



Published in final edited form as:

Bone Marrow Transplant. 2010 March ; 45(3): 570–579. doi:10.1038/bmt.2009.166.

Barriers to Mental Health Service Use among Hematopoietic Stem Cell Transplant Survivors

Catherine E. Mosher, Ph.D.¹, Katherine N. DuHamel, Ph.D.^{1,2}, Christine M. Rini, Ph.D.², Yuelin Li, Ph.D.¹, Luis Isola, M.D.³, Larissa Labay, Psy.D.⁴, Scott Rowley, M.D.⁵, Esperanza Papadopoulos, M.D.⁶, Craig Moskowitz, M.D.⁶, Eileen Scigliano, M.D.³, Celia Grosskreutz, M.D.³, and William H. Redd, Ph.D.²

¹Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY

²Department of Oncological Sciences, Mount Sinai School of Medicine, New York, NY

³Department of Medicine, Mount Sinai School of Medicine, New York, NY

⁴Department of Pediatrics, Hackensack University Medical Center, Hackensack, NJ

⁵Department of Hematology and Oncology, Hackensack University Medical Center, Hackensack, NJ

⁶Department of Medicine, Memorial Sloan-Kettering Cancer Center, New York, NY

Summary

This study examined barriers to mental health service use and their demographic, medical, and psychosocial correlates among hematopoietic stem cell transplant (HSCT) survivors. A sample of 253 HSCT survivors who were 1- to 3-years post-transplant completed measures of demographic, physical, psychological, and social characteristics as well as a newly modified measure of barriers to mental health service use. Only 50% of distressed HSCT survivors had received mental health services. An exploratory factor analysis of the barriers to mental health service use scale yielded four factors: Scheduling Barriers, Knowledge Barriers, Emotional Barriers, and Illness-related Barriers. Patients with higher social constraints (perceived problems discussing the illness experience with significant others) reported higher levels of all four types of barriers. General distress and transplant-related posttraumatic stress symptoms were positively associated with emotional, knowledge, and illness-related barriers to mental health service use, whereas physical and functional well-being were inversely associated with these barriers. Having more knowledge barriers and more emotional barriers predicted a lower likelihood of receiving mental health services, as did lower levels of education and general distress. Results suggest that a significant number of HSCT survivors may benefit from education about mental health services that is tailored to individual barriers.

Users may view, print, copy, and download text and data-mine the content in such documents, for the purposes of academic research, subject always to the full Conditions of use:http://www.nature.com/authors/editorial_policies/license.html#terms

Correspondence: Catherine E. Mosher, Ph.D., Memorial Sloan-Kettering Cancer Center, Department of Psychiatry and Behavioral Sciences, 641 Lexington Avenue, 7th Floor, New York, NY 10022. Phone: 646-888-0091. Fax: 212-888-2584. E-mail: mosherc@mskcc.org.

Keywords

hematopoietic stem cell transplantation; cancer survivorship; barriers; mental health services; psychological

Over 45,000 individuals receive hematopoietic stem cell transplantation (HSCT) annually throughout the world.¹ For nearly two decades, researchers have documented high levels of anxiety and/or depressive symptoms among a significant minority of HSCT recipients (5% to over 40%),² including those who are several years post-transplant.³ The estimated incidence of probable cancer-related posttraumatic stress disorder (PTSD) ranges from 5% to 19% of HSCT survivors.⁴⁻⁸ These figures suggest a need for mental health services in this population. Yet, little is known about HSCT survivors' use of these services.

Underuse of mental health services has been documented among general cancer populations. Specifically, 20-40% of cancer survivors in the U.S. show a significant level of distress,^{9, 10} but less than 10% are identified and referred for mental health care.¹¹ In addition, cancer survivors often report that their health care providers did not attend to their psychosocial needs and fail to offer resources to meet these needs.^{12, 13} According to the National Health Interview Survey of the U.S. population, if all cancer survivors with mental health problems and those who reported financial barriers to mental health service use had received services, there would have been a 62% increase in use (7.2% to 11.7%) over a 3-year period.¹⁴ It is unclear whether HSCT survivors demonstrate similar levels of underuse. To the extent that they have more severe post-treatment psychological problems than general cancer populations,² they may be more likely to seek mental health services. Yet their extended physical limitations associated with treatment may make it relatively difficult to do so. Understanding whether they underuse mental health services, the characteristics of HSCT survivors who do and do not seek these services, and the reasons why some do not receive the care they need would enable development of resources to improve their post-transplant adjustment and quality of life.

Sociodemographic and medical predictors of mental health service use have been identified in general cancer populations and may also be relevant for HSCT survivors. In a representative U.S. sample of cancer survivors, use of mental health services was significantly greater among younger adults and those diagnosed with cancer at younger ages, those who were formerly married (i.e., divorced, widowed, or separated), and those with three or more other chronic medical conditions.¹⁴ Interestingly, mental health service use was not associated with gender or time since cancer diagnosis. Another study examined predictors of using a HMO cancer counseling center among breast, prostate, and colon cancer survivors.¹⁵ Physician referral and greater education and illness intrusiveness (illness-related disruption of important life domains) were positively associated with use of the counseling center. Other demographic variables (e.g., gender, age) and medical variables (e.g., receipt of chemotherapy) did not predict use of the counseling center.

These studies investigated associations between characteristics of cancer survivors and their use of mental health services. However, survivor-reported barriers to mental health service use have rarely been examined. Understanding survivors' reasons for using (or avoiding)

mental health services is necessary for guiding the development of programs to promote appropriate use of such services. The few studies that exist have identified both practical and psychological barriers. For example, in the National Health Interview Survey almost 1 in 6 (16.1%) cancer survivors who had mental health problems said they had needed mental health services but did not receive them because of the expense.¹⁴ Eakin and Strycker¹⁵ examined barriers to use of a cancer counseling center among breast, prostate, and colon cancer survivors who belonged to a HMO. The top three barriers were as follows: (1) “I get all the support I need from other sources” (32%); (2) “I didn't know the Cancer Counseling Center existed” (25%); and (3) “My provider never recommended the Cancer Counseling Center” (13%).

