



Survivorship

Survivor and Clinician Assessment of Survivorship Care Plans for Hematopoietic Stem Cell Transplantation Patients: An Engineering, Primary Care, and Oncology Collaborative for Survivorship Health



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A B S T R A C T

The long-term care of hematopoietic stem cell transplantation (HSCT) survivors poses special challenges owing to a myriad of possible chronic and/or late complications. Survivorship care plans (SCPs) have been proposed as tools to communicate information on the late effects of treatment and recommended follow-up care to clinicians and survivors. The primary aims of this study were to determine SCP content and format, as well as to assess the preferred timing of SCP provision following HSCT. HSCT survivors and nontransplantation clinicians (oncologists and primary care physicians) were invited to participate in a survey evaluating the usefulness and utility of a sample HSCT-specific SCP with a treatment summary generated by autopopulation from an electronic health record (EHR). All participating HSCT survivors (n = 29) and clinicians (n = 18) indicated a desire to receive an SCP. More than 85% of the participants perceived information about treatments received, recommended follow-up and health maintenance including vaccinations, survivor and clinician resources, and graft-versus-host disease and other late/chronic side effects to be useful. The majority of survivors also believed that care team contact information was useful. In addition, >85% of survivors and clinicians agreed that the SCP increased their understanding of treatments and chronic/late side effects, improved health care provided, and were satisfied with the SCP and found it understandable and easy to use. The majority of survivors indicated that additional information should be added to the SCP, whereas some clinicians deemed the SCP too long. Survivors preferred to receive the SCP as a paper document at the end of a regular follow-up visit and review it with a cancer clinician, whereas clinicians preferred to receive the SCP through the EHR. These findings will help improve the design of future SCPs for use by HSCT survivors and clinicians. Future work will include leveraging the EHR to ease the burden of creating user-centered documents.

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INTRODUCTION

Worldwide, roughly 60,000 hematopoietic stem cell transplantations (HSCTs) are performed annually to treat various malignant and nonmalignant conditions [1]. Long-term HSCT survivors, defined as those who are alive and without disease recurrence at 12 months post-HSCT, are a growing population. It is estimated that the number of HSCT survivors will increase

by 5-fold to 500,000 by 2030 [1]. Although HSCT may control or even cure underlying disease, it can entail numerous chronic complications. HSCT survivors face potential acute and chronic graft-versus-host disease (GVHD), persistent or late complications from chemotherapy, and a host of wellness problems, including physical, emotional, and financial toxicities [2–4]. Two-thirds of HSCT survivors have at least 1 chronic condition, and survivors are 3.5-fold more likely than a sibling to develop a severe or life-threatening health condition [5]. Owing to these concerns, post-HSCT care is complex, and close coordination is imperative [6].

At some point after successful HSCT, a survivor is transitioned from the transplantation center back to local clinicians,

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such as a local oncology or primary care clinician. This transition marks a period of potential vulnerability and uncertainty that may unmask or exacerbate care coordination deficits [2,7–9]. Although published guidelines and recommendations for HSCT survivor care exist, nontransplantation clinicians may be unfamiliar with these recommendations or lack confidence in treating these complex patients [10–13]. Communication and a formal care transition process between transplantation and nontransplantation clinicians are needed to help minimize clinician uncertainty and prevent further care gaps for survivors. In addition, HSCT survivors report desiring more information about their long-term health maintenance needs [11]. Therefore, both survivors and nontransplantation clinicians need additional support to ensure that survivors receive high-quality care. This is especially important for those who live far away from the transplantation center. Research shows that these survivors have worse health outcomes compared with survivors living closer to transplantation centers, possibly owing to the compounding of care fragmentation, difficulty in regularly returning to the transplantation center for follow-up, and local clinician inexperience with recommendations [8].

One proposed solution to meet the care coordination and information needs of HSCT survivors and nontransplantation clinicians is the creation and use of survivorship care plans (SCPs) and associated care planning visits. The Institute of Medicine has envisioned that SCPs will be created after the completion of treatment and used in cancer survivorship care planning sessions to educate survivors and their clinicians on their diagnoses and treatments, long-term complications, and recommended follow-up care [14,15]. Although SCPs are applicable to all types of cancer, they are more widely available for solid tumor cancer survivors and are not frequently provided after HSCT [6,16,17]. This is due in part to the complicated national recommendations for follow-up care and the varied, complex patient population with extensive monitoring and multifaceted care needs, including reimmunization and GVHD management [2,10].

