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Ascertainment of Unmet Needs and Participation in Health Maintenance and Screening of Adult Hematopoietic Cell Transplantation Survivors Followed in a Formal Survivorship Program

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This study aimed to ascertain unmet needs in autologous and allogeneic hematopoietic cell transplantation (HCT) recipients actively followed in an established long-term survivorship clinic at Roswell Park Cancer Institute from 2006 to 2012. The Survivor Unmet Needs Survey (SUNS) was mailed to 209 eligible patients and returned by 110 (53% participation rate). SUNS includes 89 items covering 5 domains: Emotional Health, Access and Continuity of Care, Relationships, Financial Concerns, and Information. The top 5 specific unmet needs for autologous HCT patients were inability to set future goals/long-term plans, changes in appearance, bad memory/lacking focus, losing confidence in abilities, and paying household or other bills. For allogeneic HCT patients these 5 unmet needs were tied at 21% of respondents: ability to earn money, pay bills, feeling tired, feeling depressed, and dealing with others' expectations of "returning to normal." The top 5 needs reported by females were all from the emotional health domain, whereas males reported financial domain unmet needs. Self-reported participation in health maintenance and screening tests varied greatly from 88% of patients having routine annual bloodwork to 13% of patients having an exercise stress test in the past year. Our findings demonstrate unmet needs in emotional health and financial burden in HCT survivors and variable compliance with survivorship screening.

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INTRODUCTION

Over the last 6 decades, the use of hematopoietic cell transplantation (HCT) has increased significantly with a worldwide cumulative number of transplants surpassing 1 million in 2012 [1] and a growing number of HCT survivors in the United States expected to exceed 240,000 by 2020 and 500,000 by 2030 [2]. HCT-specific long-term survival and specialized care needs have been described to guide screening and preventive practices [3]. These guidelines, first published in 2006 [4] and revised in 2012 [5], have provided a foundation for a concerted effort in providing healthcare recommendations for an optimal post-HCT care continuum.

In 2006 Roswell Park Cancer Institute (RPCI) developed an HCT Annual Survivorship Clinic with the intent to guide this group of patients to an optimal health trajectory despite altered health risks from treatment. Now a decade later, the program has evolved to a comprehensive cancer survivorship initiative that provides a venue to address long-term care needs and unveil unmet needs resulting from surviving a complex therapy.

Primary prevention education has been a portion of the foundational content undertaken in our HCT survivorship specialty clinic by providing health maintenance strategies [5-10]. A variety of topics, such as maintaining a healthy body mass index (Obesity Screening), use of sunscreen and limited exposure to direct sunlight (Skin Cancer Counseling), cessation or abstinence education for substance abuse (Alcohol Misuse: Screening and Behavioral Counseling/Intervention and Tobacco Smoking Cessation in Adults), and cancer screenings (Breast, Cervical, Skin, and Colorectal), are discussed during clinic appointments and are enhanced with primary care follow-up

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[8]. However, potential discordance between general population versus specialty evidence-based guidelines due to risk endured from treatment exists and is sometimes not within the knowledge base of our community partners. Additionally, identification of unmet needs is also imperative for peak recovery and quality of life.

In an effort to build on the initial success of our survivorship program and to further identify potential enhancements, a cross-sectional descriptive study was undertaken to ascertain the unmet survivorship needs of our adult HCT population and to describe the degree of adherence to specialty and general health evidence-based screening recommendations. This information will be vital as comprehensive cancer centers contemplate evolving formalized HCT survivorship clinics which focus on this aspect of the care continuum.

METHODS

Recruitment and Procedure

All autologous and allogeneic HCT recipients are routinely scheduled for annual appointments starting 1 year post-HCT in the RPCI BMT Long-term Survivorship Clinic established in 2006. The Long-term Survivorship Clinic performs routine structured visits including history and physical, review of test results and provides recommendations for follow-up care per American Society for Blood and Marrow Transplantation, National Comprehensive Cancer Network, and American Cancer Society guidelines [5,9,10].

Participants were recruited from 209 eligible, consecutive autologous and allogeneic HCT survivors who had been treated at RPCI from 2006 to 2012 and were 1 to 5 years post-HCT. Inclusion criteria were 18 years or older at time of HCT, no disease progression post-HCT, and ability to read/write English. All eligible candidates were mailed a study packet that included the Survivor Unmet Needs Survey (SUNS) and a brief demographic questionnaire regarding personal survivor characteristics such as age, gender, and primary cancer diagnosis, as well as self-reported compliance with recommended post-HCT screening tests. Study materials were returned to RPCI in a self-addressed stamped envelope, at which time the participant was mailed a \$15 gift card to a local grocery store or gas station. Initial nonresponders were sent follow-up postcards at 3-week intervals for a maximum of 2 times after the first mailing. Institutional Review Board approvals were obtained from RPCI and The State University of New York at Buffalo.

