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## Expanding access to cancer peer support: development of a website to deliver written peer support that meets patients' individual emotional and informational needs while reducing potential harms

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### Abstract

Cancer patients often want information from “peers” with the same diagnosis or treatment. To increase access to this valuable resource, we developed a website to deliver written peer support to cancer patients undergoing stem cell transplant. Because little evidence describes how to optimize benefits or reduce potential harms of written peer support, we gathered multiple forms of stakeholder feedback to inform the website’s ethical approach, personalization, design, function, and content: a Community Advisory Board; a longitudinal study of patients’ written peer support needs and motivations; focus groups; semi-structured interviews; and usability testing. Findings provide a rich foundation for website development.

### Keywords

written peer support; website development; stakeholder engagement; hematopoietic stem cell transplant

## 1. Introduction

Patients undergoing cancer treatment often report a need for more – and different types of – information and support than their medical providers are able to provide [1, 2]. Some of the information that patients desire, such as insights into the daily experiences and side effects of treatment [3–5], may be most informative coming from others who have been through similar experiences – i.e., through peer-support [1, 6, 7]. Receiving peer support can address patients' informational needs, including improving knowledge and feelings of being informed [8], empowered [9], and prepared [10]. Peer support also appears useful for enhancing psychosocial outcomes such as patients' engagement with social support [9, 11], reduction of distress [8, 10] and social isolation [9, 12], and increased feelings of optimism and hope [13]. Finally, receipt of peer support has also helped patients normalize their experience [4, 9], identify helpful resources [14], support their ability to make care-related decisions [15], and model alternative methods of coping and problem solving [4, 9, 16].

Limited research to date has evaluated the use of written peer support compared to peer support through interpersonal interactions (e.g., support groups or peer coaches). A recent study reported that written peer support delivered via booklet to parents who had lost a child to childhood cancer was an acceptable and effective method for delivering information and support [17]. Although written peer support precludes the ability to ask questions or reciprocate the support [18–20], benefits include its availability at any time (e.g., real-time accessibility without need for interpersonal contact), increased privacy and autonomy, and reduction of barriers such as travel or discomfort participating in support groups. To optimize the benefits of written peer support, consideration of potential limitations/harms is also important. Possible harms include the potential for written peer support to provide inaccurate or irrelevant medical information, increase distress or anxiety due to 'negative' content, or describe unhelpful coping behaviors [21–24]. When delivering written peer support in a way that does not allow for patient-peer interactions to clarify or expand on information that has been provided, new strategies are needed in order to deliver it to cancer patients in a way that optimizes benefits while minimizing harms.

We sought to develop a website to deliver written peer support resources in a safe and effective manner for individuals preparing for or undergoing hematopoietic stem cell transplant. Patients typically have a hematologic cancer (e.g., leukemia, lymphoma, multiple myeloma) and face an intense treatment regimen and significant medical and psychosocial challenges [25–27]. We chose to deliver peer support via a website to capitalize on the accessibility of digital technology and ability to tailor this type of mobile health (mHealth) platform to users' individual needs [28]. For instance, our clinical and research experience suggested that their individual needs for emotional and informational peer support would vary according to factors such as their diagnosis, transplant type, stage of transplant, medical risk, complications, mood, coping style, and coping resources. Our decision to use a technology-based approach is consistent with strong evidence for the efficacy of using online technologies to support cancer patient needs across the continuum of cancer care [29]. An online platform can also be designed to minimize potential harms and reduce

barriers to equitable access, including overcoming language barriers for Spanish speaking populations [30, 31].

The purpose of this paper is to describe the design process and content development of a website to deliver written peer support in English and Spanish for individuals undergoing hematopoietic stem cell transplant. Our written peer support was provided by transplant recipients through two randomized controlled trials of a written expressive helping intervention [32]; the intervention culminated in an exercise in which participants write a peer support narrative to share any aspect of their transplant experience they feel would help people preparing for or undergoing transplant, along with advice and encouragement. We used an iterative, person- and human-centered approach to inform the ongoing design of our website, called Mosaic (Mosaico in Spanish) [33]. Specifically, we used diverse methods to elicit input from different types of expert stakeholders and patients, in addition to following recommendations in the literature related to using qualitative methods to understand the needs of our target population [29, 33]. Our overarching goal was to create a website that, by pairing written peer support with educational and supportive resources, meets transplant recipients' individual needs for emotional and informational peer support while addressing inherent challenges of delivering written peer support via an online platform.