SCPs have been shown to increase primary care physicians' comfort with the care of cancer survivors and awareness of necessary surveillance [17,18]. In addition, cancer and HSCT survivors who received an SCP reported decreased anxiety surrounding their diagnosis and increased quality of life compared with those who did not [17,19]. However, SCP creation and provision can be time- and resource-intensive. Using the electronic health record (EHR) to create SCPs has been shown to mitigate some of these barriers while not disrupting clinical workflow [20,21]. In addition, entering HSCT data into fields with discrete values in the EHR not only facilitates SCP creation and provision, but also supports data collection and reporting for regulatory purposes.

The American Society for Blood and Marrow Transplantation recommends an SCP for every HSCT survivor discharged from transplantation center treatment to facilitate follow-up care discussions and inform clinical decision making [10]. Similarly, the Foundation for the Accreditation of Cellular Therapy and the Joint Accreditation Committee recommends “infrastructure and policies... in place for provision of appropriate long-term follow-up, treatment, and plans of care” [22]. However, there are no publicly available SCPs specifically for HSCT survivors, although generic templates from the American Society of Clinical Oncology, Journey Forward, and OncoLink can be used [23–26]. Despite the need of SCPs for HSCT survivors to assist in coordinating care and facilitating the recommended health screening and surveillance, there is a dearth of research on the use of SCPs in this population [10,27,28]. As a first step

toward meeting this need, we surveyed HSCT survivors and nontransplantation clinicians (oncologists and primary care) to determine their HSCT survivorship information needs. The objective of this study was to determine the SCP content and format preferred by HSCT survivors and nontransplant clinicians, as well as the preferred timing of SCP provision.

METHODS

Setting and Participant Population

We conducted a survey study of HSCT survivors and referring community oncology and primary care clinicians. All study activities were approved by the University of Wisconsin (UW) Health Sciences Institutional Review Board.

HSCT Survivors

HSCT survivors were recruited from UW bone marrow transplantation clinics or from the Madison chapter of the cancer community support group Gilda's Club. Survivors were eligible if they (1) had a hematologic diagnosis, including malignant and premalignant conditions; (2) had undergone HSCT; and (3) were at least 12 months from the date of the last HSCT. Survivors were ineligible if their hematologic condition had relapsed and they were actively undergoing treatment. Written consent was obtained from each survivor participants by a member of the research team.

Clinicians

Primary care and nontransplantation oncology clinicians (physicians, advanced practitioners, and registered nurses) were approached by the research team to participate in a survey regarding HSCT SCPs. Clinicians were eligible to complete the survey if they endorsed providing care to HSCT survivors. Clinician consent to participate in the study was implied based on proceeding with the electronic survey.

Survey Design

The 2 groups—survivors and clinicians—were surveyed to assess their views on the preferred content of an SCP for HSCT survivors. Each survey was accompanied by a sample allogeneic HSCT-specific SCP to serve as the basis for feedback.

Sample SCP

We created a sample 17-page SCP consisting of a diagnosis and treatment summary, care team contact information, follow-up care and health maintenance recommendations, information on late and chronic effects of treatment, and HSCT survivor resources (Supplement 1). A team consisting of clinicians (transplantation, oncology, and primary care), health systems engineers, and informatics and survivorship experts developed the sample HSCT-specific SCP such that it could be integrated into the EHR for future EHR-based SCP creation and provision. The EHR was chosen for SCP generation to complement UW's efforts to discretely capture HSCT data, as well as to reduce the time and personnel resources needed to generate HSCT-specific SCPs. The sample SCP was based on existing EHR-based UW templates for solid tumor survivors, which incorporate the elements recommended by the Institute of Medicine and feedback from primary care practitioners [14,15,18,20]. HSCT-specific elements were generated using current American Society for Blood and Marrow Transplantation and Center for International Blood and Marrow Transplant Research (CIBMTR) recommendations [10,29].

The SCP template was personalized for a hypothetical female patient who had received an allogeneic matched unrelated donor transplant of peripheral blood stem cells to treat myelodysplastic syndrome. This hypothetical patient had also undergone chemotherapy before transplantation and was diagnosed with both acute and chronic GVHD post-transplantation. Thus, in this sample case, personalization included providing recommendations for screening after chemotherapy, screening appropriate for female survivors, and information on managing acute and chronic GVHD, as well as complications related to specific laboratory test abnormalities (eg, ferritin for iron overload, low vitamin D).

