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RESEARCH ARTICLE

Inadequate survivorship care after allogeneic hematopoietic cell transplantation: A retrospective chart review [version 1; peer review: 1 approved, 1 not approved]

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Abstract

Background: Hematopoietic cell transplant (HCT) survivors are at risk of developing long-term complications. Guidelines for survivorship care of HCT recipients were published in 2012; however, the degree to which these guidelines are incorporated into clinical practice is unknown. The purpose of this study was to determine whether providers utilize the 2012 guidelines and analyze whether survivorship-focused providers, provider gender, or provider year of practice influenced adherence to these guidelines.

Methods: Adult allogeneic HCT recipient's medical records were reviewed at the University of Minnesota between 2010 and 2012; only patients who survived without relapse to their 2-year follow-up visit after HCT were included. A semi-quantitative scoring system was developed providing 1 point for each of the 13 organ systems assessed by the 2012 survivorship care guidelines. Data was collected on history, clinical exam, laboratory tests, preventive measures, and counseling. The primary endpoint was the overall score for adherence to the survivorship care guidelines. Wilcoxon rank-sum tests for continuous and Chi-square tests for categorical factors were used to compare the overall score between provider groups (survivorship-focused providers vs others), provider gender, and provider year of practice (≥ 10 years vs < 10 years).

Results: Fifteen providers (9 male, 3 survivorship-focused, 7 with < 10 years of practice) provided follow-up care to 77 HCT survivors. Survivorship-focused providers had a higher median overall score than other providers (median 10 vs 8, $p < 0.01$). Female providers had a higher median overall score than male providers (median 9.0 vs 8, $p < 0.01$). There was no difference in median overall score based on provider year of experience ($p = 0.43$).

Conclusions: In conclusion, survivorship-focused providers were more likely to achieve long-term screening recommendations. However, even within this group, adherence to the 2012 screening

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Any reports and responses or comments on the article can be found at the end of the article.

and preventive practice guidelines was incomplete. Further efforts to automate and standardize the survivorship assessments in HCT survivors are necessary.

Keywords

survivorship, hematopoietic stem cell transplantation, bone marrow transplant, cancer survivorship

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Introduction

Patients who undergo allogeneic hematopoietic cell transplantation (HCT) are typically exposed to chemotherapy and radiation therapy as part of their cancer treatment and transplant conditioning regimens. Two-thirds of HCT survivors have at least one chronic medical illness, and one-fifth of survivors have at least one severe health condition². Their life expectancy is estimated to be 30% lower than the general population because of excess risk of death from second malignancy, cancer relapse, infection, chronic graft-versus-host disease (GVHD), and pulmonary and cardiovascular diseases³. Follow-up care after HCT is essential to screen for long-term complications and institute preventive therapies. To standardize management of complications after HCT, a collaborative group led by the Center for International Blood and Marrow Transplant Research (CIBMTR) published guidelines for survivorship screening and preventive practices for long-term survivors after HCT⁴. The guidelines provide specific monitoring recommendations categorized into 13 organ systems commonly affected in transplant survivors. Although the guidelines were published in 2012, adherence to these guidelines among transplantation oncologists and other clinical providers has not been evaluated.

To determine whether providers utilize HCT survivorship care guidelines, we conducted a retrospective, single-institution case series of provider adherence to the guidelines at the 2-year follow-up visit after HCT. In addition, we analyzed whether survivorship-focused care, provider gender, or provider years of practice influenced adherence to the recommended guidelines for managing HCT survivors.

Methods

Study design and eligibility criteria

A retrospective chart review was performed to identify adult survivors after allogeneic HCT who attended their 2-year post-transplant visit at the University of Minnesota Medical Center between 2012 and 2014. Inclusion criteria included age ≥ 18 years and receipt of allogeneic HCT from a matched related, matched unrelated, or umbilical cord blood donor between 2010–2012. Exclusion criteria included disease relapse before the 2-year visit or lack of a follow-up visit at our center. Data was collected on history, clinical exam, laboratory tests, preventive measures, counseling, and provider. This study was approved by the Institutional Review Board of University of Minnesota Medical Center (1412M58923).

