband have to do all that, plus his job, that’s a burden...I figured out one thing I can do that the doctors won’t say no to. I can shovel snow because that’s outside, and there’s no mold in it. But that’s a hard thing.” (ID01)</p> <p>“Yeah, and I have a core group of friends who took care of my house who would in the summer, mow the lawn, clean the pool, do landscape, whatever needs to be done, they would help with. Now they come over and they shovel and that sort of thing. I have a plow guy because I live on a mountain, I have a very big, long driveway. But there is a core group of probably - one, two, three, four - five people [friends] that stay in consistent contact with me.” (ID23)</p> <p>“Yeah. I got my daughter. I live in an apartment, which is part of my youngest daughter’s house, and she takes care of my laundry. She takes care of some cleaning of the house. Any time I have that-- because of those medicines I take. I have to take insulin, and my daughters give me that-- they take the blood in the morning and the afternoon, and I take the insulin.” (ID03)</p>
		Emotional Support	<p>“My wife has been fantastic in terms of just making a home environment as pleasant as possible and being there for me every step of the way. That’s been the biggest thing. Without her, if I wasn’t happily married, I think this would be a lot more difficult to deal with.” (ID24)</p>
Unmet Support Needs	Patients reported there were areas where they felt their current support was lacking, in ways such as learning how to optimize the support they received,	Guidance on how to optimize support	<p>“Oh if I could just go down here and grab this and do this.” And I’ve had people somewhat do that for me...But I feel-- it’s like I don’t want to take advantage of people... “ (ID07)</p> <p>“He’s just running around. But it seems like everyone is like, “Let me know what I can do to help, blah, blah, blah,” everyone asks a million</p>

Themes	Description	Subthemes	Quotes
	finding resources for their caregivers to help them understand the process, and forming connections with other patients who had undergone the same treatment.		<p>questions. But a lot of it is they don't know what to do, so that's what they're saying. But we found that even though a lot of people were offering to help, there was just a few core people that actually follow through with it. And a lot of it is just people don't really know what to do."</p> <p>(ID 23)</p>
		Education and resources for caregivers	<p>"... 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 pretty tumultuous at times and it's been very, very hard and it's been stressful on the family dynamic and all these other things."</p> <p>(ID23)</p> <p>"And I've been the same way, the nagging on eating more and it's like people not understanding that you just simply can't. And that... but it's just a matter of understanding."</p> <p>(ID06)</p>
		Connection with other HSCT recipients	<p>"It could have been helpful if, besides my husband, there was more of a team ... If there were a prescription pad that said, "Get three people to alternate mowing lawns for you." And it was signed by the doctor. He [caregiver] probably would have followed it."</p> <p>(ID01)</p> <p>"Oh, certainly having somebody to talk to who's already been through it would be very helpful. Then it kind of gives you a sounding board or somebody to ask, and then they can repeat things like, don't worry, you're going through cancer treatments..."</p> <p>(ID15)</p> <p>"Maybe if during that time I was able to connect with someone else who was a just recent transplant recipient, who was a little further ahead of me, who had gone through the hundred days and had come out the other end. Someone preferably like around my age would be nice. I think that would have helped just to talk to someone to say, "Hey, is this normal if you have this experience?"</p> <p>(ID16)</p>

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Table 3.

Interview Guide Questions to Explore Social Support Experiences

Theme	Question
Sources of Social Support	What has your support system looked like?
	Who constitutes your social support system?
Benefits of Social Support	What specific things have your support system done? What has been the most helpful?
	Can you provide specific examples of what support has been like for you?
Social Support Needs	Tell me about things you could use more support for during your HSCT and recovery.
	Explore further based on examples

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