### 1.1. Identified challenges

We first identified the challenges we needed to address in order to meet this overarching goal. These challenges are based on our team's experience, existing literature [34–36], and input from our Community Advisory Board (CAB) of transplant survivors and clinical/scientific experts.

- *Challenge 1 (Safety/Ethics):* Developing a method for editing written peer support to prepare it for sharing in a safe, ethical way (e.g., to reduce potential for causing emotional distress and remove medical advice or inaccurate information while maintaining writers' intended goals for providing peer support);
- *Challenge 2 (Personalization/Relevance):* Developing categories to apply to written peer support, with the goal of ensuring that transplant recipients can find peer support that meets their specific emotional and informational support needs each time they use the website;
- *Challenge 3 (Relevance/Safety):* Determining what kinds of emotional and informational needs transplant recipients have over the course of their treatment continuum, with the goal of refining the categories applied to written peer support in Challenge 2 and informing development of educational and supportive resources to pair with written peer support to enhance its potential benefits while reducing its potential harms; and
- *Challenge 4 (Functionality/Accessibility):* Finalizing specific website features and functions to ensure they are user-friendly and enhance accessibility (e.g.,

features to improve readability and comprehension for diverse users, intuitive user interface).

## 2. Gathering data to inform website development

To address the foregoing challenges, we relied on input from stakeholders and data collected in research with transplant recipients [33]. Below we describe the process we followed and insights we gained from: 1) Interdisciplinary team expertise, 2) Our CAB, 3) Data from patients participating in an ongoing longitudinal study, 4) Interview data from Latinx participants, 4) Focus group data, and 5) Usability testing data.

### 2.1. Interdisciplinary team expertise

We relied on an interdisciplinary team to guide initial steps of development of our website. Team leaders (Rini and Graves) have over 40 years of combined experience investigating factors that affect patient outcomes and developing interventions capable of improving these outcomes, including technology-based interventions. Our team includes clinical psychologists, social psychologists, social workers, hematologists/oncologists, and a website developer with health communication expertise. After determining that a website would optimize our ability to deliver written peer-support in an accessible, flexible way, we developed initial plans for a website based on our team's expertise and our clinical and research experience with transplant recipients and other cancer populations. The team then assembled a CAB that represented varied stakeholder perspectives, experience, and expertise. We also developed plans to gather necessary data from transplant recipients through a longitudinal study, focus groups, interviews, and usability testing.

### 2.2. Community Advisory Board (CAB)

Our CAB is a stakeholder group composed of transplant recipients (some with additional expertise, including patient advocacy and social science), clinical providers (social workers, hematologists/oncologists), and research professionals. The CAB's 11 members attended regular meetings to provide feedback to help frame and overcome the challenges described above. To date, the CAB has gathered five times. Preliminary meetings were held in person and the remaining meetings were held via Zoom videoconference due to the COVID-19 pandemic. These meetings were highly interactive and designed to give members ample opportunity to provide insight into our challenges and to recommend solutions. Members also provided feedback on initial plans for the website. As we collected data from our patient research, the CAB provided further expert input to help interpret the data and apply it to website features and functions.

Early CAB meetings focused on how we might best prepare written peer support to be added to the website in an ethical and safe way (Challenge 1). Discussion focused on whether and how written peer support should be edited, including discussion of removing some information (e.g., medical information or advice, negative information) and making wording or grammar changes that could increase readability, but might unintentionally change the author's style or "voice." The CAB also discussed who should ideally make these edits (e.g., the study team, clinicians, or other transplant patients) and how to handle narratives

in which the information does not apply to everyone and thus may not be as supportive as intended (e.g., medical information or recommendations specific to a given diagnosis or type of transplant). The CAB's recommendations drove critical decisions, including an editing guide that described methods to minimally edit narratives for punctuation and grammar only when sentences were otherwise difficult to comprehend, all while keeping writers' voices intact. The CAB also helped our team distinguish between directive medical advice and descriptions of medical treatments and experiences; we reached a decision to review and potentially strike directive medical advice. The CAB also began a discussion of "disclaimers" that could be paired with stories to reduce risk for causing emotional and informational harm. For instance, one disclaimer reminds readers that any medical treatment or advice shared by a writer reflects that writer's individual situation and does not apply to everyone. Readers are reminded to talk with their own doctors about their concerns and medical situation.

