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Supportive Care

Tailoring a Survivorship Care Plan: Patient and Provider Preferences for Recipients of Hematopoietic Cell Transplantation

Ellen M. Denzen[1,2], Jaime M. Preussler[1,2], Elizabeth A. Murphy[1], K. Scott Baker[3], Linda J. Burns[1,2,*],
Jackie Foster[1], Lensa Idossa[1], Heather K. Moore[1], Tammy J. Payton[1], Darlene Haven[1],
Balkrishna Jahagirdar[4], Naynesh Kamani[5], J. Douglas Rizzo[6,7], Lizette Salazar[8], Barry A. Schatz[9],
Karen L. Syrjala[3], John R. Wingard[10], Navneet S. Majhail[11]

[1] *National Marrow Donor Program/Be The Match, Minneapolis, MN*
[2] *Center for International Blood and Marrow Transplant Research, Minneapolis, MN*
[3] *Fred Hutchinson Cancer Research Center, Seattle, WA*
[4] *Regions Hospital and HealthPartners, Saint Paul, MN*
[5] *Children's National Medical Center, Washington DC*
[6] *Medical College of Wisconsin, Milwaukee, WI*
[7] *Center for International Blood and Marrow Transplant Research, Milwaukee, WI*
[8] *Caregiver to transplant survivor, Haledon, NJ*
[9] *Transplant recipient, Chicago, IL*
[10] *University of Florida, Gainesville, FL*
[11] *Cleveland Clinic, Cleveland, OH*

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ABSTRACT

This study aimed to develop a survivorship care plan (SCP) that can be individualized to facilitate long-term follow-up care of hematopoietic cell transplantation (HCT) survivors. A sample SCP was developed that included 2 documents: a treatment summary and preventive care recommendations that combined data on treatment exposures routinely submitted by HCT centers to the Center for International Blood and Marrow Transplant Research (CIBMTR) with long-term follow-up guidelines. Focus groups were conducted by phone to characterize the critical patient-centered elements of the SCP. Focus group eligibility criteria included (1) adult patients >1 year post-HCT and their caregivers (3 groups; n = 22), (2) HCT physicians and advanced practice providers (APPs) (2 groups; n = 14), (3) HCT nurses and social workers (4 groups; n = 17), and (4) community health care professionals (3 groups; n = 24). Transcripts were analyzed for saturation of key themes using NVivo 10 software. Patients and caregivers suggested combining the treatment summary and care guidelines into a single document. They also requested sections on sexual and emotional health and the immune system. Providers wanted the treatment summary to focus only on what they absolutely must know. Themes were similar across healthcare professionals, although screening for psychosocial issues was emphasized more by the nurses and social workers. All preferred to receive the SCP electronically; however, hardcopy was considered necessary for some patients. All felt that the SCP would facilitate appropriate post-HCT care. This study highlights the need for an SCP instrument to facilitate HCT survivorship care. Furthermore, it demonstrates the feasibility and value of engaging HCT recipients, caregivers, and providers in developing an SCP. Their feedback was incorporated into a final SCP that was subsequently tested in a randomized trial.

INTRODUCTION

Hematopoietic cell transplantation (HCT) survivors face considerable risks of long-term physical and psychosocial effects that can cause substantial morbidity, impair quality of life, and contribute to late mortality [1–4]. Research shows that graft-versus-host disease (GVHD), subsequent malignancies, infections, and organ dysfunction are common causes of late deaths among HCT recipients [5–10]. Many late complications of HCT can be prevented or their impact mitigated if detected and treated early as part of survivorship care. Guidelines to address screening and preventive care practices for HCT survivors have been developed based on the literature and consensus [1,11,12]; however, research has demonstrated

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[*] Correspondence and reprint requests: Linda J. Burns, MD, NMDP/CIBMTR Health Services Research 500 N 5th Street Minneapolis, MN 55401-1206.

E-mail address: lburns2@nmdp.org (L.J. Burns).

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that survivors typically do not receive all of the recommended care, and that their follow-up is fragmented [13–15].

Survivorship care planning for HCT survivors includes a short-term follow-up phase for the first 3 to 12 months post-HCT, followed by long-term follow-up care beginning at 1 year [1,11,12]. Both transplantation center clinicians and community healthcare professionals may be involved in the survivorship care of patients. As transplantation centers expand care for a growing number of HCT recipients, the need for coordination of care across community hematologists/oncologists, other specialists, and primary care physicians will increase. Survivorship care plans (SCPs) can facilitate the successful transition of HCT recipients from transplantation centers back to the community and overcome transition barriers [16].