Understanding the full range of perceived barriers to mental health service use requires a measure that assesses a broad range of potential barriers. We expanded the range of potential barriers to mental health service use in Eakin and Strycker's¹⁵ scale based on the mental health service use literature^{14, 16} and our clinical experience with HSCT recipients. For example, we assessed lack of knowledge of services and concerns regarding insurance coverage. In addition, we used continuous rating scales, rather than a dichotomous response format to enable survivors to rate the extent to which they agreed with each barrier (i.e., whether it applied to them). This new measure, along with measures assessing demographic, medical (e.g., transplant type, time since transplant), psychological (PTSD symptoms, general distress, and transplant-specific concerns), health (physical and functional well-being), and social (social support, social constraints) factors, was completed by 253 HSCT survivors who were 1 to 3 years post-transplant. We then conducted analyses to answer five research questions. First, we conducted analyses on our expanded measure of barriers to mental health service use to determine whether there were coherent subsets of barriers to mental health service use for HSCT survivors. Second, we examined levels of psychological distress and mental health service use in our sample to determine the need for mental health services and investigate whether these survivors underused these services. Third, we examined correlates of the receipt of mental health services to compare predictors of their use in this population with general cancer populations studied in past research. Fourth, we investigated whether demographic, medical, health, and psychosocial variables were correlated with barriers to using mental health services. Finally, we explored the extent to which barriers were associated with the use of mental health services after accounting for the effects of other variables. Taken together, answers to these research questions provide information about the need for mental health services in this population, the extent of any underuse, and characteristics associated with underuse that can guide development of interventions and identification of individuals in need of interventions.

Patients and Methods

Patients

Participants were HSCT recipients recruited from three medical centers: Hackensack University Medical Center (HUMC), Memorial Sloan-Kettering Cancer Center (MSKCC), and the Mount Sinai School of Medicine (MSSM). Patients completed the study measures during screening for possible participation in an intervention trial of cognitive-behavioral

therapy designed to reduce PTSD symptoms and general distress. Eligibility criteria for screening were as follows: (1) at least 18 years of age; (2) 1 to 3 years post-HSCT; (3) able to speak, read, and write in English; (4) working phone service; and (5) not currently waiting for another transplant or receiving treatment due to disease relapse. Demographic and medical characteristics of the sample are found in Table 1. The present sample includes HSCT survivors regardless of their level of distress, and all measures reported here were completed prior to completion of any part of the intervention. All study procedures were approved by the institutional review boards of the participating medical centers.

Prospective participants were mailed a letter describing the study and a consent form. Research associates then called prospective participants to answer their questions and determine their interest in participating and eligibility for the screening assessment. Of 1033 individuals who were referred to the study, 797 (77%) completed a pre-screen assessment to determine their potential eligibility for participating in the screening assessment, 139 declined, 71 could not be contacted, and 26 postponed the assessment. Of the 439 individuals who were eligible for screening (the source of data for the present study), 29 declined to continue in the study, 11 could not be contacted, and 5 postponed the consent process, resulting in 394 people (90%) who provided informed consent. Across sites, no gender and ethnic differences were found between respondents and nonrespondents, with one exception. At HUMC, respondents differed significantly from nonrespondents with respect to ethnicity (8% vs. 20% minority, respectively), $\chi^2(1, N = 274) = 7.68, p < .01$. Individuals who provided informed consent were asked to complete a telephone assessment that included demographic measures and measures of PTSD symptoms, general distress, and physical and functional well-being. Other measures were administered on a mailed questionnaire. We report data from 253 participants who have completed the measures of barriers to mental health service use, quality of life, and distress described below. Participants received a \$20 gift certificate for their time.

Instruments

Posttraumatic stress symptoms—The PTSD Checklist—Civilian Version (PCL-C)¹⁷ is a 17-item self-report measure of PTSD symptoms that has been found to be reliable and valid for use with cancer survivors.^{18, 19} Participants rated how much they had been bothered by each symptom during the past month in response to the cancer diagnosis and/or its treatment on a 5-point scale from 1 (*not at all*) to 5 (*extremely*). The PCL-C yields a total score in addition to subscale scores for Intrusion, Avoidance-Numbing, and Arousal. According to the scale developers,¹⁷ endorsement (i.e., ratings of 3 to 5) of one or more intrusion symptoms (Cluster B), three or more avoidance-numbing symptoms (Cluster C), and two or more arousal symptoms (Cluster D) is suggestive of PTSD. We also examined rates of PTSD based on a 4-factor model, as prior research with HSCT survivors supported a 4-factor solution for the PCL-C in which avoidance and numbing are two distinct factors.⁴

General distress—The Brief Symptom Inventory (BSI)²⁰ was used to assess general psychological distress. This 53-item self-report measure lists symptoms that fall into nine clinical subscales: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism.

Participants rated how much discomfort each symptom (e.g., “feeling blue”) caused them in the past month on a 5-point scale from 0 (*not at all*) to 4 (*extremely*). For this study, we computed the Global Severity Index (GSI), a general index of distress, by dividing the total score by the total number of responses. The cutoff on the GSI for clinically significant distress was defined as a GSI *T*-score of ≥ 63 or a *T*-score of ≥ 63 on any two subscales.²⁰ The BSI has strong psychometric properties in cancer populations.²¹

Physical well-being, functional well-being, and transplant-specific concerns—

Participants completed the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT),²²⁻²⁴ a reliable and valid measure of emotional, social, physical, and functional well-being as well as transplant-related concerns. Participants rated items on a 5-point scale from 0 (*not at all*) to 4 (*very much*). FACT Physical and Functional Well-being subscales, each containing 7 items, and a 10-item subscale that assessed transplant-specific concerns were used for this research. Higher scores on each subscale indicate better quality of life.