In addition to feedback on editing and disclaimers, the CAB assisted with website design. For example, they were instrumental in the development of methods for allowing website users to find written peer support that meets their emotional and informational needs (Challenge 2). The goal was to develop easy, intuitive methods that would allow users to communicate their needs to the website to obtain a list of recommended written peer support "stories" that optimally satisfied their needs. The CAB also provided feedback on the website's functionality in terms of story identification, which involved not only these recommended stories, but also provided users with intuitive, satisfying ways to search freely through stories. CAB members proposed and discussed various user characteristics that could be applied to recommend specific stories (e.g., gender, age, diagnosis, transplant type, etc.). These discussions led to the development of story categories that were based on story content and author characteristics. Categories were used to categorize or "tag" each story so that it could be recommended by the website or identified through search and filtering features controlled by users. For instance, written peer support coded as a story describing "transplant side effects" could be delivered to a user who was seeking to learn about medical recovery from transplant. Considerable time was spent discussing how to handle written peer support that included substantial negative or sensitive content, such as stories describing severe complications or discussing feelings of hopelessness (Challenge 3). We developed a method for identifying these stories so that we could add disclaimers to them, pair them with useful resources (e.g., instructions for coping and stress management, links to therapeutic resources), and enable use of filtering capabilities to hide these stories (e.g., for users who were fearful of being exposed to highly negative or threatening information, and for users who preferred to cope by focusing on more positive stories and topics).

Finally, the CAB was instrumental in developing website functions and features (Challenge 4). Focus group findings provided valuable feedback on the necessity of pairing written peer support with psychoeducational and supportive resources. In later meetings, the CAB members helped us apply this feedback and suggested resources that should be included (e.g., specific trusted websites offering medical and patient advocacy information, instructions for talking with providers).

The CAB's recommendations reflected personal experiences and expertise that extended the study team's perspectives and expertise. Their recommendations were enlightening and often a surprise, ultimately helping to ensure our finalized website would be acceptable and effective to users.

### 2.3. Longitudinal Study Data

Prior to beginning the planning process for the website, we initiated a randomized controlled trial called Writing for Insight, Strength, and Ease (WISE) to test the efficacy of our expressive helping intervention. Expressive helping includes four brief, structured writing exercises in which stem cell transplant recipients engage in emotionally expressive writing about their transplant experience followed by peer support writing in which they share their transplant experiences, advice, and encouragement to help people preparing for or undergoing transplant (Clinical Trial: [NCT03800758](#)) [37]. In addition to completing expressive helping (or a neutral writing control condition), WISE participants also complete assessments at pre-transplant, twice during hospitalization, and four times from one to twelve months after hospital discharge. A peer support questionnaire administered at each assessment included a question asking participants to rate their interest in reading about other people's transplant experiences and two open-ended questions assessing the reasons they would or would not want to do this. Data generated in the WISE trial therefore provided longitudinal data to help us understand participants' interest in written peer support over time as well as their motivations to access or avoid it at each timepoint. Analysis of these data informed website development, with special attention to transplant recipients' changing emotional and informational peer support needs and motivations over time (Challenge 3).

Preliminary analyses provided useful insights to guide website development. For example, we examined participant interest in reading written peer support over four assessments ranging from pre-transplant to five weeks post-discharge [38]. Responses indicating moderate or high interest were most common pre-transplant (70% of participants) but remained high across subsequent assessments (approximately 50% of participants at each assessment). Findings revealed that our website would need to provide support to transplant recipients throughout the transplant process.

We conducted content analyses to evaluate themes in responses to the open-ended questions and found diverse and evolving motivations explaining why participants would or would not want to read written peer support at each stage of transplant. One notable finding was the complexity and variety of needs across transplant recipients and assessments, and this finding informed a significant change to plans for the website. Namely, we did not detect reliable patterns of needs or motivations that would facilitate use of computer-based tailoring to deliver particular types of written peer support to participants according to their individual characteristics or stage of transplant. Analysis of our quantitative and qualitative longitudinal data suggested that participants' needs and motivations for accessing written peer support vary substantially and unpredictably over time – even for the same participant. Likewise, our findings did not support use of common tailoring variables such as race, ethnicity, or gender; these characteristics were unrelated to patients' reported needs and motivations for accessing written peer support. Therefore, rather than using computer-based tailoring, as originally

planned, we developed an alternative plan for enabling the website to recommend stories and for supporting individualized searching and filtering capabilities controlled by the user. One feature allows the website to recommend written peer support based on users' emotional and informational support needs at login. Users select from a simple set of options at login (i.e., whether they have navigated to the website 'to read hopeful, inspiring stories,' 'to explore a specific topic,' or they 'just want to browse'). Users' responses allow the website to select an initial set of stories that might fit their needs in the moment; users can then apply flexible search and filter capabilities to refine or change their search to better fit their current needs.

Additional findings indicated that interest in written peer support was modestly correlated with study variables such as anxiety, social constraints, or perceptions of social isolation [38, 39]. These findings suggest that transplant recipients may be motivated to learn about others' transplant experiences in part to reduce negative emotions and/or to address deficits in social resources. Transplant recipients with higher levels of education were also more motivated to learn about others' experiences. However, different coping styles may lead transplant recipients to manage these negative emotions and social resource deficits in different ways. Specifically, content analyses of our open-ended data revealed that some participants only wanted to read about positive transplant experiences and worried that reading about others' transplant experiences would make them more anxious, whereas other participants wanted access to all information, both positive and negative. These findings are consistent with our clinical experience and led us to develop tags to identify written peer support that has significant negative content and to develop a user interface that allows website users to limit exposure to stories they wish to avoid (Challenges 2 and 3).

Later in the transplant process (i.e., after hospital discharge), our findings indicated that transplant recipients were increasingly motivated to make meaning of and understand their personal transplant experiences by comparing their experiences to others' (i.e., through social comparison [40]). However, this motivation was not universal: social comparison was described as a motivation by only 6% of participants at pre-transplant, but this motivation was described by 24-35% of participants at subsequent assessments [39]. Changing needs and motivations revealed by our longitudinal data provided further evidence that our website needed to apply flexible search capabilities. For instance, users can select which features of writers or stories are important to them and adjust these selected features each time they use the website to find stories with characteristics that are meaningful to them at that moment in time (Challenge 3).

#### **2.4. Study interview data (Latinx/Hispanic participants)**

In August of 2020, our team was awarded supplemental funding to develop a linguistically tailored version of Mosaic appropriate for, and appealing to, Hispanic/Latinx transplant recipients (Mosaico). Led by co-investigator Dr. Yanez, we conducted 18 interviews with English and Spanish-speaking Hispanic/Latinx cancer patients who had undergone transplant in the prior year. The interviews helped us learn about their transplant experiences and interest in accessing online peer support in Spanish (e.g., via a website such as Mosaico) [41].

Content analyses of interview transcripts revealed themes related to informational needs (e.g., a need for information financial and logistic challenges) and emotional needs (e.g., regarding effects of transplant on mental health). Participants reported needing more information about the course and side effects of transplant than their doctors had provided. This feedback supported the need to pair written peer support with psychoeducational and supportive information and to categorize written peer support with tags (see Section 2.2) that reflect the specific needs of this population (Challenge 3). Additionally, echoing the findings of our longitudinal data, participants reported varying desires to access written peer support. Some believed that having more information might increase their anxiety. These findings supported our plan to accommodate individual differences by allowing website users to limit exposure to peer support stories with substantial negative content (Challenge 2).

## 2.5. Focus groups

To refine our initial website design, we conducted four videoconference focus groups with a sample of 34 transplant recipients who were diverse in their medical, psychosocial, and racial/ethnic backgrounds. Our primary goal was to gain a rich view of patients' need for information and their preferences for accessing written peer support on a website. Our moderator's guide included questions eliciting participants' feedback on specific website features and functions that we had developed based on our team's expertise developing technology-based interventions [42–45], preliminary analyses of our longitudinal data, interviews with Hispanic/Latinx transplant recipients, and CAB feedback (Challenge 4).

After hearing a brief overview of the website's purpose and general features, including a definition of peer support, many participants described ongoing information needs related to transplant, especially regarding the magnitude, duration, and real-life impact of treatment side effects (Appendix A). Participants were generally enthusiastic about using a website like Mosaic to get peer support, although several stated they would not use it, consistent with longitudinal study findings showing that not all transplant recipients desire peer support (e.g., because they view it as irrelevant or potentially anxiety-provoking). Some participants felt that their caregivers would benefit from using our website even if they would not. Participants also provided feedback that reinforced the need for implementation of safety precautions (e.g., removing medical advice, adding disclaimers). They were highly enthusiastic about including a resource section with psychoeducational and supportive information, reinforcing our plans to add it and leading us to refine the content and organization of that website component. Some participants wanted the capability to interact with writers who provided written peer support for the website, which we decided was beyond the scope of our website's goals. Similarly, some participants felt that the website should be introduced to transplant recipients at the time of diagnosis—feedback we decided not to pursue because it was also beyond the scope of our website's goals (e.g., the website does not include decision support for people considering transplant). Overall, the focus group discussions underscored the existence of substantial individual variation in needs, motivations, and recommendations for delivering written peer support in a website. Findings were largely consistent with our other research but provided richer insight into needs and motivations to guide refinement of planned website features and content, allowing us to



finalize a preliminary version of the English and Spanish-language websites in preparation for usability testing.

## 2.6. Usability testing

We recently began usability testing with individuals diagnosed with cancer who received a transplant within the last 3 years. Participants complete a baseline survey followed by a “think aloud” usability testing protocol [46] in which they verbalize their thoughts as they work through pre-determined scenarios that represent examples of how the website will be used. These sessions are recorded for analysis (e.g., to identify website pages or functions that cause confusion). Afterward, participants use the website at home over the course of two weeks, taking notes about their thoughts, likes, and dislikes as they use it. They are asked to use the website for at least two hours. At the conclusion of the two weeks, participants complete a follow-up questionnaire and a semi-structured telephone interview to report their feedback and thoughts. The website gathers participants’ usage data during the home-based study and in the four weeks after the follow-up assessment. Backend usage data will help us understand more naturalistic use of the website and participants’ usage of its various sections and features. Although this stage of the research is ongoing, we have already gathered information about where participants might have issues engaging with the website and what elements might need further refinement to reduce confusion and increase ease of use. We have also received direct feedback from participants about website elements that they like and dislike. This feedback will be transcribed and qualitatively analyzed to finalize the website’s features and functions in preparation for a future randomized controlled trial (Challenge 4).

## 3. Conclusion

As we worked to develop a website to deliver written peer support to cancer patients preparing for or undergoing transplant, we identified major challenges and discovered a lack of evidence to guide optimal delivery of written peer support. We also realized that we had an ethical need to reduce potential of causing a vulnerable population emotional and informational harm (e.g., by increasing their anxiety with frightening information or sharing irrelevant or inaccurate medical information). To meet these challenges, we expanded our team’s expertise and perspectives with exceptionally rich stakeholder feedback from our Community Advisory Board, longitudinal study data, interviews with Hispanic/Latinx participants, focus groups, and usability testing. The resulting website looks quite different than the one we originally planned; the site is improved in content, features and functionality in ways that should allow us to deliver written peer support to our patients safely and effectively to improve patient health and well-being.

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## Appendix A.: Focus group themes and website features

Theme	Elements of the theme	Examples of resulting website features
Theme 1: Complicated desires for information about transplant	Participants wished they had known more about side effects, emotional responses to transplant, and recovery timelines and duration	<ul style="list-style-type: none"> <li>Website's search function allows users to search for written peer support in which survivors share their experiences about these topics; reading multiple stories educates users about the range of possible experiences</li> <li>Disclaimers remind users that everyone's experience is different and that they should talk to their healthcare providers to learn about their specific risk</li> <li>Resources provide information about talking with healthcare providers, stress and coping, links to therapy services, and other relevant topics</li> </ul>
	Participants varied in how much information they wanted about transplant	<ul style="list-style-type: none"> <li>Website provides easy access to psychoeducational resources and links for users who do not want to read written peer support</li> <li>Users can apply a filter function to hide stories with substantial negative content if they prefer to avoid this kind of information</li> </ul>
	Participants' interest in getting more information about transplant changed over time	<ul style="list-style-type: none"> <li>At each login, users can choose to focus on psychoeducational resources and links rather than reading written peer support</li> <li>Users can read recommended stories and then explore additional stories if they find they want more information</li> <li>Users can save, print, or email selected favorite stories and revisit them as desired</li> <li>Users can use a filter function to hide stories with substantial negative content when they prefer to avoid this kind of information</li> </ul>
Theme 2: Complicated desires for peer support	Most, but not all, participants were interested in reading written peer support (e.g., due to the perception that it would increase their anxiety)	<ul style="list-style-type: none"> <li>Website provides easy access to psychoeducational resources and links for users who do not want to read written peer support</li> <li>Users can use a filter function to hide stories with substantial negative content if they prefer to avoid this kind of information</li> <li>Psychoeducational resources include instructions and audio for guided stress management as well as tips for coping and links to sites offering therapeutic services</li> <li>Disclaimers suggest helpful links in case users begin to feel anxious while reading about others' transplant experiences</li> </ul>
	Participants sometimes thought that others would find peer support useful (e.g., other patients, caregivers), even if they didn't	<ul style="list-style-type: none"> <li>Instructions for using the website may include the suggestion that caregivers can use it to learn more about transplant</li> </ul>
	Participants thought it was critical for users to feel they can trust what they are reading on the website	<ul style="list-style-type: none"> <li>Text describes that the stories reflect real experiences and that experiences differ across individuals, recommending discussing specific concerns with healthcare providers</li> <li>Psychoeducational resources and links focus on high quality, trusted sources</li> <li>Medical information (e.g., resource section describing different types of transplant) reviewed by medical professionals</li> <li>Psychological information (e.g., resource sections offering coping and stress management information) reviewed by clinical psychologists</li> </ul>
	Participants sometimes described positive experiences they had when they were able to talk with peers	<ul style="list-style-type: none"> <li>Website text describes the specific benefits of having access to written peer support and reading about a variety of transplant experiences</li> <li>Psychoeducational section includes links to websites offering to connect transplant recipients to peer support services</li> </ul>
	Participants' desire for reading written peer support would depend on their	<ul style="list-style-type: none"> <li>Website is designed to offer substantial flexibility in accessing stories and psychoeducational website content, based on feedback</li> </ul>

Theme	Elements of the theme	Examples of resulting website features
Theme 3: Recognition that transplant experiences varied substantially, making it important to present written peer support in a way that accounts for a variety of unique transplant experiences	changing feelings/needs over the course of treatment--transplant is a <i>process</i>	about the most common needs, motivations, and preferences of transplant survivors
	Written peer support needs to account for a broad range of experiences	<ul style="list-style-type: none"> <li>Written peer support has the inherent benefit of allowing users to learn about a range of transplant experiences</li> </ul>
	Some participants described that they would want to read positive or uplifting stories, whereas others described that they would want stories with both positive and negative information (e.g., to feel more prepared)	<ul style="list-style-type: none"> <li>Users can select an option that always hides stories with substantial negative content, or they can use a filter function to hide these stories during a particular visit to the website</li> </ul>
	Some participants emphasized the importance of being able to read stories about particular diagnoses, transplant types, or other factors that could affect the relevance of written peer support to an individual patient	<ul style="list-style-type: none"> <li>Search capabilities allow users to select specific characteristics of stories or writers when searching for stories to read (i.e., rather than assuming the need to match on particular demographic or medical characteristics)</li> </ul>
	Participants felt that the website should be transparent about the substantial variation in transplant experiences	<ul style="list-style-type: none"> <li>Website text and disclaimers are designed to help users understand the substantial variability in transplant experiences and cope with this information and resulting uncertainty (e.g., reminders that everyone's transplant experience is different, reminders to talk with their healthcare providers to learn about their personal risks and options/resources available to them if they experience an adverse outcome, tips for talking with healthcare providers)</li> </ul>

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