




ORIGINAL ARTICLE

Optimizing use of written peer support as a supportive resource in cancer: Focus group insights

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Abstract

Purpose: Cancer survivors frequently describe wanting to learn from others who have had similar diagnoses or treatments (*peer support*). We conducted focus groups to investigate hematopoietic stem cell transplant survivors' attitudes and preferences regarding accessing written peer support through a website. Although written peer support does not allow for interpersonal interactions with peers, it could increase transplant recipients' access to evidence-based benefits of informational and emotional peer support.

Methods: We conducted four videoconference focus groups with 34 adult transplant survivors who were diverse in their medical and sociodemographic characteristics and geographic location. Discussions were recorded, transcribed, and content analyzed.

Results: Many participants reported need for information about transplant beyond what they received from their healthcare providers. Needs varied across participants, as did preferences for characteristics and timing of information optimally

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provided through peer support. Participants were enthusiastic about the value of written peer support but emphasized that it should be delivered in a way that accommodates variation in transplant experiences, underscores its trustworthiness, and pairs it with useful psychoeducational content.

Conclusions: Findings provide guidance for making written peer support an accessible, supportive resource for transplant survivors. Future research should evaluate personalized online delivery of written peer support paired with psychoeducational content that enhances its benefits.

Implications for Cancer Survivors: Written peer support delivered online could be a useful, valued resource for transplant survivors.

KEYWORDS

cancer, cancer survivors, focus groups, hematologic malignancy, hematopoietic stem cell transplantation, oncology, peer support, psycho-oncology, social support

1 | INTRODUCTION

People diagnosed with cancer often receive substantial education from healthcare providers to prepare them for treatment. Although patient education is critical, patients frequently describe needing types of information and emotional support that are not typically available from providers^{1,2} (e.g., insight into day-to-day treatment and recovery experiences,³ realistic information about side effects and management strategies⁴), but that are best provided by patients with a similar diagnosis or treatment—that is, *peer support*.^{1,5,6} Informational and emotional support from peers^{7,8} can reduce patients' distress^{9,10} and social isolation^{8,11}; increase hope and optimism¹²; help patients feel more informed,⁸ empowered,⁸ and prepared¹⁰; normalize their reactions and experiences^{4,8}; alert them to available resources¹³; support and inform their decision making¹⁴; and model new ways of coping with potential problems.^{4,8}

Despite these benefits, peers may provide inaccurate information, reinforce unhelpful health behaviors, and increase distress and anxiety through negative stories.^{15–18} Furthermore, patients differ in their coping and information-seeking styles (e.g., preferring little vs. substantial information about possible future medical concerns⁴). Negative experiences with peer support—or the expectation of negative experiences—can lead patients to avoid seeking it.

The present study was conducted to inform development of a website (“Mosaic”) designed to maximize potential benefits of peer support while reducing potential harms. Mosaic will deliver written peer support—survivors' *written* accounts of their treatment experiences, combined with advice and encouragement—to people who are preparing for or undergoing an allogeneic or autologous hematopoietic stem cell transplant. This is a particularly challenging cancer treatment due to its toxicity, lengthy hospitalization and recovery, and persistent medical and psychosocial challenges.^{19–21}

Although to date there has been little research specifically conducted to inform its use, we focus on written peer support because it is a potentially cost effective, scalable, and accessible resource

compared to peer support obtained through interpersonal interactions (e.g., with peer mentors or support groups). However, its written format also raises potential shortcomings, including patients' inability to ask questions as they would if they were interacting with peers. This shortcoming may limit their ability to obtain support that meets their specific needs. Although we are not aware of specific research on this shortcoming, a study of parents bereaved by childhood cancer revealed that written peer support delivered in a booklet caused some parents to feel upset, angry, or overwhelmed, although it was generally rated as highly acceptable and effective at providing useful information and emotional benefits.²² Additionally, accessing peer support in written form eliminates potential to reciprocate support that has been received by also providing it to others—a therapeutically important feature of support groups.^{23–25} These shortcomings notwithstanding, written peer support is a potentially valuable resource, particularly for patients who would have difficulty finding time for scheduled interactions, who prefer not to interact with peers (e.g., due to privacy concerns), or who have difficulty accessing formal or informal peer support.

We propose that it may be possible to reduce potential negative responses to written peer support and to mitigate the shortcomings described above by delivering written peer support via a website that allows people to search for written peer support narratives that are a good match for their informational needs (e.g., searching for specific topics) or coping style (e.g., learning about or, if preferred, avoiding peers' negative experiences). A website could also pair written peer support with psychoeducational content personalized to patients' needs, such as information about how to clarify personal risks by asking healthcare providers questions, instructions for using evidence-based coping and stress management strategies, or links to resources such as therapists or peer support groups.