Social support—A valid and reliable 8-item scale from Manne's Partner Responses to Cancer Inventory (PRCI)²⁵ assessed emotional and instrumental support. Participants rated the behavior of family and friends during the past month with reference to their illness and transplant on a 4-point scale from 1 (*never responds this way*) to 4 (*often responds this way*) and 5 (*not applicable*). A sample item is “During the past month, when dealing with my illness and transplant, my family and friends asked me how I was feeling.” We supplemented this scale with two items from a measure of social support²⁶ (i.e., “Let me talk about my experience” and “Helped me get information”) that were rated in the same way as PRCI items. A confirmatory factor analysis supported a 1-factor solution for this 10-item scale (data not shown).

Social constraints—The Social Constraints Scale (SCS)²⁷ was used to assess barriers to expressing thoughts and feelings related to the illness and transplant. The original scale has excellent reliability and validity^{28, 29} and was modified in several ways for this study. First, to minimize participant burden, we deleted 5 items that were largely redundant with other items, resulting in a 10-item scale. Second, items were adapted to refer to “other people,” rather than presenting two sets of items that referred to spouses/partners and friends/family members separately. Third, the instructions and items were reworded to refer to “your experience” or “your illness and transplant.” Participants rated the behavior of others during the past month (e.g., “how often in the past month did other people avoid you?”) on a 4-point scale from 1 (*never*) to 4 (*often*). Finally, we added two items from another social support measure²⁶ that assessed other aversive behaviors that may cause HSCT survivors to feel constrained in sharing their experiences. The items were as follows: “How often in the past month did other people express too much worry or pessimism when you talked about your experience?” and “How often in the past month did other people give you unhelpful advice or information when you talked about your experience?” A confirmatory factor analysis supported a 1-factor solution for the current 12-item scale (data not shown).

Barriers to mental health service use—A newly modified measure, Awareness and Barriers to Counseling-Revised (ABC-R), included 13 items that were adapted from a measure of barriers to using a HMO Cancer Counseling Center and prostate cancer support group.¹⁵ This measure was initially developed after consulting with experts and patients and showed low internal consistency in the original study (.35 for Cancer Counseling Center barriers and .50 for prostate support group barriers). We modified it in several respects to improve its reliability. First, definitions of mental health services, anxiety and distress symptoms, and cognitive-behavioral therapy were provided before participants were asked to “indicate the extent to which these statements may impact your decision to obtain mental health services such as cognitive-behavioral therapy.” Second, items were reworded to refer to “mental health services” and all health care providers, rather than HMO providers. Third, four new items were added to the scale to assess lack of knowledge of services, embarrassment related to service use, and concerns about insurance coverage. Finally, rather than using a yes-no item format, we asked participants to rate the extent to which they agreed with each of the 17 items on a 9-point scale from 0 (*do not agree at all*) to 8 (*agree extremely*).

History of mental health service use—Participants responded yes or no to the question, “Have you ever seen anyone for emotional or psychiatric problems, not including psychiatric hospitalization?” Participants also indicated whether they received mental health services for cancer-related problems.

Medical factors—Information about patients' medical diagnosis and transplant was abstracted from medical charts and included current disease status, transplant type, years since the transplant, and histories of acute and chronic GVHD.

Results

Principal components analysis of barriers items

Intercorrelations among items regarding barriers to mental health service use were computed. Item 12 (“I get all the support I need from other sources”) was not associated with most of the other items and was therefore excluded from subsequent analyses. The remaining 16 items were submitted to a principal components analysis with an oblique (i.e., oblimin with Kaiser Normalization, $\delta = 0$) rotation to allow the factors to be correlated. A 4-factor solution, accounting for 82% of the variance, best characterized the data, as indicated by eigenvalues greater than 1.0, high factor loadings of items on their respective factors ($> .50$), and low loadings on all other factors ($< .35$). The break in the scree plot also supported a 4-factor solution. One item (“I have to wait too long to get an appointment for mental health services”) did not meet factor inclusion criteria due to relatively low loadings on all factors (range = .09 to .36) and was dropped from further analyses. As shown in Table 2, the four factors were highly interpretable, providing evidence for the factorial validity of the scale: (1) Scheduling Barriers; (2) Knowledge Barriers; (3) Emotional Barriers; and (4) Illness-related Barriers. Intercorrelations between subscales ranged from .33 to .52.

Descriptive statistics on study variables

Table 3 shows descriptive statistics and Cronbach's coefficient alphas for study variables. The PCL-C scores of 29 participants (11.5%) indicated that they were likely to meet *DSM-IV* three-symptom cluster criteria for PTSD, whereas 17 participants (6.7%) were likely to meet 4-symptom cluster criteria for PTSD (i.e., reexperiencing, avoidance, numbing, and arousal).⁴ The mean level of PTSD symptoms and the percentage of participants with probable cancer-related PTSD were comparable to those reported for HSCT survivors in past research.³¹ Sixty-three participants (24.9%) met criteria for clinically significant distress on the GSI of the BSI.²⁰ Cronbach's alpha coefficients for the ABC-R and its subscales indicated adequate internal consistency reliability (see Table 3). A total of 91 participants (36%) had received mental health services, and approximately half reported cancer-related reasons for doing so ($n = 46$, 51%). Among participants who met 3 or 4-symptom cluster criteria for PTSD or criteria for clinically significant general distress, only 50% had received mental health services and 27.9% indicated that the services targeted cancer-related problems.

Correlates of mental health service use

To predict the use of mental health services and its use for cancer-related reasons, we first examined correlations between these variables and demographic, medical, physical, psychological, and social factors. We then entered variables that showed significant correlations with each of the two dependent variables into logistic regressions with simultaneous predictor entry. Analyses also were conducted by transplant type (autologous versus allogeneic; data not shown).^a A history of mental health service use was positively correlated with education ($r = .15$, $p < .05$), general distress ($r = .20$, $p < .01$), PTSD symptoms ($r = .17$, $p < .01$), and social constraints ($r = .17$, $p < .01$). In the logistic regression these four variables correctly classified 68.2% of the sample with regard to their use of mental health services (see Table 4); however, only higher levels of education and general distress uniquely predicted mental health service use. In the logistic regression examining the use of therapy for cancer-related reasons, greater income correctly classified 67.4% of the sample with regard to its use for cancer-related reasons (see Table 4). It should be noted that this analysis excluded participants who had never used therapy, essentially comparing people who had ever used therapy with those who had used it for cancer-related reasons. In addition, among allogeneic transplant survivors who received mental health services, those with a history of acute GVHD were less likely to have received mental health services for cancer-related reasons, $\chi^2(1, N = 33) = 4.25$, $p < .01$.