Surveys

A 30-question survey was e-mailed or mailed to participants, depending on their preference. The surveys were analogous for the 2 groups, eliciting survivors' and clinicians' views on the sample HSCT-specific SCP for our hypothesized patient, including content, usability, format, and delivery of the care plan (Supplement 1). Participants rated content on a 5-point Likert scale ranging from “not at all useful” to “very useful,” with a sixth option for “don't include,” and utility and format on a 5-point Likert scale ranging from “strongly disagree” to “strongly agree,” with a sixth option for “no opinion.” Study participants received up to 2 e-mail or phone reminders at 7 and 14 days after the initial contact. After completion of the survey, each survivor participant received a \$20 gift card.

Table 1
Participant Characteristics for BMT survivors (N=29) and Clinicians (N= 18)

Survivor Variables	Frequency n (%)	Clinician Variables	Frequency n (%)
Age (mean, SD)	58.3 (10.8)	Age (mean, SD)	43.1 (9.9)
Years Since Bone Marrow Transplant		How many years have you been in clinical practice	
1 to 5 years	21 (72.4)	Less than 10 years	9 (50.0)
More than 5 years	8 (27.6)	10 or more years	9 (50.0)
Distance of home from Bone Marrow Transplant Center		Practice Distance from Bone Marrow Transplant Center	
Less than a one-hour drive	10 (34.5)	Less than a one-hour drive	14 (77.8)
One to two-hour drive	15 (51.7)	One to two-hour drive	4 (22.2)
More than a two-hour drive	4 (13.8)	More than a two-hour drive	0 (0)
Sex		Sex	
Male	13 (48.1)	Male	6 (33.3)
Female	14 (51.9)	Female	12 (66.7)
Hispanic or Latino Ethnicity	0 (0)	Hispanic or Latino Ethnicity	1 (5.6)
Race		Race	
White or Caucasian	27 (100)	White or Caucasian	14 (77.8)
Highest Level of Education		Asian	2 (11.1)
High School Graduate	4 (14.8)	Other	1 (5.6)
Some College	9 (33.3)	Prefer not to answer	1 (5.6)
Associate Degree	2 (7.4)	Professional Degree	
Bachelor's Degree	9 (33.3)	Physician	13 (72.2)
Master's Degree	2 (7.4)	Advanced Practitioner	4 (22.2)
Professional Degree (MD, JD)	1 (3.7)	Other (RN, MA, Patient Navigator, PT, OT)	1 (5.6) RN
Household Income		Type of Practice	
<\$24,999	1 (3.7)	Primary Care	10 (55.6)
\$25,000-\$49,999	0 (0)	Oncology	7 (38.9)
\$50,000-\$74,999	5 (18.5)	Other- Cancer Survivorship	1 (5.6)
\$75,000-\$99,999	6 (22.2)	Survivorship Care Plan (SCP) Exposure	
\$100,000-\$149,999	5 (18.5)	Seen a SCP for an oncology patient	11 (61.1)
\$150,000+	4 (14.8)	Seen a SCP for a HSCT patient	2 (11.1)
Prefer not to answer	6 (22.2)	Discussed a SCP with an oncology patient	9 (50)
Survivorship Care Plan (SCP) Exposure		Discussed a SCP with a HSCT patient	2 (11.1)
Received a SCP	5 (17.2)	Referred an oncology patient to receive a SCP	4 (22.2)
Discussed an SCP of your own	8 (27.6)	Referred a HSCT patient to receive a SCP	1 (5.6)
Been referred to receive a SCP	1 (3.4)	Not Sure	1 (5.6)
None of the above	20 (69.0)	None of the Above	6 (33.3)

Survey Timeline

Recruitment of survey participants and dissemination of surveys began in June 2018 for both groups. All surveys were completed by August 2018.

Statistical Analysis

Statistical analysis was conducted using SPSS version 25 (IBM Corp., Armonk, NY). Summary statistics of observed overall and subscale scores were tabulated. Analyses of survivor and clinician characteristics, perceived usefulness and thoroughness of care plan content, format, and delivery method of plans were determined, and suggestions for improving the SCP were tabulated with descriptive statistics.

RESULTS

Participant Characteristics and Exposure to SCPs

Participant characteristics, including previous exposure to SCPs, are summarized in Table 1. Of the 36 HSCT survivors consented, 29 submitted the survey (81% response rate); however, 2 surveys were incomplete. Twenty-two clinicians were sent the survey, and 18 completed it (11 primary care physicians and 7 oncology physicians; 82% response rate).

Usefulness of SCP Content

The majority of HSCT survivors and clinicians agreed that SCP content was useful (Figure 1). One clinician stated "Overall, I

think the care plan provides excellent information." Survivors echoed this sentiment, with one reporting "I really like the [survivorship care] plan idea and think it will be useful to me." As shown in Figure 1, clinicians and survivors generally rated similar content as very useful, especially information on recommended vaccinations. Overall, compared with survivors, clinicians found information on radiation treatments received and preventative screenings impacted by HSCT more useful. Distinct from clinicians, >85% of HSCT survivors found the following information to be very useful: diagnosis, cancer workup and staging, contact information for the transplantation care team, contact information for their local health care team, and all sections on GVHD.

SCP Utility and Layout

Survivors and clinicians agreed that an SCP improved their understanding of care surrounding HSCT (Figure 2). More than 70% of survivors and clinicians strongly agreed that the SCP would increase their understanding of treatments given, transplantation-related side effects, and GVHD. In addition, 70% of survivors agreed that an SCP would allow them to make better health decisions. All clinicians and survivors agreed or strongly agreed that an SCP would improve follow-up care and care coordination.

More than 85% of survivors and clinicians were satisfied with the SCP and agreed that the sample care plan was understandable, easy to use, and clearly written; however, 22% of clinicians were either neutral or disagreed that information was easy to find. One clinician summarized this feeling: *“Using a 20+ page document to figure out if I need to order an echo for screening after chemo exposure 5 years later is cumbersome.”* More than one-half (56%) of survivors wanted more information, especially about GVHD, to be added to the SCP, whereas 78% of clinicians were neutral or did not want more information added. Despite not necessarily wanting more information overall, some clinicians commented that they would like more information regarding immunosuppression, such as *“how immunocompromised is the patient now?”* and clarification of clinician roles through improved communication, elucidated by *“a phone call or direct e-mail communication by the transplant with the referring oncologist pointing out the plan of care and referring to the survivorship plan and clearly defining how the local clinician can help implement the plan, as specifically as possible. Local clinicians generally are happy to help as long as there is an efficient method of communication and clarity.”* In addition, survivors would like more information regarding a timeline for how long they should be concerned about exposures, such as *“what do I need to avoid and for how long? I felt like there were all these guidelines about what you shouldn't do after the transplant, but no guidelines stating how long you need to avoid it.”* Clinicians suggested dividing the document into sections for survivors and clinicians. In addition, some survivors suggested further simplification of language and removal of many of the acronyms to make the document easier for all survivors to understand.

Format and Timing of an SCP

All survivors and clinicians reported a desire for SCPs. The majority (93%) of HSCT survivors preferred to receive their SCP as a paper document at the end of a clinic visit, whereas clinicians (89%) preferred a copy available in the EHR. Both survivor and clinician groups would also accept SCPs as a copy on an electronic patient portal (82% and 61%, respectively), a mailed letter or fax (74% and 61%, respectively), or a secure PDF via e-mail (67% and 50%). All survivor participants would find it acceptable to review the SCP with their cancer physician, and the majority also would find it acceptable to review with cancer advanced practitioners (93%), cancer nurses (85%), and cancer navigators (74%). One survivor was worried about reviewing the SCP with a transplant navigator, stating, *“I might have considered a cancer navigator, except BMT patients have such a plethora of complications including, but not exclusive to, GVHD that a navigator might need a second opinion, and that could waste precious time.”*

Nearly all survivors (96%) would prefer to review the SCP as part of a regular follow-up visit in the clinic. Most survivors (70%) would like to receive the SCP immediately on completion of HSCT, and 67% would like to receive it within a few months after HSCT. Regardless of when the SCP was originally applied, many survivors indicated a desire to routinely review the SCP with an oncologist or transplant clinician, stating *“as a patient, I want to know what my transplant clinician is thinking about my care on a regular basis. I don't want to pry [out] answers as I don't often know the questions to ask.”*

DISCUSSION

Overall, the content of our sample SCP was rated highly by both survivors and clinicians. In addition, both groups perceived that use of an SCP would improve follow-up care and

knowledge about HSCT survivorship. Much of the highly rated and personalized content included in our sample SCP is not included in the generic SCP templates, including care team contact information, dates and results of most recent laboratory tests, and necessary future laboratory and screening tests [24–26]. However, survey results also indicated some remaining areas needing improvement, namely the addition of more information about GVHD and immunosuppression, timelines for exposures to avoid, increased clarity in survivor and clinician roles, simplification of language, and a desire for the SCP to be dynamic and personalized.

Although most participants did not want content removed, some voiced a concern that the SCP may be too long. One approach to addressing these concerns could be to condense some content, but that could lead to important information being missed or removed altogether. Another solution could be to format the SCP in user-specific sections to facilitate the search for information in a large document. Making the SCP more user-friendly can be achieved in many ways; however, we believe that using the EHR for creation and provision of HSCT-specific SCPs is the best option. Benefits include reducing the time and resources needed to compile records to create an SCP, creating an electronically searchable document, and allowing for updates to the plan as the survivor progresses through follow-up care. However, such challenges as limited formatting options or the lack of discrete data capture may prevent these benefits from ever coming to fruition [21]. If the document that an EHR creates is not usable and results in problematic user experience, pertinent information could be missed, which could be detrimental to patient safety [30,31].

Although the SCP may be a useful tool for patient education, care coordination, and adherence to screening and maintenance recommendations, it should be acknowledged that it is a tool and not a cure-all. Many comments that we received alluded to the desire for an SCP to set up follow-up appointments and outline every possible complication a survivor could encounter. These expectations regarding the functionality of SCPs are likely unrealistic, and attempting to address them may adversely impact the overall usefulness of the document. For example, attempting to include every possible complication may result in a document that is long and difficult to navigate and use. SCPs can facilitate conversations between clinicians, serve as a reminder of when follow-up appointments should be made, and provide education on possible future complications. However, an SCP will be unlikely to optimize survivorship care if (1) the EHR and clinical workflows do not support discrete HSCT data capture, (2) works systems do not have organizational policies and technologies that are designed to support clinician needs, and (3) roles and responsibilities to support clinical workflows for accomplishing survivorship tasks are not clearly assigned [32,33]. Engineering approaches may optimize work systems by identifying and adapting the work system to allow the use of SCPs to their full-est potential [34].

As one of the first studies to evaluate what HSCT survivors desire in an HSCT-specific SCP, this study has several strengths, including the incorporation of feedback from multiple end user groups with varying needs. Because of how we recruited clinicians, more than one-half of them had seen and used SCPs previously for patients with solid tumor cancers, whereas fewer than a one-quarter of oncology and primary care clinicians nationally have seen SCPs [32,35]. This allowed our clinician participants to provide useful feedback on how our SCP could be used in the HSCT survivor population and on how its usability compares with that of SCPs for patients with other types of

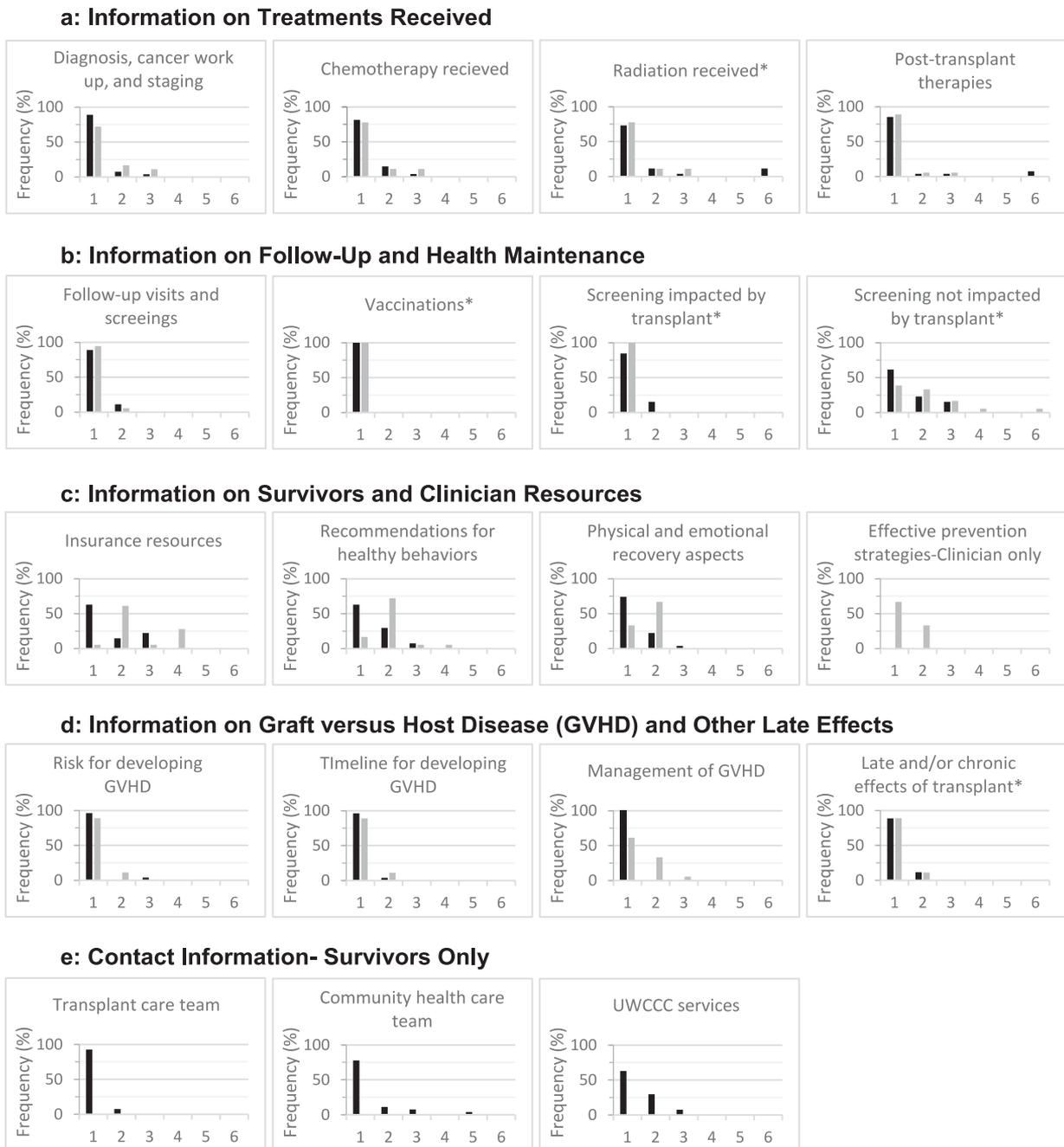


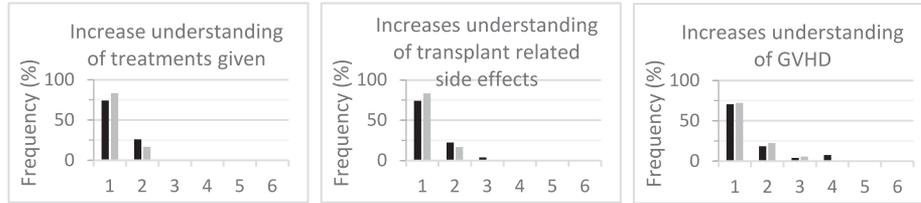
Figure 1. Usefulness of SCP content. On the x-axis: 1, very useful; 2, somewhat useful; 3, neutral; 4, not very useful; 5, not at all useful; 6, don't include. *Missing 1 response (n = 26). UWCCC, University of Wisconsin Carbone Cancer Center.

cancer. Another strength of our study is the inclusion of survivors with lower educational levels (48% with less than an associate's degree) and from rural and suburban areas (two-thirds living >1 hour from a transplantation center). SCPs are especially important for this latter group, who tend to have worse outcomes than their urban counterparts [8].

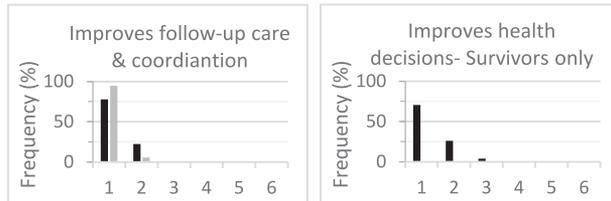
Our study also has several limitations. Selection/recruitment bias likely played a role in who chose to participate in our survey; those who had a stronger desire to improve HSCT survivorship care or were more familiar with SCPs may have responded at higher rates. In addition, although our survivor participants were socioeconomically and educationally diverse, they were

uniformly Caucasian. Although this is an accurate representation of the racial diversity in rural and suburban Wisconsin, it limits the generalizability of our findings to more racially/ethnically diverse populations. Our clinician respondents were primarily within a 1-hour drive from a transplantation center (77.8%) and were predominately physicians (72.2%), which might limit the generalizability to more rural or suburban and nonphysician clinicians. However, this was a pilot study to determine the content, layout, and format preferred by users, and future studies can assess a larger and more representative population. In addition, survivors and clinicians were not provided survivor-specific SCPs, which could have caused them

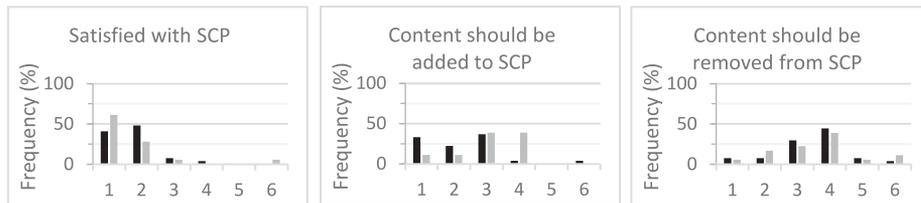
a: Survivorship Care Plan Increases Understanding Regarding Treatment and Late/Chronic Side Effects



b: Survivorship Care Plan Improves Health Care



c: Satisfaction with Survivorship Care Plan and Amount of Content



d: Survivorship Care Plan is Understandable and Easy to Use

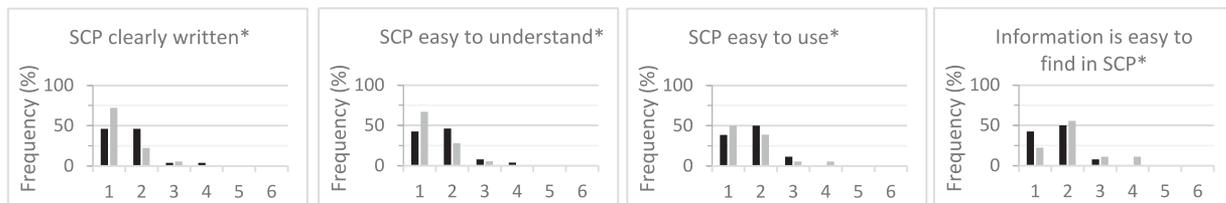


Figure 2. SCP utility and satisfaction. On the x-axis: 1, strongly agree; 2, agree; 3, neither agree nor disagree; 4, disagree; 5, strongly disagree; 6, no opinion. *Missing 1 response (n = 26).

to envision an SCP that would have been more or less useful to them. Finally, both clinicians and survivors were queried on how they supposed they would use the SCP, which could vary from their behavior in a real-world clinical setting.

This feedback will help shape further redesign of the HSCT-specific SCP template to better fit both survivor and clinician needs. Future work includes finalizing the implementation of discrete/structured data for EHR generation of SCPs. As indicated by many participants, if the SCP is not up-to-date or specific to what the patient is currently experiencing, it will be less useful or not used at all. EHR-based creation is necessary to develop dynamic SCPs that incorporate personalized patient data in real time. In addition, SCPs that are dynamic and readily available in the EHR can aid clinical decision making, especially for non-transplant clinicians as they assume more responsibility for HSCT survivorship care [18,36]. Furthermore, the discrete data capture used to create EHR-based SCPs can also inform the reporting to the CIBMTR database as well as the development of a dynamic, real-time EHR registry to facilitate post-HSCT management of survivors. Finally, internal EHR-based creation may allow the delivery of SCPs sooner than CIBMTR-generated SCPs, given the lag in reporting of data to the CIBMTR (estimated lag

time can be 2 to 6 months for a complete data capture). Once a HSCT-specific SCP is built into the EHR and is in use for all HSCT survivors at UW, future work will be needed to evaluate the usefulness of SCPs in the HSCT survivor population.

CONCLUSION

Our sample SCP was well received by both HSCT survivors and clinicians. Notably, all participants expressed the desire to receive an SCP and agreed that the SCP would improve care provided and care coordination. This study will serve to further improve HSCT-specific SCPs with the goal of streamlining SCP creation and provision through use of the EHR.

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SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at doi: [10.1016/j.bbmt.2019.02.003](https://doi.org/10.1016/j.bbmt.2019.02.003).

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