To increase awareness of late complications and recommended preventive care, the Commission on Cancer implemented a requirement that all oncology patients receive an SCP by January 2019 [2]. However, barriers to implementation have been identified in the literature [17–21]. The most common barrier identified for primary care physicians is insufficient knowledge of cancer survivor issues [17]. Moreover, cancer survivors frequently are not included in development of SCPs, and therefore SCPs are not targeted to the specific needs of those individuals [18]. Patients report liking SCPs but often view them as too technical or not having enough health promotion/prevention recommendations. Furthermore, no standardized SCP instruments are available for HCT survivors, and SCPs available for other cancer survivors are difficult to adapt to this population. Time needed for health care providers to complete the SCP also has been cited as a barrier [17]. A proposed solution to address these barriers is a standardized template designed to automatically populate fields to decrease provider burden [17]. To impact survivors' needs, it has also been suggested that SCPs be tailored to HCT or to the specific malignancy or hematologic disease [22].

The objectives of the present study were to identify HCT patient and provider (both transplantation and nontransplantation) preferences for SCPs and to improve the patient-centeredness of a prepopulated SCP template.

METHODS

Participant Eligibility Criteria and Recruitment

A convenience sample was used to enroll focus group participants from 4 stakeholder audiences: patients and caregivers, HCT physicians and advanced practice providers (APPs; physician assistants and nurse practitioners), HCT nurses and social workers, and community healthcare professionals. Inclusion criteria were intentionally broad to capture a range of perspectives. Patients and caregivers were eligible if the patient was age ≥18 years at the time of HCT and the patient was ≥1 year post-HCT. Any disease diagnosis, HCT type, and graft source were permitted. HCT healthcare professionals were eligible if they were a physician, APP, nurse, or social worker practicing at a transplantation center and routinely cared for HCT recipients. Eligible community healthcare professionals included physicians (hematology/oncology specialists or primary care pediatric, internal medicine, and family medicine physicians) and APPs with or without clinical experience in caring for post-HCT survivors. Patients and caregivers were excluded if they were not fluent in reading and speaking English. Community healthcare professionals were not eligible if they performed HCT or routinely cared for patients undergoing HCT.

Patient and caregiver recruitment efforts included direct mail, e-mail, social media, and through transplantation centers. Community healthcare professionals were recruited by a vendor, and HCT healthcare professionals were recruited from a research advisory panel to the National Marrow Donor Program (NMDP)/Be The Match via e-mail. Patient and caregiver participants were screened to include diversity in length of time since HCT, diagnosis, distance to transplantation center at time of HCT, level of education, sex, ethnicity, race, type of provider for post-HCT follow-up care (eg, transplantation physician, hematologist/oncologist, or primary care physician), and geographic location. HCT and community healthcare professionals were screened to include diversity in representation of years in practice, experience in caring for post-HCT recipients (specific to community healthcare professionals), and geographic location. The study was approved by the NMDP/Be The Match Institutional Review Board.

Sample SCP

The sample SCP consisted of 2 parts: (1) a treatment summary (Supplementary Figures 1 and 2 for patients/caregivers and healthcare professionals, respectively), which identified important HCT data related to the risk of developing late complications (ie, age, sex, HCT type, graft source, chemotherapy, total body irradiation, steroid use, GVHD) routinely submitted by HCT centers in the United States to an international, federally funded HCT outcomes registry, the Center for International Blood and Marrow Transplant Research (CIBMTR); and (2) preventive care recommendations based on published guidelines for long-term HCT survivors [1,23] (Supplementary Figures 3 and 4 for patients/caregivers and healthcare professionals, respectively). In contrast to the sample SCP for healthcare professionals, the sample SCP for patients and caregivers incorporated principles of plain language to meet the needs of those with different levels of health literacy. These principles included the use of logical organization with the reader in mind, active voice, short sentences, common words, and such design features as ample white space for reading ease [24].

Focus Group Procedures

Focus groups were conducted via phone call to obtain feedback on the SCP. Sample treatment summaries and preventive care recommendations were distributed to participants before the calls. There were 2 to 4 groups per stakeholder category to ensure that observations were made not in just 1 group. Each focus group consisted of 4 to 10 participants and was 60 to 90 minutes long. Independent, experienced moderators (E.A.M. and D.H.) with background knowledge of HCT survivorship care issues facilitated the focus groups following a discussion guide to standardize and structure the discussion.