Correlates of barriers to mental health service use

To predict barriers to mental health service use, we first examined correlations between barriers (both the ABC-R total score and the four subscale scores, yielding five dependent variables) and demographic, medical, physical, psychological, and social factors. We then entered variables that showed significant correlations with relevant dependent measures into

^aAmong autologous transplant recipients, greater education, general distress, and PTSD symptoms predicted mental health service use and higher income predicted mental health service use for cancer-related reasons. None of the study variables predicted mental health service use or its use for cancer-related reasons among allogeneic transplant recipients.

multiple regressions with simultaneous predictor entry. Analyses also were conducted by transplant type (data not shown).^b The ABC-R total score and scores for emotional, scheduling, and illness-related barriers had high kurtosis distributions, so we used a square root transformation of the scores to reduce the kurtosis.³⁰

Relations of barriers to participant characteristics—Significant correlates of the ABC-R total score and its subscale scores appear in Table 5. Of note was the fact that correlates of barriers varied across the different types of barriers. Several patterns emerged. First, sociodemographic characteristics were only related to some types of barriers, possibly accounting for the mixed findings reported in past research. Having higher general distress and PTSD were associated with greater barriers of all types, as was reporting higher social constraints and greater transplant-specific concerns. Transplant type, other aspects of quality of life, and social support were less consistently related to barriers.

In the regression analyses (see Table 6), social constraints emerged as the only unique predictor of the ABC-R total score, scheduling barriers, illness-related barriers, and knowledge barriers, with greater social constraints predicting greater barriers.

Unique predictors of emotional barriers to use of mental health services were more varied and included male gender, younger age, poorer social support, and greater social constraints. Among allogeneic transplant survivors, chronic GVHD was positively associated with emotional barriers ($r = .30, p < .01$), even when controlling for correlates of chronic GVHD (i.e., income and functional well-being).

Relations of barriers to mental health service use—Finally, we examined whether perceived barriers to mental health service use predicted mental health service use. Four hierarchical logistic regression analyses were conducted in which significant correlates of mental health service use (i.e., education, social constraints, and symptoms of general distress and PTSD) were entered on the first step of the equation and one of four types of barriers was entered on the second step. When examining knowledge barriers, the full model correctly classified 67.1% of the sample with regard to their use of mental health services, $\chi^2(5, N = 240) = 25.81, p < .001$. Even after controlling for significant correlates of this outcome, knowledge barriers uniquely predicted mental health service use (adjusted OR = .84, $p < .05$). Regarding emotional barriers, the full model correctly classified 67.5% of the sample with regard to their use of mental health services, $\chi^2(5, N = 240) = 25.94, p < .001$. After controlling for significant correlates of this outcome, emotional barriers uniquely predicted mental health service use (adjusted OR = .64, $p < .05$). Scheduling and illness-related barriers did not uniquely predict mental health service use.

^bSimilar physical and psychosocial correlates of barriers to mental health service use were obtained for autologous and allogeneic transplant recipients. Regression analyses as outlined in Table 6 were conducted according to transplant type, and the pattern of results was highly similar to that obtained for the full sample among autologous transplant recipients. Among allogeneic transplant recipients, greater general distress predicted total barriers and knowledge barriers to mental health service use. In addition, younger age was associated with greater scheduling barriers and worse functional well-being was associated with greater illness-related barriers in this subsample.

Discussion

This study was designed to examine demographic, medical, and psychosocial predictors of mental health service use and patient-reported barriers to service use among HSCT survivors. In order to accomplish these goals, we developed the ABC-R, a modified version of Eakin and Strycker's 15 barriers to mental health service use scale, and used it to assess a range of potential barriers to seeking mental health care among HSCT survivors. An exploratory factor analysis of the ABC-R indicated that a four-factor structure best described the data and provided evidence for the factorial validity of the new scale. The first factor, Scheduling Barriers, reflected time constraints that may impact the decision to receive mental health care. The second factor, Knowledge Barriers, represented a lack of knowledge regarding mental health services. The third factor, Emotional Barriers, reflected feelings of discomfort and embarrassment that may deter people from seeking mental health care. The fourth factor, Illness-related Barriers, represented physical limitations and a focus on medical treatment to the neglect of mental health care. These barriers are consistent with our clinical experience with this patient population, suggesting the usefulness of this measure as a guide for the development of interventions to increase use of mental health services.

In this study, the proportion of HSCT survivors with clinically significant distress was comparable to that found among general cancer populations.^{9, 10} In addition, only 50% of our sample with clinically significant distress had ever sought mental health services, which is comparable to the utilization rate among advanced cancer patients with psychiatric disorders.³² Thus, results suggest that mental health services are underutilized among HSCT survivors, despite their availability at the three participating medical centers.

A variety of factors were associated with barriers to mental health service use, providing insight into characteristics that place HSCT survivors at greater risk for underuse of mental health services. Positive correlations emerged between social constraints and all types of barriers to receiving mental health services. That is, to the extent that HSCT survivors experienced difficulties when they attempted to discuss their transplant experience with people in their lives, they also reported a broad range of barriers to receiving mental health services. Further research is needed to examine mechanisms underlying this relationship. For example, HSCT survivors who feel that they cannot talk to others about their illness experience may have fewer opportunities to disclose stressor-related thoughts and feelings that might prompt others to suggest psychosocial services. There may also be dispositional characteristics that contribute both to social constraints and a tendency to report barriers to use of mental health services. Understanding which of these and other potential mechanisms can account for the observed associations is important because different mechanisms will require different intervention approaches.