Scoring provider adherence to survivorship care guidelines

For semi-quantitative assessment of adherence to the HCT survivorship care guidelines, a scoring system was developed that provided 1 point for each quality measurement implemented (Table 1). Scores were determined for 13 individual organ systems: immunization status, ocular system, oral system, respiratory system, cardiovascular system, hepatic system, renal system, musculoskeletal system, central nervous system, endocrine system, mucocutaneous system, second cancer screening, and psychological system. Individual system scores were added to determine an overall score for follow-up care. There were 41 questions under the 13 categories. Each individual organ

system score was determined by adding one point for each question addressed. The questionnaire used is available as [Supplementary File 1](#). The overall score assessment was determined by adding one point for each organ system if at least one question in the category for that organ system was addressed. Points were only assigned if there was documentation in the medical chart that a question was addressed; missing data were analyzed as not being addressed.

Study endpoints and definitions

The primary endpoint was the overall score for adherence to the HCT survivorship care guidelines. Secondary endpoints involved analyzing the association between guideline adherence and potential modifiers of follow-up care: provider gender, provider year of experience, and self-reported specialization in survivorship care. Providers were transplantation oncologists who cared for the patients during their 2-year follow-up visit. The time allotted on 2-year visit for providers was 30 minutes. A survivorship-focused provider was a self-identified individual conducting education and research on survivorship.

Statistical analysis

The Wilcoxon rank sum test was used to compare the overall score between provider groups (survivorship-focused providers vs others), provider gender (male vs female), and provider year of practice (≥ 10 years vs < 10 years). For the 13 individual system scores, statistical comparisons between factors were completed using Wilcoxon rank-sum test for continuous and Chi-square test for categorical factors. All analyses were performed using SAS 9.4 (Institute Inc., Cary, NC, USA).

Results

Patient and provider characteristics

Of 111 adult patients surviving to 2 years after HCT, 34 patients were excluded due to disease relapse before the 2-year visit or lack of a follow-up visit at our center. 77 patients who completed a 2-year visit at the University of Minnesota Medical Center were included (Table 2). 15 providers delivered care for these patients. Of these, 6 (40%) were female providers, 3 (20%) were survivorship-focused providers, and 7 (47%) were providers with < 10 years of experience.

Overall and individual scores for adherence to survivorship care guidelines

The median overall score for adherence to survivorship care guidelines was 8.0 (6.0–13.0; Table 3). Notably, providers did not perform assessments in a substantial percentage of patient organ systems, including immune (36.4%), ocular (59.7%), musculoskeletal (62.3%), central nervous (39.0%), endocrine (27.3%), mucocutaneous (27.3%), and psychological (92.2%). In addition, a large majority of providers did not perform second cancer counseling and screening (84.4%). Responses to all 41 questions on the questionnaire are shown in [Supplementary Tables S1 through S3](#). All patients received a perfect score on the renal system assessment, which included blood pressure screening and routine laboratory tests for blood urea nitrogen and creatinine. Laboratory test for hepatic function score was also completed in the entire cohort of patients.

Table 1. Score definition (adapted from 2012 guidelines by Majhail NS et al.⁴).

SYSTEM (SCORE RANGE)	
IMMUNE (0–1) Up-to-date for 2-year immunization (Y/N)	RENAL (0–2) Blood pressure screening (Y/N) BUN/creatinine or urine protein screening (Y/N)
OCULAR (0–2) Clinical assessment of visual symptoms (Y/N) Completion of annual eye exam by an expert or referral made (Y/N)	MUSCULOSKELETAL (0–6) Evaluation of muscle weakness (Y/N) Counseling on physical activity (Y/N) Counseling on fall prevention (Y/N) Counseling on calcium/vitamin D supplementation (Y/N) Assessment of the need for bone density testing (Y/N) Monitoring of bone density if indicated (Y/N)
ORAL (0–3) Education on preventive oral health practices (Y/N) Clinical oral exam (Y/N) Completion of annual dental exam (Y/N)	CENTRAL NERVOUS (0–2) Clinical nervous system exam (Y/N) Evaluation of cognitive function (Y/N)
RESPIRATORY (0–4) Clinical respiratory exam (Y/N) Assessment and counseling on tobacco use (Y/N) Assessment of pulmonary symptoms (Y/N) Ordering a pulmonary function test and radiologic assessment if indicated (Y/N)	ENDOCRINE (0–3) Thyroid function test (Y/N) Assessment of gonadal function (Y/N) Ordering gonadal function test based on symptoms (Y/N)
CARDIOVASCULAR (0–3) Clinical cardiovascular exam (Y/N) Cardiovascular risk factor evaluation and appropriate treatment (Y/N) Education on heart healthy life style, endocarditis prophylaxis (Y/N)	MUCO-CUTANEOUS (0–3) Clinical skin exam (Y/N) Counseling on protection against sun exposure (Y/N) Gynecological exam in women (Y/N)
HEPATIC (0–5) Liver function test monitoring (Y/N) Assessment of the need for hepatitis B/C viral load monitoring (Y/N) Hepatitis B/C monitoring and hepatology/infectious disease referral if indicated (Y/N) Assessment of the need for serum ferritin monitoring (Y/N) Monitoring serum ferritin level if indicated (Y/N)	SECOND CANCER (0–2) Counseling on second cancer vigilance (Y/N) Up-to-date on cancer screening (Y/N)
	PSYCHOLOGICAL (0–5) Psychosocial/quality of life assessment (Y/N) Inquiry about family functioning (Y/N) Inquiry about STD screening and protection (Y/N) Inquiry about sexual functioning (Y/N) Inquiry about substance abuse (Y/N)