The protocol team, which included patient and caregiver research partners, developed the discussion guide a priori. Major themes included (1) experience with access to/providing follow-up care after HCT, (2) feedback on the content and usefulness of the SCP, and (3) preferences for SCP delivery and implementation.

Proceedings were recorded and then transcribed verbatim for thematic content analysis. Focus group participants received $50 (patients and caregivers) or $100 (healthcare professionals) Visa gift cards as honoraria.

Focus Group Analysis

Systematic, transcript-based analysis was performed concurrently with data collection to identify saturation of themes across the data [25]. Two experienced protocol team members (J.M.P. and T.J.P.) familiar with the area of study, and preliminary research reviewed and defined the themes, developed initial codes (nodes), and reviewed the data. Coded textual data were explored inductively using content analysis for saturation of themes to generate categories of codes, explanations, and hierarchical relationships at an increasingly general level [26]. NVivo 10 software (QSR International, Doncaster, Australia) was used to analyze the data. The reliability and validity of coded data were assessed through intercoder agreement measures ($\kappa > .75$ is standard for reliable coding) [27]. To ensure consistency in subsequent analysis steps, an additional study team member resolved any remaining intercoder discrepancies in the text passages.

RESULTS

Participant Characteristics and Discussion Guide

A total of 12 focus groups were held (3 with patients and caregivers and 9 with healthcare professionals) with a total of 77 participants, including 19 patients, 3 caregivers, and 55 health care professionals. A majority (59.1%) of the HCT recipients, with a median age of 46 years at the time of HCT, continued to receive follow-up care from their HCT physician (Table 1), and all had undergone allogeneic HCT. Healthcare professional focus group participants included HCT physicians and APPs (n = 17), nurses and social workers (n = 14), and community healthcare physicians and APPs (n = 24). Healthcare professional participants represented all regions of the United States, with <10 to >20 years in practice and a range of transplantation center and community patient volumes (Table 2). The discussion guide for the focus groups is presented in Table 3.

Patient and Caregiver Themes

Experiences with access to HCT

Patients and caregivers reported having more confidence and trust in healthcare providers at the transplantation center compared with community healthcare professionals for HCT-related issues. Furthermore, they experienced challenges in accessing care in the community due to those providers' unfamiliarity with HCT:

> *"I don't have a local primary care physician. Initially following transplant for about 2 years, maybe even 2 and a half years, I tried to establish [care with] someone locally, and we just had lots of problems. They were not very willing to work with my transplant doctor…transplant center, and so I just sort of have given up."*

Regardless of where they received post-HCT care, patients and their caregivers faced challenges with scheduling follow-up examinations and tests. Patients reported receiving care for HCT-related effects and complications from as many as 12 specialists. Even when specialists were in the same institution, coordinating the appointments (eg, scheduling multiple same-day appointments to reduce travel) was difficult and a source of distress.

Perspectives on usefulness of the SCP

Patients and caregivers preferred that the SCP be a single document with a glossary of medical terms in language they could understand. They wanted the treatment summary to include details about all chemotherapy and radiation therapy received, any emotional (psychosocial) care, and diagnosis/complications of GVHD. Patients and caregivers felt that the preventive care recommendations could be more personalized to "speak" directly to them and be better organized by body system. Requests included adding robust sections on sexual and emotional (psychosocial) health and the immune system. (Table 4). They also suggested a space for notes to keep track of contact information for multiple specialists and healthcare providers.

Table 1
Characteristics of Focus Group Participants, Patients and Caregivers (n = 22)

Characteristic	Value
Participant	
Patient	19 (86.4)
Caregiver	3 (13.6)
Patient age at transplantation, yr, median (range)	46 (26-69)
Time since transplantation, yr, n (%)	
1-2	12 (54.5)
3-5	10 (45.5)
Transplant type, n (%)	
Allogeneic (unrelated adult donor)	20 (90.9)
Allogeneic (unrelated cord blood unit)	2 (9.1)
US region, n (%)	
Midwest	9 (41.9)
Northeast	2 (9.1)
South	5 (22.7)
West	6 (27.3)
Travel time to transplantation center from home, h, mean (range) (n = 12)*	1.1 (.25-3)
Distance to transplantation center from home, miles, mean (range) (n = 10)	320.4 (10-1780)
Provider for post-transplantation follow-up care, n (%)	
Transplantation physician	13 (59.1)
Primary care physician	1 (4.5)
Hematologist/oncologist	7 (31.8)
Both primary care and transplantation physicians	1 (4.5)
Level of education, n (%)	
High school	5 (22.7)
Associate degree	3 (13.6)
Undergraduate or bachelor's degree	7 (31.8)
Graduate or doctoral degree	7 (31.8)
Ethnicity, n (%)	
Not Hispanic or Latino	21 (95.5)
Hispanic or Latino	1 (4.5)
Race, n (%)	
White	21 (95.5)
Did not disclose	1 (4.5)