A number of demographic and psychological and physical health variables also were associated with perceived barriers to mental health service use. For example, men were more likely than women to report emotional barriers to service use. Men's greater discomfort with seeking services may be related to masculinity norms that emphasize self-reliance and emotional control.³³ In addition, HSCT survivors with lower income and those who were unemployed reported greater illness-related barriers than did survivors with higher income.

One of the items in the illness-related barriers subscale (“I don’t have transportation”) may be associated with economic hardship as well as functional limitations. This finding suggests a potential need for practical assistance in obtaining services among those with lower income.

Regarding medical correlates of barriers to mental health service use, survivors with chronic GVHD reported more emotional barriers. Further research may assess whether chronic GVHD is viewed as a stigmatizing or uncontrollable condition that cannot be addressed with mental health services. Although chronic GVHD was not associated with general distress or PTSD symptoms, allogeneic transplant survivors were more likely than autologous transplant survivors to endorse general distress, PTSD symptoms, and emotional barriers to mental health service use. Our clinical experience suggests that HSCT survivors with greater distress (e.g., allogeneic transplant survivors) may be hesitant to seek mental health services as they anticipate painful emotions associated with discussing stressful life events.

Finally, survivors with greater physical and functional limitations reported more barriers of all types, with the exception of scheduling barriers. Additional appointments and interventions may be viewed as taxing by those with limited physical resources, suggesting a need for particular attention to overcoming barriers among survivors experiencing a complicated or difficult physical recovery from their transplant. We recently found that cognitive-behavioral therapy can be delivered successfully by telephone in this population, an approach that facilitates access to therapies traditionally delivered in face-to-face settings.

The extent to which all four types of barriers predicted mental health service use was assessed. Knowledge barriers and emotional barriers uniquely predicted mental health service use. These results point to the need to educate HSCT survivors about existing mental health services and to address feelings of discomfort with service use. Importantly, our research suggests that attempts to increase use of mental health services should be tailored to the specific barriers reported by a particular individual. A helpful next step in this line of research that would enhance development of effective interventions would be to investigate relations between barriers and service use in longitudinal studies of HSCT survivors that incorporate measures of satisfaction with prior services and socioeconomic, physical, and mental health status.

In this study, education and general distress were positively associated with a history of mental health service use. Although education has been associated with mental health service use in the U.S. population at large,^{14, 34} it has not shown consistent associations with mental health service use among cancer survivors.^{14, 15} Furthermore, among survivors who received mental health services, those with higher incomes were more likely to say they had received mental health services targeting cancer-related problems. Income may be associated with having behavioral health insurance and other resources following diagnosis, which may influence the decision to receive mental health services.

Limitations of the findings and directions for future research warrant discussion. Participants were primarily White and well-educated adults who had undergone HSCT 1 to 3 years prior to the study assessment. Further research is required to establish the reliability and validity

of this measure for use with culturally diverse HSCT survivors. In addition, participants were willing to participate in a psychological intervention trial and therefore they may differ in important ways (e.g., distress level) from HSCT survivors who would refuse participation. However, only a minority of the current sample were eligible for the intervention based on their level of distress. Furthermore, levels of PTSD symptoms and general distress in the current sample did not differ from those found in prior survey research with HSCT survivors,^{31, 35} suggesting that any bias, if present, was minimal. A second limitation is the cross-sectional design that precluded assessment of the test-retest reliability of the barriers measure and causal relations among variables. Relatedly, because we performed multiple statistical tests and selected predictors from correlated variables at one time point to enter into regressions, findings warrant replication. Another limitation is that we examined a restricted range of potential correlates of barriers to mental health service use. For example, the extent to which insurance status, co-morbid medical conditions, coping efforts (e.g., emotional approach coping), and doctor-patient communication are associated with perceived barriers requires study.

Despite limitations, findings carry implications for theory and clinical practice. The ABC-R shows good psychometric properties that will enhance its promise for facilitating future research in this area. In general, acceptable levels of internal consistency reliability were found.³⁶ Evidence of the validity of the ABC-R was obtained in that certain types of barriers were related to current distress, physical functioning, the receipt of mental health services, and the receptivity of one's social environment to illness-related disclosure. Results support a multifactorial model of perceived barriers to mental health service use that includes practical barriers, lack of knowledge, and negative anticipatory emotions related to service use. Regarding clinical applications, findings tentatively suggest that a significant proportion of HSCT survivors may benefit from education regarding psychosocial services that is tailored to personal barriers (e.g., financial situation, knowledge level). In addition, referrals to phone or Internet-based mental health services may be preferable for those with physical limitations or demanding schedules. Given the high prevalence of distress among individuals with cancer histories^{10, 37} and the benefits of participation in psychosocial interventions,^{38, 39} assessing and overcoming barriers to service use should be a high priority for future research and clinical practice.

Acknowledgments

We gratefully acknowledge the contributions of Yeraz Markarian, Julian Silva, and the participating HSCT survivors. This research is supported by National Cancer Institute Grants No. R01CA093609, 1F32CA130600 (CM), and K07CA104701 (CR).