Factors Influencing Adherence to Survivorship Care Guidelines

Survivorship-focused providers and other providers had significant differences in completeness of screening assessment. Survivorship-focused providers had a higher median overall score than other providers (median 10 vs 8; $p < 0.01$; Table 3). Survivorship-focused providers were more complete in assessment of the ocular system, oral system, cardiovascular system, musculoskeletal system, central nervous system, and mucocutaneous system (Table 3 and Supplementary Table S1). In addition, survivorship-focused providers were more likely to perform counseling on second cancer awareness and screening than other providers. However, most survivors had no documented assessment of their psychological and behavior health by either survivorship-focused providers or any other providers (85.7% vs 91.2%, $p = 0.52$).

Female providers had a higher median overall score than male providers (median 9.0 vs 8, $p < 0.01$; Table 3). Female providers

covered more organ systems than male providers with higher median scores in the ocular system, cardiovascular system, endocrine system, and second cancer screening and counseling (Table 3 and Supplementary Table S2).

There was no statistically significant difference in median overall score based on provider year of experience (Table 3; $p = 0.43$); however, providers with <10 years of experience performed better in assessments of the immune system, while providers with ≥ 10 of experience performed better in assessments of the endocrine system (Table 3 and Supplementary Table S3).

Dataset 1. Underlying study data with data dictionary

<http://dx.doi.org/10.5256/f1000research.15633.d215885>

Discussion

HCT survivors are at risk of developing long-term complications. Guidelines for survivorship care of HCT recipients were

Table 2. Patient characteristics at 2-year visit.

	All Groups
	N=77
SEX	
Male	41 (53.2%)
Female	36 (46.8%)
TRANSPLANT AGE	
Median(Min-Max)	53.9 (20.6-72.5)
DIAGNOSIS	
Aplastic anemia	4 (5.2%)
Acute lymphoblastic leukemia	9 (11.7%)
Acute myeloid leukemia	30 (39.%)
Chronic myeloid leukemia	3 (3.9%)
Chronic lymphocytic leukemia	3 (3.9%)
Myelodysplastic syndrome	14 (18.2%)
Non-Hodgkin's Lymphoma	10 (13.0%)
Hodgkin's Lymphoma	3 (3.9%)
Multiple myeloma	1 (1.3%)
STEM CELL SOURCE	
Bone marrow	10 (13.0%)
Peripheral blood	32 (41.6%)
Umbilical cord blood	35 (45.5%)
REASON FOR TRANSPLANT	
Relapse	3 (3.9%)
Initial Bone marrow transplant (BMT TX)	69 (89.6%)
Other	5 (6.5%)
TYPE OF DONOR	
Related	33 (42.9%)
Unrelated	44 (57.1%)

published in 2012; however, the degree to which these guidelines are incorporated into clinical practice is unknown. In the present study, we demonstrate that adherence to the 2012 guidelines is sub-optimal and identified areas needing diligent assessment attention in the long-term care of HCT recipients. While all providers followed certain guidelines of survivorship care, such as liver function screening, renal screening, and blood pressure screening, there were several areas identified where extra training in survivorship care would enhance the implementation of screening measures. Our study showed that survivorship-focused providers performed more extensive screening assessments and counseling in 7 organ systems (ocular, oral, cardiovascular, musculoskeletal, central nervous system, mucocutaneous, and second cancer screening) as compared to other providers. Given the discrepancy in these areas, further oncology education in HCT survivorship care for all providers is needed to improve the health of HCT survivors.