Survey

The SUNS is a public domain tool available online from the University of Waterloo, Canada (https://uwaterloo.ca/propel/sites/ca.propel/files/uploads/files/SurvivorUnmetNeedsQuestionnaire_en.pdf). The SUNS is an 89-item tool covering 5 domains: Emotional Health (33 questions), Access and Continuity of Care (22 questions), Relationships (15 questions), Financial Concerns (11 questions), and Information Needs (8 questions) [11]. The SUNS has been validated for use with hematologic cancer survivors including HCT recipients [12]. The instrument uses a Likert scale, ranging from 0 (no unmet needs) to 4 (very high unmet need). Campbell et al. [13] reported the Cronbach's alpha for the SUNS at .990 with subscale ratings ranging from .932 to .983.

Statistical Analysis

Descriptive statistics were calculated to summarize patient characteristics and survey responses. Chi-square or Fisher's exact tests were used, where appropriate, to compare survey responses by HCT type (autologous/allogeneic), gender (M/F), age (<50 years/ > 50 years), marital status (married/other), and education (completed high school/other). Qualitative data from responses to the open-ended question at the conclusion of the survey were coded and clustered by theme. The overall domain score was calculated by adding the scaled response (range, 0 to 4) to each question within the domain then dividing by the total number of questions in that domain.

RESULTS

Survey Response Rate and Respondent Characteristics

Of 209 eligible HCT survivors who received invitation packets, 110 returned the completed survey materials. Table 1 compares the characteristics of the respondents and nonrespondents, showing respondents were representative of the overall eligible population. Key demographic characteristics (Table 2) of the responders included mainly European-

Table 1

Comparison of Respondents and Nonrespondents to the SUNS

Characteristic	Respondents (N = 110)	Nonrespondents (N = 99)	P
Age, yr			NS
18-40	16 (15%)	23 (23%)	
40-59	56 (51%)	46 (47%)	
60-75	38 (35%)	30 (30%)	
Male	62 (56%)	57 (58%)	NS
Race			NS
White	103 (94%)	89 (90%)	
Other	7 (6%)	10 (10%)	
KPS			NS
60-70	19 (17%)	25 (25%)	
80	65 (59%)	53 (54%)	
90-100	26 (24%)	21 (21%)	
Diagnosis			NS
NHL	27 (25%)	28 (28%)	
MM	25 (23%)	29 (29%)	
AML	27 (25%)	12 (12%)	
MDS/MPD	11 (10%)	6 (6%)	
ALL	9 (8%)	6 (6%)	
HL	6 (6%)	8 (8%)	
Other	5 (5%)	10 (10%)	
Disease status pre-HCT			.047
CR1	48 (44%)	29 (29%)	
CR ≥ 2	12 (11%)	20 (20%)	
Not in CR	50 (46%)	50 (51%)	
Prior HCT			NS
None	100 (91%)	91 (92%)	
Autologous	9 (8%)	6 (6%)	
Allogeneic	1 (1%)	2 (2%)	
Donor			NS
Autologous	57 (52%)	62 (63%)	
6/6 HLA matched related	24 (22%)	15 (15%)	
10/10 HLA matched	18 (16%)	16 (16%)	
unrelated			
9/10 HLA mismatched	11 (10%)	6 (6%)	
unrelated			
Conditioning regimen			NS
Myeloablative	64 (58%)	69 (70%)	
Reduced intensity	46 (42%)	30 (30%)	

NS indicates not significant ($P > .05$); KPS, Karnofsky Performance Score; NHL, non-Hodgkin lymphoma; MM, multiple myeloma; AML, acute myeloid leukemia; MDS, Myelodysplastic syndrome; MPD, myeloproliferative disorder; ALL, acute lymphoblastic leukemia; HL, Hodgkin lymphoma; CR, complete remission.

American respondents (89%) and males (56%). Participants indicated they were currently married (67%), had a college degree (36%), and were either employed full-time (22%) or retired (29%). Respondents most frequently lived with their spouse or partner (55%), spouse/partner and (grand)child(ren) (18%), or alone (13%). Most had 2 or fewer people living in their household (67%), with only 16% of respondents living in households with children under age 19 years.

Ninety-one percent of respondents indicated they had a primary care physician (PCP) involved in their current follow-up care, with 27% having a PCP visit within 1 month, 44% within 2 to 5 months, 21% within 6 to 11 months, and 8% >12 months before completing the SUNS. For the respondents with a PCP, 77% believed their PCP understood their cancer diagnosis, treatment, and potential long-term effects their treatment (HCT) might have on their health (9% did not answer). Forty-seven percent of respondents stated they lived within a 30-minute drive of the cancer center, clinic, or hospital where they receive their cancer therapy; an additional 27% travel 30 to 60 minutes, and 10% each traveled 1 to 2 hours or 2 to 4 hours, with 2% living more than 4 hours away.

Forty-five percent of respondents stated they had a follow-up visit in a cancer clinic in the last month, 31% had no

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