References

1. Copelan EA. Hematopoietic stem-cell transplantation. *N Engl J Med.* 2006; 354:1813–1826. [PubMed: 16641398]
2. Mosher CE, Redd WH, Rini CM, Burkhalter JE, DuHamel KN. Physical, psychological, and social sequelae following hematopoietic stem cell transplantation: A review of the literature. *Psychooncology.* 2009; 18:113–127. [PubMed: 18677717]

3. Rusiewicz A, DuHamel KN, Burkhalter J, Ostroff J, Winkel G, Scigliano E, et al. Psychological distress in long-term survivors of hematopoietic stem cell transplantation. *Psychooncology*. 2008; 17:329–337. [PubMed: 17621377]
4. DuHamel KN, Ostroff J, Ashman T, Winkel G, Mundy EA, Keane TM, et al. Construct validity of the posttraumatic stress disorder checklist in cancer survivors: Analyses based on two samples. *Psychol Assess*. 2004; 16:255–266. [PubMed: 15456381]
5. Jacobsen PB, Widows MR, Hann DM, Andrykowski MA, Kronish LE, Fields KK. Posttraumatic stress disorder symptoms after bone marrow transplantation for breast cancer. *Psychosom Med*. 1998; 60:366–371. [PubMed: 9625227]
6. Jacobsen PB, Sadler IJ, Booth-Jones M, Soety E, Weitzner MA, Fields KK. Predictors of posttraumatic stress disorder symptomatology following bone marrow transplantation for cancer. *J Consult Clin Psychol*. 2002; 70:235–240. [PubMed: 11860050]
7. Lee SJ, Loberiza FR, Antin JH, Kirkpatrick T, Prokop L, Alyea EP, et al. Routine screening for psychosocial distress following hematopoietic stem cell transplantation. *Bone Marrow Transplant*. 2005; 35:77–83. [PubMed: 15502851]
8. Widows MR, Jacobsen PB, Fields KK. Relation of psychological vulnerability factors to posttraumatic stress disorder symptomatology in bone marrow transplant recipients. *Psychosom Med*. 2000; 62:873–882. [PubMed: 11139008]
9. Carroll BT, Kathol RG, Noyes R Jr, Wald TG, Clamon GH. Screening for depression and anxiety in cancer patients using the Hospital Anxiety and Depression Scale. *Gen Hosp Psychiatry*. 1993; 15:69–74. [PubMed: 8472942]
10. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psychooncology*. 2001; 10:19–28. [PubMed: 11180574]
11. Holland JC, Andersen B, Breitbart WS, Dabrowski M, Dudley MM, Fleishman S, et al. Distress management. *J Natl Compr Canc Netw*. 2007; 5:66–98. [PubMed: 17239328]
12. Institute of Medicine. Implementing cancer survivorship care planning. The National Academies Press; Washington, DC: 2007.
13. President's Cancer Panel. Living beyond cancer: Finding a new balance President's Cancer Panel 2003-2004 annual report. National Cancer Institute, National Institutes of Health, Department of Health and Human Services; Bethesda, MD: 2004.
14. Hewitt M, Rowland JH. Mental health service use among adult cancer survivors: Analyses of the National Health Interview Survey. *J Clin Oncol*. 2002; 20:4581–4590. [PubMed: 12454116]
15. Eakin EG, Strycker LA. Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: Patient and provider perspectives. *Psychooncology*. 2001; 10:103–113. [PubMed: 11268137]
16. Carlson LE, Angen M, Cullum J, Goodey E, Koopmans J, Lamont L, et al. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer*. 2004; 90:2297–2304. [PubMed: 15162149]
17. Weathers, FW.; Litz, BT.; Herman, DS.; Huska, JA.; Keane, TM. The PTSD Checklist: Reliability, validity, and diagnostic utility. Paper presented at the annual meeting of the International Society for Traumatic Stress Studies; San Antonio, TX. 1993.
18. Andrykowski MA, Cordova MJ, Studts JL, Miller TW. Posttraumatic stress disorder after treatment for breast cancer: Prevalence of diagnosis and use of the PTSD Checklist--Civilian Version (PCL-C) as a screening instrument. *J Consult Clin Psychol*. 1998; 66:586–590. [PubMed: 9642900]
19. Cordova MJ, Andrykowski MA, Kenady DE, McGrath PC, Sloan DA, Redd WH. Frequency and correlates of posttraumatic-stress-disorder-like symptoms after treatment for breast cancer. *J Consult Clin Psychol*. 1995; 63:981–986. [PubMed: 8543720]
20. Derogatis, LR. Brief Symptom Inventory: Administration, scoring, and procedures manual. 3rd. National Computer Systems, Inc.; Minneapolis, MN: 1993.
21. Zabora JR, Blanchard CG, Smith ED, Roberts CS, Glajchen M, Sharp JW, et al. Prevalence of psychological distress among cancer patients across the disease continuum. *J Psychosoc Oncol*. 1997; 15:73–87.