Caring for HCT survivors requires understanding their long-term morbidity and probability of high mortality. The challenge for clinicians in caring for HCT survivors is tremendous and a major responsibility of the transplant team. In our case series, there were several important areas where clinicians could improve their assessment of HCT survivors, including immunization assessment and completing immunizations on schedule, assessment of endocrine dysfunction, cardiovascular disease, cognitive function, sexual function, psychosocial and quality of life, inquiry of family functioning, substance abuse, counseling on physical activity, fall prevention, supplementation with calcium/vitamin D, and awareness of second malignancies. All of these areas were noted to be significantly deficient in many patients in our series. Having a provider with a background and interest in survivorship care improved the number of long-term health screenings an HCT recipient received; however, there is still room for improvement as less than a quarter of HCT survivors received a truly comprehensive clinical assessment during their 2-year visit.

Over a decade ago, the Institute of Medicine proposed that all cancer survivors have a survivorship care plan (SCP), which should include a treatment summary and follow-up care plan^{5,6}. The American Society of Clinical Oncology and other professional organizations put tremendous effort into developing various survivorship care models, such as the SCP, treatment summaries, and implementation strategies to attain improved quality care for all cancer survivors; however, the implementation of these SCPs has not been satisfactorily accomplished in oncology practices⁷⁻¹⁰. There are several practical issues: lack of time and staff, lack of coordination and communication among providers, and potentially reimbursement. In addition, evaluation of the benefits in terms of improved outcomes of survivorship care is ongoing^{11,12}.

The post-transplant visit is allocated 30 minutes for each patient, with labs studies completed prior to the provider visit. Addressing complex medical issues and potential complications during 30 minutes is challenging for providers. A high-quality post-transplant visit can only be completed with expert time management and thorough preparation and coordination of care among providers. Using electronic methods or automation to ensure the thirteen identified areas are covered during the 2-year visit would ensure that all HCT patients receive the recommended care.

One proposed strategy to overcome the above-mentioned barriers is a risk-stratified shared-care model with delegation of roles and responsibilities between the oncologist and primary care provider. For example, subspecialists such as a dentist, an ophthalmologist, and a psychologist could be closely involved in coordination of long-term follow-up care¹³. It has been shown that the frequency of health promotion and health behavior discussions are suboptimal by clinicians because of the fact that approximately 25% of cancer survivors are not engaged in any such discussions¹⁴. Cancer survivors are likely to receive appropriate interventions for their comorbid conditions if they routinely follow up with their primary care providers¹⁵. Educating HCT survivors with ongoing care by their primary

Table 3. Hematopoietic cell transplant (HCT) Survivorship Care Score by Subgroups.

	All groups	Other	Survive	P-value	<10year	>10year	P-value	Female	Male	P-value
	N=77	N=56	N=21		N=41	N=36		N=33	N=44	
OVERALL				<0.01			0.43			<0.01
Median (Min-Max)	8.0(6.0–13.0)	8.0(6.0–12.0)	10.0(7.0–13.0)		9.0(6.0–13.0)	8.0(6.0–12.0)		9.0(6.0–13.0)	8.0(6.0–13.0)	
Immune				0.85			0.02			0.15
0	28(36.4%)	20(35.7%)	8(38.1%)		10(24.4%)	18(50.0%)		9(27.3%)	19(43.2%)	
1	49(63.6%)	36(64.3%)	13(61.9%)		31(75.6%)	18(50.0%)		24(72.7%)	25(56.8%)	
Ocular				<0.01			0.66			0.03
0	46(59.7%)	39(69.6%)	7(33.3%)		25(61.0%)	21(58.3%)		14(42.4%)	32(72.7%)	
1	19(24.7%)	11(19.6%)	8(38.1%)		11(26.8%)	8(22.2%)		12(36.4%)	7(15.9%)	
2	12(15.6%)	6(10.7%)	6(28.6%)		5(12.2%)	7(19.4%)		7(21.2%)	5(11.4%)	
Oral				<0.01			0.05			0.08
0	5(6.5%)	3(5.4%)	2(9.5%)		4(9.8%)	1(2.8%)		2(6.1%)	3(6.8%)	
1	60(77.9%)	52(92.9%)	8(38.1%)		33(80.5%)	27(75.0%)		22(66.7%)	38(86.4%)	
2	10(13.0%)	1(1.8%)	9(42.9%)		2(4.9%)	8(22.2%)		8(24.2%)	2(4.5%)	
3	2(2.6%)	0	2(9.5%)		2(4.9%)	0		1(3.0%)	1(2.3%)	
Respiratory				0.13			0.58			0.68
1	1(1.3%)	1(1.8%)	0		0	1(2.8%)		0	1(2.3%)	
2	7(9.1%)	6(10.7%)	1(4.8%)		4(9.8%)	3(8.3%)		2(6.1%)	5(11.4%)	
3	65(84.4%)	48(85.7%)	17(81.0%)		34(82.9%)	31(86.1%)		29(87.9%)	36(81.8%)	
4	4(5.2%)	1(1.8%)	3(14.3%)		3(7.3%)	1(2.8%)		2(6.1%)	2(4.5%)	
Cardiovascular				<0.01			0.87			<0.01
0	3(3.9%)	3(5.4%)	0		1(2.4%)	2(5.6%)		1(3.0%)	2(4.5%)	
1	44(57.1%)	37(66.1%)	7(33.3%)		23(56.1%)	21(58.3%)		12(36.4%)	32(72.7%)	
2	20(26.0%)	12(21.4%)	8(38.1%)		11(26.8%)	9(25.0%)		13(39.4%)	7(15.9%)	
3	10(13.0%)	4(7.1%)	6(28.6%)		6(14.6%)	4(11.1%)		7(21.2%)	3(6.8%)	
Hepatic				0.76			0.82			0.40
1	64(83.1%)	46(82.1%)	18(85.7%)		34(82.9%)	30(83.3%)		25(75.8%)	39(88.6%)	
2	2(2.6%)	2(3.6%)	0		1(2.4%)	1(2.8%)		1(3.0%)	1(2.3%)	
3	10(13.0%)	7(12.5%)	3(14.3%)		5(12.2%)	5(13.9%)		6(18.2%)	4(9.1%)	
5	1(1.3%)	1(1.8%)	0		1(2.4%)	0		1(3.0%)	0	
Renal				0.81			0.63			0.13
1	3(3.9%)	2(3.6%)	1(4.8%)		2(4.9%)	1(2.8%)		0	3(6.8%)	
2	74(96.1%)	54(96.4%)	20(95.2%)		39(95.1%)	35(97.2%)		33(100.0%)	41(93.2%)	
Musculo-skeletal				<0.01			0.60			0.06
0	48(62.3%)	42(75.0%)	6(28.6%)		26(63.4%)	22(61.1%)		15(45.5%)	33(75.0%)	
1	10(13.0%)	7(12.5%)	3(14.3%)		3(7.3%)	7(19.4%)		4(12.1%)	6(13.6%)	
2	6(7.8%)	2(3.6%)	4(19.0%)		4(9.8%)	2(5.6%)		4(12.1%)	2(4.5%)	
3	7(9.1%)	3(5.4%)	4(19.0%)		4(9.8%)	3(8.3%)		5(15.2%)	2(4.5%)	
4	5(6.5%)	2(3.6%)	3(14.3%)		3(7.3%)	2(5.6%)		4(12.1%)	1(2.3%)	
5	1(1.3%)	0	1(4.8%)		1(2.4%)	0		1(3.0%)	0	

	All groups	Other	Survive	P-value	<10year	>10year	P-value	Female	Male	P-value
Central nervous system				<0.01			0.19			0.12
0	30(39.0%)	28(50.0%)	2(9.5%)		17(41.5%)	13(36.1%)		13(39.4%)	17(38.6%)	
1	44(57.1%)	27(48.2%)	17(81.0%)		21(51.2%)	23(63.9%)		17(51.5%)	27(61.4%)	
2	3(3.9%)	1(1.8%)	2(9.5%)		3(7.3%)	0		3(9.1%)	0	
Endocrine				0.42			0.04			<0.01
0	21(27.3%)	18(32.1%)	3(14.3%)		8(19.5%)	13(36.1%)		2(6.1%)	19(43.2%)	
1	48(62.3%)	33(58.9%)	15(71.4%)		30(73.2%)	18(50.0%)		27(81.8%)	21(47.7%)	
2	2(2.6%)	1(1.8%)	1(4.8%)		2(4.9%)	0		1(3.0%)	1(2.3%)	
3	6(7.8%)	4(7.1%)	2(9.5%)		1(2.4%)	5(13.9%)		3(9.1%)	3(6.8%)	
Mucu-cutaneous				<0.01			0.65			0.03
0	21(27.3%)	18(32.1%)	3(14.3%)		13(31.7%)	8(22.2%)		9(27.3%)	12(27.3%)	
1	48(62.3%)	38(67.9%)	10(47.6%)		25(61.0%)	23(63.9%)		17(51.5%)	31(70.5%)	
2	6(7.8%)	0	6(28.6%)		2(4.9%)	4(11.1%)		6(18.2%)	0	
3	2(2.6%)	0	2(9.5%)		1(2.4%)	1(2.8%)		1(3.0%)	1(2.3%)	
2nd CANCER				0.02			0.23			0.05
0	65(84.4%)	51(91.1%)	14(66.7%)		34(82.9%)	31(86.1%)		24(72.7%)	41(93.2%)	
1	3(3.9%)	2(3.6%)	1(4.8%)		3(7.3%)	0		2(6.1%)	1(2.3%)	
2	9(11.7%)	3(5.4%)	6(28.6%)		4(9.8%)	5(13.9%)		7(21.2%)	2(4.5%)	
Psychosocial				0.73			0.49			0.71
0	71(92.2%)	52(92.9%)	19(90.5%)		37(90.2%)	34(94.4%)		30(90.9%)	41(93.2%)	
1	6(7.8%)	4(7.1%)	2(9.5%)		4(9.8%)	2(5.6%)		3(9.1%)	3(6.8%)	

care providers will be an important element in post-transplant care. In general, coordinating the shared care of a cancer survivor between oncology and primary care appears insufficient because of primary care providers' knowledge, attitudes and comfort in caring for cancer survivors^{16,17}. With effective and efficient communication, this strategy is likely a feasible option to achieve.

Several transplant centers have adopted the concept of a dedicated clinic of providers that focus on the long-term effects of cancer and previous treatment and deliver education on healthy lifestyle behaviors to reduce complications and lower the risk of additional cancers, while the non-transplant oncologist focuses on cancer surveillance. Our study suggests the potential benefit of having dedicated providers for HCT survivors as the providers' interest, enthusiasm and additional training would likely lead to a comprehensive review of all important clinical assessment in a well-organized fashion.

Several professional oncology organizations have proposed a SCP in a denotable template and web applications with data storage (e.g., [The American Society of Clinical Oncologists, Journey Forward](#) and [OncoLink](#)) to assist in developing a survivor's own care plan and delivering health education. It is critical to allow the survivors to be actively involved in their SCP. One other potential approach would be to have patients complete their clinical assessment questionnaire prior to their visit; this questionnaire

would allow the provider to focus on clinical assessment and counseling rather than data collection. In addition, the electronic medical record could be customized to ensure a comprehensive assessment by providing clinicians with a SCP to-do list.

Our analysis also supports the notion that some categories in assessment (eg, laboratory testing for liver function, renal function and blood pressure measurement) were completed 100% of the time as simply a result of routine practice. Further work is needed to examine how the electronic medical record can more efficiently automate these measures.

Our analysis may be limited in that it is a retrospective chart review at a single transplant center a few years after guidelines were published. It captures one time point in the management of HCT survivors who are likely followed by their primary care clinic in addition to our transplant clinic; important clinical issues during other visits or by their primary care providers may have occurred. Given there is currently no standard for being an expert in survivorship care, providers also self-reported their expertise in survivorship care. Another factor that has to be taken into account in this chart review is the comprehensiveness of the documentation of topics addressed at these visits. For example, mental health screening may have occurred; however, if not documented, the screening was not captured. Nonetheless, this study is the first step to recognize how

effectively HCT survivorship care is being provided. Despite these limitations, this study demonstrates that providers need more education in long-term complications of cancer treatment, as well as strategies and tools about how to implement these screening recommendations in a timely, efficient manner given the other demands of their clinical practice.

In conclusion, post-transplantation care by survivorship-focused providers was more likely to achieve the long-term screening recommendations set forth by experts from international transplant professional societies; however, there is room for improvement in adherence to the guidelines even within this group of providers. Our study highlights the critical need of survivorship education for providers as well as better tools to automate this process. Given the complexity of caring for HCT survivors,

new comprehensive and efficient tools to improve adherence to these guidelines are needed to provide optimal survivorship care.

Data availability

Dataset 1: Underlying study data with data dictionary [10.5256/f1000research.15633.d215885](https://doi.org/10.5256/f1000research.15633.d215885)¹⁸

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Supplementary material

Supplementary File 1: Study questionnaire.

[Click here to access the data.](#)

Supplementary Table 1: Overall and individual system scores by survivorship-focused vs. other providers.

[Click here to access the data.](#)

Supplementary Table 2: Overall and individual system scores by provider's gender.

[Click here to access the data.](#)

Supplementary Table 3: Overall and individual system scores by provider's experience.

[Click here to access the data.](#)

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This manuscript is aimed at answering an important question in the field of survivorship care after allogeneic HCT. Authors have used a novel and interesting approach to quantify the rate of compliance with recommended guidelines. However, there are several major issues in their methodology:

First, authors have used provider gender, provider years of practice, and providers' focus of practice (survivorship-focused or not) as independent variables. However, considering that survivorship care is provided longitudinally and often by different providers over time, categorizing subjects based on these variables is almost impossible. Which category do we put a patient in if they were seen twice by a female provider and three times by a male provider over the course of two years? Unless patients were seen exclusively by the same providers for the entire period, I do not think we can categorize them accurately based on these characteristics. We cannot take only one visit into account either as survivorship care involves more than a single visit.

Second, for overall score assessment, authors have added one point for each organ system if at least one question in the category for that organ was addressed. The questions grouped together in each category are of very different importance though, and they cannot be a substitute for each other. For example, in the Respiratory System, there are four questions, and one of them is "Clinical Exam," which is very likely to be documented in almost any clinicians' note. Taking this alone as an overall assessment of adherence to survivorship guidelines for the respiratory system will be rather misleading as we can have a group of patients with 0% adherence to PFTs, who are marked as 100% compliant with overall respiratory survivorship care just because they all had a clinical exam.

Third, missing data were analyzed as not being addressed, even though this is not an accurate assumption. Some aspects of survivorship care such as "inquiry about family functioning" or "Inquiry about sexual functioning" are inherently less likely to be documented in the records, whereas other components such as renal function or liver function tests almost always get recorded and can be captured retrospectively. Authors should distinguish these from each other,

and either report missing data separately or state that assessment of adherence in certain areas were not possible.

At the end, an alternative scoring system (or a different reporting methods) that is based on more objective and specific measures instead of lumping together a group of questions with different clinical significance and rates of documentation would be a more reliable and informative approach. For instance, separately reporting on the rate of compliance with PFTs, measurement of bone densitometry, colonoscopy, or referral to ophthalmology is far more informative and reliable than providing a summative score for how many questions in each organ system were addressed.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

No

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

No source data required

Are the conclusions drawn adequately supported by the results?

No

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Allogeneic HCT, GVHD, late effects and survivorship

I confirm that I have read this submission and believe that I have an appropriate level of expertise to state that I do not consider it to be of an acceptable scientific standard, for reasons outlined above.

Reviewer Report 27 September 2018

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Asmita Mishra

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The authors of this study aimed to retrospectively evaluate the utilization of published long-term follow-up guidelines from 2012 for adult allogeneic transplant recipients. This was evaluated in a single institution amongst the fifteen providers at that location.

The authors conclude the following

- Survivorship focused providers are more likely to adhere to the recommendations of the guidelines
- However overall adherence is incomplete amongst all providers and thus further efforts are needed to improve upon this

Suggestions

One of the major limitations of this study includes limited study period. At least 2+ years of additional patient volume can be added to this analysis that is likely to further clarify areas that are routinely being limited and if there has been any performance improvement in survivorship assessment.

Details regarding clinical practice may also be helpful. While authors do note that patients were evaluated at 2 year followup, it would be helpful to know standard practice at the institution i.e. are patients transitioned back to oncologists, primary care etc for followup as several of the long term followup needs as noted by the guidelines, are apart of routine non-transplant long term management, thus reflecting the lack of adherence to all 13 categories. This is alluded to in the discussion regarding proposed strategies.

For provider year of practice ≥ 10 years vs < 10 years was utilized as cutpoint, however the guidelines themselves have been out for ~ 6 years. A difference based on more recent adapters i.e. 5 years may be a better cut off as their practice may be different than those who have been practicing a certain way even prior to guidelines being updated.

The authors noted that there were gender differences in the survivorship care. What did the authors think was the etiology of this?

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

No source data required

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

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