* Includes travel by car and/or airplane per 12 participants.

SCP delivery preferences

Patients and caregivers preferred to receive the SCP electronically and were especially interested in a mobile app format and integration with their online health record. Mobility was the key theme:

> *"You'd be able to say to the doctor, "Hey, I'm a transplant survivor, and here's the link to go to," and have a nice little form to download into your chart, because for some of these docs to have something in front of them is what they really need."*

However, they acknowledged that patients without computer access would need a hard copy, and that others may want a hardcopy for taking notes. Additional supportive quotes are included in the Supplementary Table 1.

Healthcare Professional Themes

Experiences in providing follow-up care to HCT survivors

Both HCT and community healthcare professionals acknowledged that the transition away from the transplantation center is challenging and can be difficult for patients and caregivers (Supplementary Table 2). HCT providers voiced concerns that community healthcare professionals might not feel comfortable caring for HCT survivors. Community providers reported that their comfort level in caring for HCT survivors declines with greater time from completion of training, because they do not see these types of patients very often. In addition, when patients return to their care, the information they receive on what care is to be provided in the community setting might not be understandable to them. There was also concern, given the many providers of care involved, about poor coordination of care:

> *"You don't necessarily know if other specialists have gotten the same list…so [it's difficult] to know what's been done and then what you're responsible for."*

Perspectives on usefulness of the SCP

Healthcare professionals wanted the treatment summary to focus only on what they must know to care for their patient, with information on complications, toxicities, post-HCT procedures, psychosocial needs and GVHD details. A schedule of immunizations was especially important to the PCPs. Additional feedback on the treatment summary section is provided in Supplementary Table 3. Feedback on the SCP's preventive care recommendations by healthcare professional group is shown in Table 5.

All healthcare professionals considered the SCP a helpful tool for communicating peer to peer. Community professionals noted that the SCP would be an improvement on the notes received from the HCT center at time of patient transition back to their care:

> *"We (community healthcare professionals) sometimes…don't actually ever get a note back from them [transplantation centers], so it would be nice to have one of these."*

Table 2
Characteristics of Focus Group Participants, Healthcare Professionals

Characteristic	HCT Physicians and APPs (N =14), n (%)	HCT Nurses and Social Workers (N = 17), n (%)	Community Physicians and APPs (N = 24), n (%)	Total (N = 55), n (%)
US region				
Northeast	1 (7.1)	5 (29.4)	10 (41.7)	16 (29.1)
Midwest	4 (28.6)	3 (17.6)	2 (8.3)	9 (16.4)
South	4 (28.6)	2 (11.8)	8 (33.3)	14 (25.5)
West	5 (35.7)	7 (41.2)	4 (16.7)	16 (29.1)
Number of years in practice				
<10	4 (28.6)	9 (52.9)	11 (45.8)	24 (43.6)
10-20	5 (35.7)	7 (41.2)	11 (45.8)	22 (40.0)
>20	5 (35.7)	1 (5.9)	2 (8.3)	9 (14.5)
Annual number of transplants performed at HCT center				
1-50	6 (42.9)	5 (29.4)	-	11 (20.0)
51-150	2 (14.3)	5 (29.5)	-	7 (12.7)
151-500	6 (42.9)	7 (41.2)	-	13 (23.6)
Annual patient volume at community practice				
1-500	-	-	2 (8.3)	2 (3.6)
501-1000	-	-	4 (16.7)	4 (7.3)
>1000	-	-	18 (75.0)	18 (32.7)

Table 3
Focus Group Discussion Guide for Patients/Caregivers and Healthcare Professionals

Patients and Caregivers	Healthcare Professionals
Introductions • What are your questions or concerns about participating in the study? • Are you a transplant recipient or caregiver? Your or the patient's diagnosis? Type of transplant received? How long it has been since your or the patient's transplant?	Introductions • What are your questions or concerns about participating in the study? • What is your provider type/specialty? What is your work setting? Have you previously cared for HCT patients?
Survivorship care experience • What types of doctors currently provide your/the patient's post-transplant care? How often do you see them? How far is the doctor from where you live? • How sure do you feel about what care you need after transplant? • Have you been asked questions about your treatment that you couldn't answer? Or missed appointments?	Providing survivorship care • How many transplant patients have you seen in clinic? How often do you see them? • How comfortable are you in caring for HCT survivors? What challenges have you faced? • How confident are you in knowing the recommended screening and preventive care for transplant recipients? How do you learn about care recommendations? • What appointment reminder system do you use?
Evaluation of the SCP • What information was of interest to you? Not of interest? • Is there information in this sample tool that is missing? • Is there information that you didn't understand?	Evaluation of the SCP • What information was of interest? Not of interest? • What information is missing? What information not transplant-related would be helpful?
Delivery and implementation • How do you prefer to get survivorship care information? • How would you use a tool like this to talk to your doctor about your post-transplant care? • Do you get reminders for post-transplant follow-up appointments from your doctor(s)? How do you get reminders? • What else would you like to share about the tool?	Delivery and implementation • How will you use something like this? • Is it better than what you receive now? In what ways? Does this solve any challenges you identified earlier? • How do you prefer to get patients' survivorship care information? How do you give this information? • At what time point post-transplant would it be most optimal for you to receive this? • How would you prefer to update patients' care plans as they progress in their follow-up? • How can we best implement a tool such as this? Are there other challenges to implementation? What suggestions do you have for managing these challenges? • What would help with reminding patients of their follow-up care appointments?

SCP delivery preferences

Healthcare professionals acknowledged the need to have the SCP available to patients and caregivers in multiple formats, with a strong preference for a mobile app version for their own use (Supplementary Table 4). The HCT healthcare professionals felt that using the CIBMTR registry data to populate the template would reduce provider burden of completing forms, and thus supported the feasibility and acceptability of implementing the SCP on a larger scale:

> *"I think that anything that we could do that's more automated would be helpful."*

Table 4
HCT Patient and Caregiver Quoted Feedback on the Preventive Care Recommendations in the SCP

Theme 1. Survivors want the care plan to “speak” directly to them
It doesn't feel very personal to me, nor does it, kind of, grab me and say this is really concerning you and you need to pay attention. That's just me, I want something much more personalized. . . I want to see something that says, Okay, well you're at this point and you should be thinking about this, this and this, or talk to your oncology team about this, this and this. For me, personally, I'm not as interested in the high gloss publication, I need something that is much more detailed and to the point.
Theme 2. Survivors want a dedicated section on sexual health and fertility
The thing that really sticks out to me is that skin and genital are listed together and for me, graft versus host disease vaginally is very different than skin. And then the other thing that I think is missing and, at least for me because of vaginal graft versus host disease, is sexual health; sexual function is very important. I would put more along the lines of fertility and female because I know. . .I mean, I'm young but, I know when they told me about chemo and I found out when I was diagnosed, everything had to happen real quick, so I really didn't have time like, think about fertility and stuff like that. Right now, I don't even know where I stand with fertility. I mean, I've never made the effort to go and check, but I know I had a 95% chance of being able to have children.
Theme 3. Survivors want a robust section on emotional (psychosocial) health
Emotional health, I thought honestly might be (described) a little more, you know, psychiatrists, psychologists, because we didn't know what we were getting into in the long term. I agree about the emotional health, it's very. . . nobody here is discussing PTSD and that's very common for BMT transplant recipients.
Theme 4. Survivors need information on the immune system and guidelines for resuming activities
As my doctors have said to me, you may not want to go to a large field sport outing at such and such a time because your immune system is suppressed. So I've always had the question, what would the travel restrictions be, or what would be a guideline for travel.
Theme 5. Survivors have difficulty locating information
There's no mention about GI tract in here, and I've had a lot of GI tract stuff. And, the only issue that I deal with is. . .that I don't see on here would be joints, joint pain. And that is probably part of muscles; you know I'm not real sure.
Theme 6. Survivors request information on cancers
Also maybe at the very bottom where it says “new cancers” you could put “new cancers or pre-existing cancers” like that you need to keep on top of, or maybe they're said there differently. . .like if you have more than one form of cancer, just making sure that you're keeping track of how they interact in the treatment, that kind of thing.
Theme 7. Survivors need assistance in tracking multiple specialists and care providers
If you could put it in a checkup list and you could write in which doctor [to make an appointment with] to keep a record for yourself because I think that piece is so important. Sometimes I have a hard time remembering who I saw for infectious disease. There needs to be a lot more room for the care team [names and type of doctor]. Most of us have listed at least six to ten doctors and one common one seemed to be ophthalmology, was that on there? An ophthalmologist seems to be common and an endocrinologist seemed to be, I heard a couple of times.

BMT indicates blood and marrow transplantation; PTSD, post-traumatic stress disorder.

Revised SCP Template for Patients

Based on focus group feedback, the preventive care section of the SCP was redesigned to include a checklist format and questions to support patient-provider discussion and treatment decision making. An example of the section addressing lung issues is shown in Figure 1. Additional sections were added for sexual and psychosocial health, the immune system, diet/nutrition, and healthcare professional contacts and space was provided to take notes. Plain language principles were again applied. The revised complete SCP template, as shown in Supplementary Figure 5, was designed to be individualized with CIBMTR-reported data and subsequently tested for effectiveness in a randomized controlled study; the preliminary results have been reported separately [28].

DISCUSSION

This study demonstrate the immense value of engaging patients, caregivers, and healthcare professionals from transplantation centers and community practices to improve the design of a tool to improve survivorship care of HCT recipients. Insights from focus groups highlighted the need for a robust, individualized SCP to facilitate optimal survivorship care among patients and caregivers as well as healthcare professionals. These findings are in alignment with several studies that have identified a need for greater consideration of sexuality, mood, social, and general health concerns in survivorship planning [16,18,29−35]. In addition, feedback has suggested that SCPs can potentially ease transitions to long-term HCT follow-up care in the community, increase patient and provider understanding of risk factors, increase awareness of screening and treatment for complications, and reduce distress among survivors.

As with all qualitative research, there are limitations to generalizability and design. Most patients were receiving care from their transplant providers, which limited the perspectives from patients receiving post-HCT care in the community. However, patients receiving care from their transplantation providers could have further insight into how the SCPs could better help facilitate their transition. Although participants represented a range of sociodemographic backgrounds, transplantation experiences, and clinical practices, participants were primarily white and not Hispanic or Latino, and only allogeneic HCTs were represented. Therefore, some perspectives might not have been obtained, and our results might not be generalizable to all hematology/oncology or HCT populations. The impact of holding the focus groups by phone versus in-person was unknown; however, all group participants provided comments. A major strength of this study is the variety of stakeholders who participated, including patients, caregivers, and health care providers, which allowed for a broader perspective from those who may be impacted by the SCP.

HCT survivors require coordinated care for many years post-transplantation to achieve optimal patient-reported and clinical outcomes. Although some SCP templates exist, most require significant time and resources (including staff time and funding support) to complete [17,36]. To reduce these barriers, we leveraged health information technology and registry data to develop an SCP that can be populated for an individual patient based on data already provided by the transplantation center to the CIBMTR. This process may reduce barriers and promote care that is individualized as well as generalizable to all HCT recipients. The SCP has been incorporated into a multicenter, prospective randomized controlled study in comparison with a transplantation center's standard care of adult HCT survivors; the preliminary results have been reported separately [28]. However, more research is needed to evaluate the impact of this and other SCPs on health behaviors and care utilization. Evidence is also needed regarding the most efficient and effective ways to deliver SCPs to educate patients and healthcare professionals.

Table 5
Healthcare Professionals' Feedback on the Preventive Care Recommendations

HCT Nurses and Social Workers	HCT Physicians and APPs	Community Physicians and APPs
Theme 1. The helpfulness of the care plan compared to the current standard		
I think the care plan is a great tool both for patients and for referring oncologists or providers that we are sending people back to; it's pretty comprehensive in its review, systems and possible complications.	So, is it better than what I have now? Absolutely. As something that would be generated from our data that's already been submitted to CIBMTR, with some data and recommendations that I could also provide to referring docs.	I think it's great information. From a family practice standpoint, to get this as a discharge summary would be excellent. It gives us all the information about the patient right in front of us.
Like what we're trying to do here, a workbook that they can take with them to work through life long and just keep that record for themselves. Because I think it would be just a little bit more specific [to the patient].	Creating these treatment summaries on our own is very tedious and I would even estimate that each patient takes about a couple of hours to go through all of the records and kind of create their treatment summary. So having something created like this at least as a start I think is a huge help.	We sometimes. . .some of the transplant centers we refer to, we don't actually ever get a note back from them, so it would be nice to have one of these.
Theme 2. More robust information on psychosocial screening and referral is needed		
I would actually like it if sexual and reproductive health could be together, and if the sexual dysfunction was out of the psychosocial, because it makes it very easy for to defer asking about those things. It also doesn't say who it's going to, like who is going to recognize the symptoms, and I was just a little worried about that. I think there needs to be official screening for their symptoms. Often what we find with the local providers, when the patients go back to them, they don't have a social worker in their office. And they have no one to refer to, or they don't know how to refer their patient for psychosocial services. The only other thing that I would add. . .in the psychosocial section, is to regularly assess the level of spousal and caregiver support.	None	None
Theme 3. Make the care plan specific to the patient		
Even something as easy as immunizations post-transplant might be a little bit different for somebody who is treated for GVHD on steroids and then their immunizations needed to be started a little bit later. I think if it is as specific as possible to referring providers, they would love that.	I think if you were really hoping to make this a really functional document, that really educates providers as well as patients, I would suggest maybe a bit more specificity. This does not perform that kind of duty where it allows you to individualize, meaning "okay, well they never got total body radiation, so maybe they're not at risk for cataracts". In other words, I'm presenting everything instead of being able to limit it to what is actually applicable to that patient, is what the care plan to me looks like.	This one is very non-specific. Basically these are suggestions and things to look out for, but it's really nothing that concrete.
Theme 4. Immunization schedules are important for community providers		
None	I think one thing that is helpful is it says "immunizations according to public guidelines" but the local doc may not have those guidelines available, so I think it would make it more likely that they'll get effective intervention if you can link to the published guidelines for the immunizations.	I felt like there was a little bit of a lack of detailed instruction. Immunizations according to published guidelines - I find this confusing; do you mean general population guidelines or are there specific guidelines for someone who's been through bone marrow transplant?
Theme 5. Other critical elements for the care plan		
Under the oral section - more specifics to look for mouth sores or changes or some of those oral chronic GVHD specific symptoms that they might not really recognize as GVHD in the beginning.	The other thing is weight management and diet. That's really important in some of our allogeneic population.	I would also maybe add the most important system, which is the hematological system. Make sure that the patient had their counts in check. Make sure that their numbers are up to par.
I'm thinking of diet and nutrition.	There are concerns that once they get to a point where they have symptoms, then you've already lost lung function [as with] other complications, including cardiac issues, so I think for cardiac and the respiratory issues, having more of a frequency recommendation, and triggers to do more aggressive evaluation of those patients, would be helpful for the person who normally doesn't deal with [these] types of complications.	

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(A) **Blood and Marrow Transplant Recommendations for Preventive Care**
Patient Name: John Smith **Date of Birth:** 4/22/1961

LONG TERM EFFECT **Risk Factors:** Male, Adult, GVHD, Steroid exposure, TBI	**RECOMMENDATIONS FOR ANNUAL PREVENTIVE CARE**
Lungs	• Routine lung exam • Discuss tobacco use and quitting smoking, if applicable • Pulmonary function tests and imaging studies (e.g. chest x-ray, CT scan) for if you currently have breathing problems or a history of breathing problems • Lung exams and pulmonary function tests may be needed more often

(B) **Your Blood and Marrow Transplant Survivorship Care Plan**
For: John Smith

RECOMMENDATIONS FOR YOUR ANNUAL PREVENTIVE CARE	
LUNGS	**QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES**
○ Lung exam at least 1 time every year If you have problems breathing or have breathing problems in the past, you may need more tests such as: ○ Pulmonary function tests ○ Chest x-ray ○ CT scan ○ Because you have a history of GVHD, you might need to have lung exams and pulmonary function tests more often. Talk to your doctor about when you should have these check-ups. ○ Don't smoke or use tobacco. Stay away from places where people usually smoke.	• What can I do to minimize my risk of getting infections? • What tests should I have and how often? • What can I do to help me quit smoking?

CT, computerized tomography; GVHD, graft-versus-host-disease; TBI, total body irradiation

Figure 1. Example of design and format changes for preventive care recommendations for lung issues. (A) Sample format. (B) Revised format based on feedback from focus groups.

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SUPPLEMENTARY DATA

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