22. Cella, DF. FACT manual: Functional Assessment of Cancer Therapy Scale and the Functional Assessment of HIV Infection (FAHI) Scale. Rush-Presbyterian-St. Luke's Medical Center; Chicago: 1994.
23. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, et al. The Functional Assessment of Cancer Therapy Scale: Development and validation of the general measure. *J Clin Oncol.* 1993; 11:570–579. [PubMed: 8445433]
24. McQuellon RP, Russell GB, Cella DF, Craven BL, Brady M, Bonomi A, et al. Quality of life measurement in bone marrow transplantation: development of the Functional Assessment of Cancer Therapy—Bone Marrow Transplant (FACT-BMT) scale. *Bone Marrow Transplant.* 1997; 19:357–368. [PubMed: 9051246]
25. Manne S, Schnoll RA. Measuring supportive and unsupportive responses to cancer treatment: A factor analysis of the Partner Responses to Cancer Inventory. *J Behav Med.* 2001; 24:297–321. [PubMed: 11523330]
26. Frazier PA, Tix AP, Barnett CL. The relational context of social support: Relationship satisfaction moderates the relations between enacted support and distress. *Pers Soc Psychol Bull.* 2003; 29:1133–1146. [PubMed: 15189609]
27. Lepore SJ, Ituarte PHG. Optimism about cancer enhances mood by reducing negative social interactions. *Cancer Res Ther Control.* 1999; 8:165–174.
28. Lepore, SJ. A social-cognitive processing model of emotional adjustment to cancer. In: Andersen, BL.; Baum, A., editors. *Psychosocial interventions for cancer.* American Psychological Association; Washington, DC: 2001. p. 99-116.
29. Lepore SJ, Silver RC, Wortman CB, Wayment HA. Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. *J Pers Soc Psychol.* 1996; 70:271–282. [PubMed: 8636882]
30. Tabachnick, BG.; Fidell, LS. *Using multivariate statistics.* 4th. Allyn & Bacon; Needham Heights, MA: 2001.
31. Smith MY, Redd W, DuHamel K, Vickberg SJ, Ricketts P. Validation of the PTSD Checklist—Civilian Version in survivors of bone marrow transplantation. *J Trauma Stress.* 1999; 12:485–499. [PubMed: 10467557]
32. Kadan-Lottick NS, Vanderwerker LC, Block SD, Zhang B, Prigerson HG. Psychiatric disorders and mental health service use in patients with advanced cancer. *Cancer.* 2005; 104:2872–2881. [PubMed: 16284994]
33. Addis ME, Mahalik JR. Men, masculinity, and the contexts of help seeking. *Am Psychol.* 2003; 58:5–14. [PubMed: 12674814]
34. Wang PS, Berglund P, Olfson M, Pincus HA, Wells KB, Kessler RC. Failure and delay in initial treatment contact after first onset of mental disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry.* 2005; 62:603–613. [PubMed: 15939838]
35. Vickberg SMJ, DuHamel KN, Smith MY, Manne SL, Winkel G, Papadopoulos EB, et al. Global meaning and psychological adjustment among survivors of bone marrow transplant. *Psychooncology.* 2001; 10:29–39. [PubMed: 11180575]
36. Ponterotto JG, Ruckdeschel DE. An overview of coefficient alpha and a reliability matrix for estimating adequacy of internal consistency coefficients with psychological research measures. *Percept Mot Skills.* 2007; 105:997–1014. [PubMed: 18229554]
37. Massie MJ. Prevalence of depression in patients with cancer. *J Natl Cancer Inst Monogr.* 2004; 32:57–71. [PubMed: 15263042]
38. Devine EC, Westlake SK. The effects of psychoeducational care provided to adults with cancer: Meta-analysis of 116 studies. *Oncol Nurs Forum.* 1995; 22:1369–1381. [PubMed: 8539178]
39. Meyer TJ, Mark MM. Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychol.* 1995; 14:101–108. [PubMed: 7789344]

Table 1

Sample Characteristics

Characteristic	Descriptive Statistic
<i>Gender</i>	
Male	48.6%
Female	51.4%
<i>Ethnicity</i>	
White	87.4%
African American	5.1%
Hispanic	3.2%
West Indian	1.2%
Other	2.4%
Not reported	0.8%
<i>Age</i>	
<i>M</i> ± <i>SD</i>	50.89 ± 12.49
Range	19-69
<i>Education</i>	
12 years	15.0%
Some college or college degree	58.9%
Post-college or advanced degree	26.1%
<i>Annual Household Income</i>	
Below \$30,000	10.3%
\$30,000-\$79,000	34.0%
Above \$80,000	51.4%
Not reported	4.3%
<i>Employment Status</i>	
Employed	43.9%
Not employed	54.2%
Not reported	2.0%
<i>Marital Status</i>	
Married or marriage equivalent	73.9%
Not married	26.1%
<i>Medical Diagnosis</i>	
Multiple myeloma	31.6%
Lymphoma	30.0%
Acute leukemia	14.6%
Chronic leukemia	3.6%
Other diseases	19.8%
Data unavailable	0.4%
<i>Current Disease Status</i>	
No evidence of disease	67.2%
Evidence of disease	28.5%

Characteristic	Descriptive Statistic
Data unavailable	4.3%
<i>Type of Transplant</i>	
Allogeneic	31.6%
Autologous	68.0%
Data unavailable	0.4%
<i>Years since HSCT</i>	
<i>M ± SD</i>	1.31 ± 0.55
Range	0-3
<i>History of Acute GVHD (n = 80)</i>	
Yes	28.8%
No	60.0%
Data unavailable	11.3%
<i>Chronic GVHD (n = 80)</i>	
Yes	23.8%
No	62.5%
Data unavailable	13.8%

All values are percentages of participants ($N = 253$) unless otherwise specified. HSCT = hematopoietic stem cell transplantation. GVHD = graft-versus-host disease.

Table 2
Items Regarding Barriers to Mental Health Service Use and Factor Loadings

Item	Factor ^d				h ²
	Scheduling Barriers	Knowledge Barriers	Emotional Barriers	Illness-related Barriers	
The location is inconvenient.	.75	-.01	.09	.18	.71
I am too busy.	.73	.13	.29	-.20	.72
Mental health services are offered at inconvenient times.	.60	.04	.12	.28	.63
My doctor/nurse/health care provider didn't tell me about mental health services.	.01	.79	-.09	-.11	.56
I didn't know it existed.	.15	.77	-.14	.07	.63
I have never heard of cognitive-behavioral therapy.	-.26	.67	.15	-.01	.51
I don't know enough about it.	.16	.61	.26	-.00	.64
I am concerned that my insurance company would not cover bills for mental health services.	.12	.51	.06	.26	.49
I am uncomfortable seeking counseling.	.08	.07	.75	-.06	.62
Mental health services can be more upsetting than helpful.	.13	-.05	.72	.04	.58
I would be too embarrassed to seek mental health services.	.01	.13	.66	.13	.60
Mental health services are not relevant to dealing with cancer.	.02	-.06	.60	-.01	.34
I don't have transportation.	.26	-.02	-.13	.79	.72
I am too sick.	.00	.00	.05	.78	.63
My time and energy are focused on my treatment.	-.28	.06	.34	.59	.58
Trace	2.884	3.411	3.611	3.133	13.039
% of variance	18.0	21.3	22.6	20.0	81.5

High loadings for each factor are indicated in bold. Percentage variance is postrotation. Because there were 16 variables, percentage of variance is trace divided by 16 times 100. The eigenvalue of the fifth, unretained factor was .982. h² = communality coefficient.

^dFactor loadings (standardized coefficients) from a principal components analysis with an oblimin with Kaiser Normalization rotation.