The purpose of this study was to gain a rich view of patients' need for information and their preferences for accessing written peer support. Our goal was to inform development of a website capable of

maximizing benefits of written peer support while minimizing its harms, with the ultimate goal of improving survivorship outcomes.

2 | METHODS

2.1 | Participants

We used purposive sampling to recruit participants from three comprehensive cancer centers in the United States Midwest, North-east, and Mid-Atlantic regions. Some were referred by a clinician; others had completed a related study and consented to future contact. Eligible participants received an autologous or allogeneic stem cell transplant for cancer within 3 years and were English proficient, ≥ 18 years old, able to access the internet, and free of vision or hearing problems that would interfere with joining online focus groups.

2.2 | Procedures

We conducted four 120-minute focus groups via videoconference (due to COVID-19) in June 2021. Staff sent potential participants a letter describing the study, then called to answer questions and conduct a brief screening interview. Eligible participants were emailed the informed consent form and completed consent procedures by phone with trained staff. Prior to their scheduled group, participants completed an online questionnaire to self-report socio-demographic and transplant characteristics, community type (urban, suburban, rural), and computer/internet access.

Groups were led by an experienced moderator (CR or KG) using a moderator's guide developed by the lead author and co-authors. Questions were designed to elicit: 1) unmet information needs before and during transplant; 2) personal experiences with transplant-related peer support; 3) initial attitudes towards a broad description of the planned website; 4) feedback on and ideas for website features intended to reduce potential harms of peer support; and 5) feedback on an early version of the website. Instructions emphasized that participants should feel free to share negative feedback. Group discussions were recorded and transcribed by a HIPAA-compliant transcription company. Participants were paid \$75. The institutional review boards of Georgetown University (STUDY00003111), Northwestern University (STU00213817), and Hackensack Meridian Health (PRO2020-1131) approved the study.

2.3 | Analysis

We conducted an inductive, conventional content analysis.²⁶ Led by MW, the analysis team first read the transcripts in their entirety and met to discuss emerging themes. MW then identified excerpts related to each initial theme and connections across themes.²⁶ CR reviewed the transcript excerpts, then MW and CR discussed and addressed discrepancies. Next, MW organized the excerpts based on the

saliency of the themes and identified exemplar, illustrative quotes. Finally, MW and CR presented the excerpts and quotes to the analysis team, which met to review and finalize the themes.

3 | RESULTS

3.1 | Participants

Of 111 potential participants sent study announcements, 56 (50.4%) did not respond; 16 (14.4%) responded but were not screened due to lack of interest, loss to contact, poor health, being busy, or unknown reasons; and 2 (1.8%) were waitlisted because their preferred group was full. Thirty-seven participants were scheduled for a group and three failed to attend, yielding a final sample of 34. The sample was heterogeneous in their demographic characteristics (including nearly 30% representing racial/ethnic minority groups), recruitment site, and medical characteristics, therefore representing a variety of perspectives. Most could access the internet with a household computer (94.1%) and all could access the internet with a smartphone (Table 1).

3.2 | Focus groups

Analyses reached saturation and revealed that most participants expressed a need for the types of information offered by peer support and positive views about written peer support as a resource. However, there was notable individual variation in specifics of their preferences, as indicated by three main themes: 1) complicated desires for information about transplant; 2) complicated desires for peer support; and 3) recognition that a website presenting written peer support must account for a variety of unique transplant experiences.

3.2.1 | Complicated desires for information about transplant

Participants were asked to reflect on what took them by surprise during transplant and what they wished they had known before transplant. Many mentioned three topics: side effects (e.g., fatigue, gastrointestinal symptoms), emotional responses to transplant, and recovery timelines and duration. For example, one participant described how she was warned about possible nausea, but not its full extent, saying "For me, the magnitude of my nausea and not being able to eat was really bad... Even though you're warned... I wish I had been more prepared or more warned the extent it could be" (S2, Group 3). Another described wanting to know more about the emotional toll of transplant, saying "I'm having trouble adjusting to the fact that this might be where I'm at now, and... I can't do many of the things I enjoyed" (S7, Group 4). Other participants would have liked more information about the duration of recovery. One recounted, "I thought I would go back to life in three, six, months.

TABLE 1 Participant characteristics (N = 34)

Variable	N (%)
Age (years)	
18–34	4 (11.8%)
35–54	8 (23.5%)
55–74	21 (61.8%)
75+	1 (2.9%)
Gender	
Male	21 (61.8%)
Female	13 (38.2%)
Race	
Black/African American	5 (14.7%)
White	23 (67.6%)
Other race/multiple races	4 (11.8%)
Prefer not to say	2 (5.9%)
Ethnicity	
Hispanic/Latinx/Spanish	3 (8.8%)
Not Hispanic/Latinx/Spanish	31 (91.2%)
Relationship status	
Married/marriage-like relationship	23 (67.6%)
Other	11 (32.4%)
Education	
High school or less	3 (8.8%)
Some college or vocational/technical school	6 (17.6%)
4 year college degree	10 (29.4%)
Graduate/professional degree	15 (44.1%)
Work status	
Working for pay/self-employed	20 (58.8%)
Retired	7 (20.6%)
Unable to work	6 (17.6%)
Not employed	1 (2.9%)
Annual household income	
\$20,000–\$59,999	7 (20.6%)
\$60,000–\$99,999	8 (23.5%)
\$100,000–\$139,999	7 (20.6%)
\$140,000+	8 (23.5%)
Prefer not to say/missing	4 (11.8%)
Home community type	
Urban	11 (32.4%)
Suburban	20 (58.8%)
Rural	3 (8.8%)

TABLE 1 (Continued)

Variable	N (%)
Diagnosis	
Acute leukemia	9 (26.5%)
Lymphoma	9 (26.5%)
Multiple myeloma	13 (33.2%)
Other	3 (8.8%)
Type of transplant(s)	
Autologous	17 (50.0%)
Allogeneic	14 (41.2%)
Autologous and allogeneic	2 (5.9%)
Don't know	1 (2.9%)
Time since (last) transplant	
3–6 months	2 (5.9%)
6–12 months	2 (5.9%)
1–2 years	30 (88.2%)
Study site	
Hackensack Meridian health	21 (61.8%)
Georgetown University	7 (20.6%)
Northwestern University	6 (17.6%)

There is no way. We got to be honest. It's tough... I was shocked..." (S12, Group 1). Another said:

Everything was a surprise to me. I knew nothing going in. And not only can I not work; I can't walk. I can't really do a whole lot of anything... I thought, 'I'm going to be back to normal by Thanksgiving.'... Now it's like two years later... (S8, Group 2)

Although participants often wished they had more information *before* transplant, their desire for information *during* transplant varied. Some wanted as much information about transplant as possible; others recalled avoiding information to reduce anxiety. For instance, one participant said that during transplant, "I needed to know everything." He attributed this desire to his background, saying "I come from a scientific background, and my first inclination when something new comes up is to hit the books. And I did" (S8 Focus Group 1). Highlighting how people with similar backgrounds can have different preferences, another participant responded, saying "I also have a medical background and I was, I think, overwhelmed by the information that my doctors were giving me. And I appreciated it, but it was a bit too much" (S11, Group 1).

3.2.2 | Complicated desires for peer support

Many participants said they wanted peer support or that they would have sought it through a website like Mosaic. For example, one said, “I would read all the stories” (S8, Group 2). A participant who wanted written peer support described how he sought peer support during his own transplant, wanting as much information as possible to prepare himself:

I just felt very lucky and fortunate to be able to talk to [a] retired physician, because his story was good. He had a stem cell transplant, and three months later he said he was in Hawaii... So it was optimistic for me to hear that. Obviously, everybody's experience isn't like that, but quite frankly, the more experiences I hear, whether they're good or bad or indifferent, is only a help... (S4, Group 3)

Another participant said he would not have used a website like Mosaic himself, but he highlighted an alternative use and the importance of building trust:

I think the best thing you could make sure you do with the site is make sure it has proper authority, so people know..., “Okay. This is a legitimate source of information. These are actual patients who have gone through this. I can trust what I'm reading here....” And I'll tell you how I would have used the site is if it had some benefits to my spouse... I wanted to make sure my wife felt comfortable. And she's the exact opposite type of person where she's like, “I want to read everything. I want to know everything I can...” And I'm not, but I want to support her in that... (S13, Group 2)

Other participants spoke positively about talking with peers and were open to accessing peer support in written form. One participant described useful information provided by a woman who had undergone transplant, but also suggested the effort that went into connecting with peers:

The woman I spoke to... gave me a lot of tips on just clothes to bring, what things to bring to the hospital. That really helped me a lot.... But I didn't have it on a website... I had to reach out and find two people I could call and get the information from.... (S2, Group 2)

Some participants were not interested in peer support, although many commented that others would find it useful. For example, when asked about reading other people's transplant experiences on a website, one participant said, “Personally, I wouldn't use that, but I can definitely understand that [other] people would want to use it” (S3, Group 3). Participants who did not want to engage with written peer support often cited anxiety as a reason. As one participant said,

“I didn't want to know anything...because I was afraid if I looked up on it I might not have gone through with [the transplant]... I think [reading the narratives] would have been too much.” However, he noted that the website is “a good idea for people that want to read up on what they could go through” (S8, Group 3).

Like participants' varying desires for peer support, when participants wanted to engage with peer support also varied. This variation was attributed to transplant being a “process” with “different steps and feelings” (S8, Group 3), including feelings about reading other people's transplant experiences. A participant described these shifts when thinking about accessing written peer support through a website:

I feel like different parts of the site might have appealed to me at different points during the transplant or before. Before I probably wouldn't want to have read a lot of narratives of people's experiences, but quite possibly during the transplant I might have wanted to.... But I might have wanted to read a lot of the resource sections right away.... (S11, Group 1)

Similarly, another participant thought it would be valuable to engage with only the written peer support that one wants to engage with at the time, because his own desire for peer support changed as the process went on. He said:

I think the best feature of the website [will] be that people can pick and choose what they want to—what information they want or need. Personally, I wasn't too interested in talking to anybody about the pre-stem cell transplant or even what you went through while you were going through it. But the recovery and the continuing—because I'm still getting treatment... I have a go-to person that I can get good information from.... (S5, Group 3)

Some participants had distinct ideas about what kinds of written peer support they thought would be most helpful. For instance, one said:

We all know what could potentially happen... but the type of stories I would want to hear are more uplifting stories, stories that are really going to encourage us or motivate us to really keep the proper mindset, keep a positive outlook... That's really what we need when we're going through this battle.... (S10, Group 2)

Another participant agreed, but advocated for a more “balanced” and “factual-based” perspective, saying:

Having uplifting stories, the fact that there are so many of us that survived the process, I think, is uplifting in itself. But being able to come in there as a new patient

and sort of hear a variety of experiences, good, bad, and otherwise, is a great thing... (S5, Group 2)

3.2.3 | Need for the website to account for a variety of unique transplant experiences

In addition to differing desires for peer support, participants recognized differences between their transplant experiences. They felt that a website's written peer support would need to account for a broad range of experiences and diagnoses. Summarizing the need to account for these differences, one participant asked:

Are you going to differentiate between the reasons, the different diseases, the different conditions? Because it's apparent to me here that almost everybody in this room probably had something different.... I don't need to read about a brain tumor. I have myeloma. That's what I want to read about... (S7, Group 2).

Participants also shared that even similar diagnoses and treatments can result in fundamentally different transplant experiences. One participant said, "Two people can go through exactly the same thing but feel completely different." A website providing written peer support should thus present "a diverse sort of representation of experiences" (S11, Group 2). This participant continued, saying: "If one person's like, 'Oh, this went really fine, but this is the thing you got to worry about...' then you have this on your mind, and then it's like your experience is totally different and you feel blindsided." Echoing this call for diverse narratives, another participant observed that transplant is "different for everybody. It affects different parts of the body... To have a site like what you're doing [with the variety of patients' stories], I think, is great" (S6, Group 4). One participant underscored the importance of being transparent when taking differences into account:

The entire website should be set up for...how people that want that information, that they can hear what other people have gone through, not that someone is telling them, "You're going to go through this." Well, you might go through this or you might go through that. Everybody is different. We should have something really—a caveat that everybody is so different in this journey we're all taking. You shouldn't put too much stock on any one thing because a lot of different things can happen... (S8, Group 1)

Feedback about how to make the website most useful revealed the need to consider the match between transplant recipients' needs and the written peer support they read, although participants recognized that the characteristics on which to make these matches would differ across recipients. For instance, one participant commented on the extensive range of perspectives that would need to be

accommodated, saying "A lot of different people are coming at it from different perspectives, and trying to figure out how to hit them all is going to be really tough" (S8, Group 1). Some participants suggested solving this problem by categorizing peer support narratives "so that people can see what they want to see [and] whatever they don't want to read, they won't" (S13, Group 1).

4 | DISCUSSION

In focus group discussions, cancer survivors treated with stem cell transplant provided insight into use of written peer support as a supportive resource. Results revealed strong need for information about transplant beyond what they received during their own transplant, including kinds of information optimally offered by peer support (e.g., information about side effects, emotional responses, and the timing and duration of recovery).¹ Participants had generally positive attitudes towards peer support and accessing it in written form. They emphasized the importance of meeting highly individualized, changing needs throughout the transplant process. A few described having little interest in getting peer support or in getting too much information about their treatment and recovery, indicating that a website that shares written peer support would appeal to many, but not all transplant recipients. These findings are consistent with prior evidence that cancer survivors' information needs vary substantially across individuals and change over time.²⁷ Results also extend prior evidence to cover written peer support and survivors of stem cell transplant—a particularly challenging cancer treatment. We believe these findings suggest that written peer support may be best delivered via a website with search capabilities or computer-based tailoring,²⁸ similar to methods used in a recent psychoeducational intervention for transplant recipients.²⁹

Our findings indicating significant unmet informational needs were also consistent with prior evidence—specifically, that patient education often does not sufficiently meet cancer survivors' needs, although information from providers is a preferred and critical information source.^{30,31} When information from the healthcare team did not increase participants' understanding of emotional and practical experiences, or when it led to expectations that did not match reality, the disconnect was viewed as problematic. Other research has revealed the importance patients place on information that allows them to have realistic expectations.³⁰

Participants' general support for offering written peer support via a website is promising because an internet-based intervention could expand access to peer support. A website would allow survivors to access it at their convenience, when they have the cognitive and emotional resources to seek the information it provides, or when topics are especially salient. Moreover, pairing written peer support with psychoeducational resources could help address clinical concerns. For example, people often have difficulty comprehending and recalling treatment information offered by medical providers.^{32,33} Written peer support that raises questions about treatment and recovery could help survivors frame questions for their healthcare

team or motivate them to ask about information they misunderstood in earlier consultations,³⁴ especially if the website includes psychoeducation to support effective patient-provider communication. Yet, information about potential adverse transplant outcomes may raise anxiety in some transplant recipients. One way to mitigate this risk is to pair potentially worrisome or frightening information with education about protective actions and how to implement them,³⁵ such as high-quality educational content or information about psychosocial resources, stress management, or coping skills. When offering complementary psychoeducation, we believe it will be critical to address participants' recommendation to communicate the credibility and accuracy of the information and to underscore that each person's situation is different.

Finally, providing written peer support could make it easier to offer patients a realistic view of the substantial variability in transplant experiences and the emotional and psychosocial consequences of transplant. Reading a number of peer support narratives is likely to be easier than speaking to a similar number of individual peers. Understanding this variability could, in turn, help people frame questions for their medical team and promote planning to accommodate potential complications.

4.1 | Study limitations

Our findings should be interpreted in light of several limitations. First, participants were recruited through large academic medical centers and all agreed to participate in a focus group about written peer support; therefore, they may have had relatively high interest in hearing about peers' experiences. Second, many participants had a college or graduate degree. Future studies should include samples with greater representation from people with less education. Third, participants' feedback on their peer support needs and preferences were retrospective. We recruited survivors because of concern that focus groups would be burdensome for people preparing for transplant. However, our findings are consistent with evidence for the importance of peer support to cancer survivors, individual variability in information needs and preferences, and changing needs and preferences throughout treatment, suggesting that retrospective reporting did not substantially affect findings regarding the potential value of written peer support and the diversity of participants' needs and preferences. We plan to validate these findings in a study gathering data from patients who use the website as they undergo transplant.

5 | CONCLUSIONS

Our sample's diversity allowed us to capture a wide range of experiences and attitudes, including significant variation in feedback and preferences for written peer support. Findings highlight the role that written peer support may play in meeting the needs of people undergoing a difficult cancer treatment. They also provide guidance to

inform features of technology-based interventions that use written peer support to extend existing medical education and formal peer support programs, while meeting patients' complex individual preferences and changing needs. Future research is needed to develop and test the effects of such interventions.

6 | CLINICAL IMPLICATIONS

Peer support is a valuable but often difficult-to-access resource for people affected by cancer. Providing it in written form could extend access, but the therapeutic value of written peer support will depend on how well it delivers desired informational and emotional support. Our findings inform consideration of critical features of a website to deliver written peer support to a population with a demonstrated need for peer support, with the goal of optimizing its potential to improve survivorship outcomes.

AUTHOR CONTRIBUTIONS

All authors contributed to study conception and design. Material preparation, data collection and analysis were performed by Christine Rini, Margaret Waltz, Kristi Graves, and Katrin Bovbjerg. The first draft of the manuscript was written by Christine Rini, Margaret Waltz, and Katrin Bovbjerg, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

Dr. Yanez is a consultant for Blue Note Therapeutics. The other authors have no relevant financial or non-financial interests to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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