Table 3

Descriptive Statistics for Study Variables

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	α
Brief Symptom Inventory Global Severity Index	253	.48	.45	.95
PCL-C total score	248	28.59	10.03	.88
FACT Physical Well-Being	253	23.59	4.63	.81
FACT Functional Well-Being	253	21.87	5.36	.83
FACT transplant-specific concerns	253	30.36	5.59	.65
Social constraints	250	1.84	.62	.88
Social support	242	3.16	.68	.88
Barriers total score	252	1.28	1.24	.84
Scheduling barriers	249	1.12	1.65	.76
Knowledge barriers	251	1.75	1.87	.74
Emotional barriers	251	1.07	1.40	.71
Illness-related barriers	252	.97	1.53	.63

PCL-C = Posttraumatic Checklist—Civilian Version; FACT – Functional Assessment of Cancer Therapy.

Table 4

Logistic Regression Analyses Predicting Mental Health Service Use

Outcome	Predictors	β	Wald	df	Odds ratio
History of mental health service use	Education	1.31*	7.56	1	3.70
	General distress	.03*	4.80	1	1.03
	PTSD symptoms	-.02	.41	1	.98
	Social constraints	.28	1.24	1	1.32
History of cancer-related mental health service use	Income	.24*	6.88	1	1.27

For history of mental health service use, $\chi^2(4, N = 242) = 21.94, p < .001$; for history of cancer-related mental health service use, $\chi^2(1, N = 89) = 7.73, p < .01$.

PTSD = posttraumatic stress disorder.

* $p < .05$.

Table 5
Correlations between Participant Characteristics and Perceived Barriers to Mental Health Service Use

Participant Characteristic	Total Barriers	Scheduling Barriers	Knowledge Barriers	Emotional Barriers	Illness-related Barriers
Gender	.06	.12	.05	-.13*	.13*
Age	-.11	-.15*	.03	-.18**	-.08
Income	-.08	-.03	-.10	.00	-.17**
Employment status	-.07	.00	-.03	.02	-.21**
Transplant type	-.07	-.14*	.04	-.14*	-.10
Physical well-being	-.20**	-.07	-.14*	-.23***	-.22***
Functional well-being	-.25***	-.12	-.19**	-.24***	-.19**
Transplant-specific concerns	-.30***	-.22**	-.22**	-.25***	-.28***
General distress	.34***	.25***	.28***	.27***	.20**
PTSD symptoms	.29***	.20**	.23***	.27***	.17**
Social support	-.12	-.07	-.05	-.21**	.00
Social constraints	.37***	.35***	.31***	.22***	.29***

For total barriers, $n = 241-252$; for scheduling barriers, $n = 238-249$; for knowledge and emotional barriers, $n = 240-251$; for illness-related barriers, $n = 241-252$. Gender coded (1 = male, 2 = female). Employment status coded (0 = not currently working, 1 = currently working). Transplant type coded (1 = allogeneic, 2 = autologous). Other variables yielding nonsignificant correlations with dependent variables were education, marital status, time since transplant, current disease status, and history of acute graft-versus-host disease. PTSD = posttraumatic stress disorder.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

Table 6

Multiple Regression Analyses Predicting Barriers to Mental Health Service Use

Outcome	Predictors	β	<i>t</i>	Partial <i>r</i>
Total barriers	Physical well-being	.04	.46	.03
	Functional well-being	-.03	-.31	-.02
	Transplant-specific concerns	-.11	-1.11	-.07
	General distress	.21	1.74	.11
	PTSD symptoms	-.06	-.51	-.03
	Social constraints	.24	3.63**	.23
Scheduling barriers	Age	-.11	-1.66	-.11
	Transplant type	-.05	-.74	-.05
	Transplant-specific concerns	-.06	-.69	-.05
	General distress	.09	.65	.04
	PTSD symptoms	-.04	-.35	-.02
	Social constraints	.26	3.72**	.24
Knowledge barriers	Physical well-being	.02	.27	.02
	Functional well-being	.02	.17	.01
	Transplant-specific concerns	-.04	-.41	-.03
	General distress	.21	1.62	.11
	PTSD symptoms	-.05	-.43	-.03
	Social constraints	.22	3.10**	.20
Emotional barriers	Age	-.14	-2.24*	-.15
	Gender	-.17	-2.50*	-.17
	Transplant type	-.09	-1.42	-.10
	Physical well-being	-.06	-.67	-.05
	Functional well-being	.03	.30	.02
	Transplant-specific concerns	-.08	-.77	-.05
	General distress	.04	.29	.02
	PTSD symptoms	.07	.58	.04
	Social support	-.16	-2.51*	-.17
	Social constraints	.14	1.98*	.13
Illness-related barriers	Gender	.04	.55	.04
	Income	-.12	-1.82	-.12
	Employment status	-.08	-1.13	-.08
	Physical well-being	-.14	-1.52	-.10
	Functional well-being	.01	.05	.00

Outcome	Predictors	β	t	Partial r
	Transplant-specific concerns	-.15	-1.50	-.10
	General distress	-.01	-.09	-.01
	PTSD symptoms	-.05	-.42	-.03
	Social constraints	.23	3.25**	.22

For total barriers, $n = 244$, $R^2 = .17$, $F(6, 237) = 7.93$, $p < .001$; for scheduling barriers, $n = 233$, $R^2 = .13$, $F(6, 226) = 5.65$, $p < .001$; for knowledge barriers, $n = 243$, $R^2 = .11$, $F(6, 236) = 4.78$, $p < .001$; for emotional barriers, $n = 226$, $R^2 = .19$, $F(10, 215) = 5.15$, $p < .001$; for illness-related barriers, $n = 229$, $R^2 = .18$, $F(9, 219) = 5.40$, $p < .001$. Gender coded (1 = male, 2 = female). Transplant type coded (1 = allogeneic, 2 = autologous). Employment status coded (0 = not currently working, 1 = currently working). PTSD = posttraumatic stress disorder.

* $p < .05$.

** $p < .01$.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript