

Published in final edited form as:

Biol Blood Marrow Transplant. 2011 July ; 17(7): 995–1003. doi:10.1016/j.bbmt.2010.10.023.

Factors associated with adherence to preventive care practices among hematopoietic cell transplantation survivors

Nandita Khera, MD¹, Eric J Chow, MD MPH¹, Wendy M Leisenring, ScD¹, Karen L Syrjala, PhD¹, K. Scott Baker, MD MS¹, Mary ED Flowers, MD¹, Paul J Martin, MD¹, and Stephanie J Lee, MD MPH¹

¹Clinical Research Division, Fred Hutchinson Cancer Research Center, Seattle, WA, United States

Abstract

Preventive care guidelines are available for hematopoietic cell transplantation (HCT) survivors. We assessed adherence to these guidelines and examined factors associated with lower adherence. A questionnaire was mailed to adult HCT survivors to collect information regarding survivor health, adherence to recommended guidelines and financial concerns. Multivariable models identified patient and transplant characteristics associated with lower adherence. Of 3066 survivors more than 2 years after HCT, 1549 (51%) responded. Median age of respondents was 54.5 years, and the median adherence to recommended preventive care based on age and gender-specific recommendations was 75%. Lower adherence was associated with autologous HCT, concerns about medical costs, non-white race, male gender, lower physical functioning, no chronic graft vs. host disease (cGVHD), longer time since HCT, and lack of knowledge about recommended tests. Although 98% of respondents had medical insurance, 26% endorsed concern about medical costs and reported efforts to limit medical costs. Concern about medical costs was associated with female gender, age younger than 65 years, no cGVHD and low physical and mental functional status. Future efforts to improve adherence should address concern about medical costs and lack of knowledge as they emerged as major modifiable predictors of lower adherence to preventive care practices in HCT survivors.

INTRODUCTION

Hematopoietic cell transplantation (HCT) is used to treat many malignant and non-malignant conditions. Improved supportive care strategies and transplantation techniques have led to an increasing population of HCT survivors, drawing greater attention to their unique problems and challenges. Observational studies show that HCT survivors have higher risks for chronic diseases and secondary cancers than the general population.^{1–12}

One approach to improving the health and health related quality of life (HRQOL) of HCT survivors is to enhance early detection and management of complications through better preventive care. Specific recommendations for screening and preventive care practices for

© 2010 The American Society for Blood and Marrow Transplantation. Published by Elsevier Inc. All rights reserved

Correspondence and reprint requests to: Nandita Khera, D-5 290, Fred Hutchinson Cancer Research Center, 1100 Fairview Ave N, Seattle, WA 98109, United States. nkher2@fhcrc.org. Telephone number: 206-667-5366. Fax number: 206-667-1034..

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Financial disclosure statement: The authors declare no competing financial interests

HCT survivors have been developed based on review of the literature and consensus.¹³ In addition, the US Preventive Services Task Force¹⁴ recommendations for preventive care for the general population, are also applicable to HCT survivors.

A few cross-sectional studies have described health behaviors or health care utilization patterns and adherence to survivorship recommendations in HCT survivors.^{15–17} The goal of our cross-sectional study was to assess the adherence rates to recommended preventive care guidelines and to examine previously unstudied factors that may be associated with adherence. We hypothesized that adherence would be high in HCT survivors but that certain potentially modifiable characteristics would predict lower adherence to recommended screening tests.

PATIENTS AND METHODS

Patients

The research was approved by the Institutional Review Board at the Fred Hutchinson Cancer Research Center (FHCRC). Survivors from the FHCRC database who met the following criteria were considered eligible for the study: age over 18 at the time of survey, prior transplantation at FHCRC, current mailing address available, and survived at least 2 years after HCT irrespective of current disease status. We could not locate approximately 5% of survivors who were two or more years after their transplant. Eligible patients were mailed a self-administered survey that asked about current health status and included specific questions pertaining to preventive care and financial concerns.

Questionnaire

A 45 item module was developed to collect information regarding adherence to preventive care guidelines and financial concerns. The survey was designed based on literature review and piloted on a small group of volunteer patients similar to the target population prior to distribution. Feedback was collected from the pilot group regarding clarity of the questions and time taken to complete the module.

Participants reported whether they had preventive health testing such as medical exams including dental, eye, and gynecologic. Specific exams assessed included blood pressure, stool occult blood, sigmoidoscopy or colonoscopy, and clinical breast exam, Pap smear and mammogram (women), and digital rectal exam for prostate cancer screening (men). Information about blood testing including thyroid function, lipids, and prostate specific antigen (men) was also collected. For each preventive measure, the time interval since last testing was collected (less than 1 year ago, 1–2 years ago, 3–4 years ago or more than 5 years ago). Additional questions asked about participants' level of interest in receiving health maintenance reminders, self-perceived knowledge about recommended testing for transplant survivors and willingness to participate in a health maintenance study for transplant survivors. The questionnaire did not ask for information about annual household income, educational status and type of provider seen.

The financial section asked about availability of medical insurance coverage, worry about lifetime caps, and bankruptcy due to medical expenses. This section also asked whether concerns regarding the cost of medical care led to one of five avoidance behaviors (cut back on prescribed medications, not purchased a prescription medication, avoided making appointments to see the doctor, not used a medically related service such as physical therapy, or did not have a medical test performed).

The supplementary module was added to a battery of 236 questions that are mailed to survivors annually along with general follow-up recommendations. Standard questions

asked about number of hospitalizations and outpatient visits, presence of chronic GVHD or other specific complications, and current medications. Physical and mental functioning were assessed by self-reported performance status and activity level, measured by the Medical Outcomes Study Short Form 12 (SF12).¹⁸ Age, sex, race and ethnicity, and information about the HCT were available from the clinical research database. The survey was mailed once to each survivor along with a stamped, self addressed return envelope. No reminders were sent to non-respondents as is the routine policy followed by the Long Term Follow-up program's for these questionnaires. Data were collected between July 2008 and July 2009.

Statistical Analysis

Current employment status was categorized hierarchically in the following order since participants may be engaged in several activities: full time work outside the home, full time school, part time work outside the home, part time school, work at home, retired, none of these. Concern about medical costs was considered present if any of the five avoidance behaviors to limit costs was endorsed. Lack of knowledge about recommended tests was determined based on the answer to "Do you know what tests are recommended for transplant survivors?" Groups were compared with Wilcoxon rank sum tests or Chi-Square tests as appropriate.

Recommended screening tests were determined from the literature based on the current age and sex of the respondent.^{13, 14, 19} Though we used the guidelines from 2006 to 2009 as our source, not many of them are new and should be familiar to the health care providers in the community. We used the recommendations for adults and not children⁴ because only 8.7% of the respondents (n=135) were children at the time of HCT. Respondents were considered adherent with screening recommendations if they reported having the screening test within an appropriate time interval plus a 1 year margin. For example, since annual mammograms are recommended for women over age 40 years¹³, respondents age 40 or older were considered compliant with the recommendation if they reported having a mammogram within the past 2 years.

Multivariable logistic regression models were constructed for binary outcomes of "concerns about medical costs" and "lack of knowledge about recommended tests for survivors" considering sex, race, age, graft source (bone marrow vs. blood), conditioning regimen (myeloablative vs. not myeloablative), type of transplant (autologous vs. allogeneic), presence of chronic graft-versus-host disease (cGVHD), interval since HCT, and physical and mental functioning (high vs. low) as candidate covariates. Proportional odds regression models were constructed for the adherence variable to evaluate associations between the ordinal variable of >50% compliance and > 75% compliance using the same covariates listed above as well as "concerns about medical costs" and "lack of knowledge". One factor, current age, did not satisfy the proportional odds assumption and for this covariate, the model was relaxed to allow different odds ratios for each cut-point.²⁰ Factors were included in final multivariable models if their associated p-value was <0.1 or if their exclusion markedly changed parameter values for other factors in the model (>10% change). All reported p-values are two-sided.

RESULTS

Of the 3066 survivors who were sent the questionnaire, 51% responded which is typical for the annual survey. Table 1 summarizes the demographic and disease related characteristics of the respondents vs. non respondents. Participants had a median current age of 54.5 years and median interval time of 11.0 years since HCT. The median time since the most recent evaluation at the transplant center was 8.0 years. Participants were 51% male and 95% White. The non-respondents were more likely to be younger, male, Hispanic/Latino, and

non-White, and to have received bone marrow, myeloablative conditioning and allogeneic HCT, have lower disease risk, with a longer time interval since HCT as well as since the most recent evaluation at the transplant center. There were no significant differences in relapse status and presence of chronic GVHD between the two groups.

Eighty-five percent of respondents perceived their general health as good to excellent. Forty-four percent worked full time outside the home or went to school full time, and 56% were able to do their usual activities without any limitation. Seventy-six percent reported seeing their doctor within the past 3 months (Table 2). Median physical and mental component score, as derived from SF-12, were 51.0 [Interquartile range (IQR) 38.9–55.8] and 55.9 (IQR 49.9–58.7) respectively.

Adherence to preventive care guidelines

Overall median adherence to recommended preventive care guidelines was 75% after making appropriate age and gender-specific adjustments. No specific screening tests accounted for lower adherence rates (data not shown). Adherence to preventive care that relies on physical exam ranged from 61% for a skin exam to 92% for breast examination. Laboratory testing ranged from 50% for thyroid function tests to 91% for cholesterol testing. Specialized testing rates were high, including 82% of colonoscopy or sigmoidoscopy, 84% for Pap smear and 90% for mammogram. (Table 3)

Patient participation in preventive health care

Most (87%) patients were interested in some form of assistance from the transplant center in health maintenance, primarily in the form of mailed information. A minority (27%) reported they felt knowledgeable about recommended tests for transplant survivors, while 46% of respondents indicated that they “did not know but would like to” and 26% indicated that they “did not know and relied on the doctor to know”. (Table 4)

Influence of financial factors on health behaviors

Ninety-eight percent of the respondents had medical insurance coverage but 26% reported attempts to limit medical costs by engaging in one or more potentially deleterious health behaviors. Twenty-six percent worried that medical expenses would reach their lifetime limit, 1% reported that they had already reached their limit, and 3% reported filing for bankruptcy due to medical expenses. (Table 5)

Regression models

An ordinal regression analysis showed that lower adherence rates were associated with autologous HCT, concerns about medical costs, interval time greater than 15 years since HCT, non-white race, male gender, lower physical functioning, not having chronic GVHD, younger current age (<40 years old) and self-reported lack of knowledge about the recommended tests (Table 6). Association with Hispanic ethnicity could not be tested because of the small number of Hispanic/Latino respondents (n=35, 2.3%). Multivariable logistic regression models showed that concerns about medical costs were associated with lower physical and mental functioning, age less than 65 years and being female and marginally, not having chronic GVHD. Lack of knowledge about recommended tests for survivors was more common among males, those who received autologous transplants, those who did not develop chronic GVHD, non-white subjects, those older than 65 years of age, and those who were more than 15 years post-HCT (Table 7).

DISCUSSION

HCT survivors have a higher risk of developing adverse medical conditions and new malignancies compared to the general population. Our study showed high rates of self-reported adherence to screening practices among the respondents. These rates are higher than those reported for the general population in 2008 by the National Center for Health Statistics. For instance, 90% of females older than 40 years in our study had a mammogram in the past 2 years as compared to 68% of the general population.²¹ Likewise, 82% of our HCT survivors over age 50 reported having had a colonoscopy/sigmoidoscopy compared to 61.8% of the general population.²²

In general, the high preventive screening rates reported by our HCT survivors have been reported in some, but not all studies in cancer survivors. Mayer et al²³ reported screening adherence rates in cancer survivors exceeding American Cancer Society recommendations, national prevalence data and Healthy people 2010 goals for individual tests. Trask et al²⁴ reported similar findings and also noted variation in adherence rates by the type of screening test. A study by Earle et al²⁵ reported increased use of preventive services by elderly breast cancer survivors compared to controls. Within the HCT survivor population, Shankar et al¹⁷ reported increased frequency of physical exams and general medical contact compared to sibling controls. These high screening rates may indicate increased survivor awareness and attention to preventive care, the so-called “teachable moment” effect,²⁶ where survivors, having survived one life-threatening disease, are more motivated to try to prevent additional illness.

In contrast, other studies have shown lower rates of preventive care in cancer survivors than in the general population. The Childhood Cancer Survivor study showed suboptimal adherence to recommended guidelines among survivors of childhood cancers.^{27, 28} In another study by Earle and Neville,²⁹ colorectal carcinoma survivors had lower rates of adherence to recommended screening practices than controls. Compared to healthy controls, the HCT survivor group in Bishop's study had similar rates of breast and colorectal cancer screening but lower rates of pap smears.¹⁵ Prasad et al¹⁶ compared non Hispanic and Hispanic HCT survivors and reported lack of insurance, absence of English proficiency and lack of concern for future health as factors associated with lower health care utilization in the Hispanic cohort.

Lower adherence to preventive care recommendations could be explained by problems related to the patient, physician or health care delivery. For example, patients who have survived one cancer may avoid cancer screening because of increased anxiety about discovering a second malignancy. Poor mental and physical functioning due to cancer or treatment-related complications might decrease the ability to maintain a healthy lifestyle and/or obtain aggressive preventive care. Prescribing physicians may be more familiar with USPTF guidelines and less aware of specific screening guidelines for HCT patients. A pediatric study showed that many pediatric oncologists who care for long term cancer survivors are not familiar with available guidelines for surveillance of late effects.³⁰ This could account for younger age being associated with lower adherence as most USPTF guidelines apply to older people and therefore are most applicable to an the older age group. A collaborative study by the NCI and the American Cancer Society is comparing the perceived roles, knowledge, and practices of primary care physicians and oncologists with regard to follow-up survivorship care with results expected by the end of 2010.

Not having a regular source of health care and access to health insurance has also been cited as a risk factor for suboptimal utilization of health care services, not only in cancer survivors but also in the general population.^{31,32} Although a number of studies have examined the

clinical consequences of being uninsured,^{33–36} very few studies have investigated the health consequences of financial barriers to medical care for the so-called “under insured” population, especially in the HCT setting. A recent study looking at health care disparities in cancer survivors reported that the prevalence of forgoing one or more medical service due to cost was about 17.6% in cancer survivors.³⁷ In the general population, 3–4 % of insured men and 5–8% of insured women reported not having received needed prescription medications or medical care due to cost concerns.³⁸ Our study documented a much higher rate of medical cost concern than the general population as well as cancer survivors, since 26% of patients in our respondent group admitted to potentially risky avoidance behaviors related to concerns about medical costs, even though nearly all respondents (98%) had insurance coverage.

In addition to cost concerns, lower adherence was predicted by male gender and non-white race, factors that have been identified in other studies to be associated with adverse health behaviors and decreased health utilization.^{15–17,39} Interestingly, lack of chronic GVHD also emerged as a predictor for lack of knowledge and thereby lower adherence. This could be explained by the fact that cGVHD patients would have more frequent follow-up with the transplant center and reinforcement of knowledge about preventive care recommendations with each visit. Similarly, the lack of follow-up with the transplant center after an autologous transplant due to lower need for continued specialized post-transplant therapy could explain our finding of lower adherence and higher likelihood of lack of knowledge in autologous transplant survivors. Another contributing factor would be the perception of treating physicians about the intensity of their prior treatment and susceptibility to complications as lower than that of allogeneic transplant survivors. This result is in contrast to the study by Bishop et al¹⁵, where autologous HCT survivors were more likely to report breast or cervical cancer screening, and there was no significant difference among the rates of all suggested cancer screenings between allogeneic and autologous groups. One possible explanation for the discrepancy is that compared to our study, Bishop's study included a higher percentage of patients with autologous transplants for breast cancer, a situation where breast and cervical cancer screening might be emphasized. Our multivariable analysis also identified longer time since transplant as a risk factor for lower adherence, similar to that reported by the Childhood Cancer Survivor study.³⁹ This finding may be due to lack of understanding of late effects of therapy if patients and physicians believe that the risk declines with time.

Our study has some limitations. Approximately half of the eligible survivors did not return the survey. The non-respondents were more likely to have characteristics associated with lower adherence, suggesting that our results may be an overestimation of the population adherence rates and therefore represent the ‘best case scenario’. Despite this, our analyses are valid for the half of patients who did respond to the survey (n=1549), reflecting a large number of survivors for whom preventive care adherence is good but could still be improved hopefully minimizing long term complications. We also acknowledge that this was a single center study from the USA and results might vary depending on the follow-up practices and resources to disseminate information about these guidelines at other transplant centers across the world. In addition, adherence rates were calculated on the basis of self-report and were not validated by review of patient records from treating physicians. This could lead to overestimation of adherence rates since self-reported data about health behaviors may be affected by a social desirability bias.^{40–42} It also gives rise to the possibility of participant bias since participants who return health surveys are usually more driven to maintain optimal health by utilization of health services and adoption of healthy lifestyle behaviors. Another limitation of our study stems from the possibility of lack of awareness of guidelines for long term follow-up of HCT survivors among non-transplant physicians. Because we did not collect information on the type of provider following the patient, we cannot comment on

whether this factor is associated with lower adherence. Another important limitation of our study is that we did not ask the survivors questions regarding their lifestyle practices. For certain cancers that are not amenable to easy screening procedures, it might be more important to maintain a healthy lifestyle than to adhere to medical testing alone. In the case of skin cancer, where prevention by avoidance of unprotected UV exposure may be of comparable benefit to regular skin exams, it would have been interesting to know whether a low adherence to recommended screening was also associated with non-adherence to preventive behaviors such as use of sunscreens. Finally, in examining financial concerns, we did not specifically assess whether the perceived cost burden was due to high out-of-pocket costs, low lifetime caps or lack of catastrophic provisions.

Our results suggest that future attempts to improve survivors' adherence to preventive practices would benefit from attention focused on patients' financial concerns and lack of knowledge, as both are potentially modifiable factors and may have emerged as even stronger predictors if our non-respondent group was included in the analysis. For example, better communication with the patient about the reasons for screening recommendations and frank discussion about the financial implications for the patient along with approaches to mitigate personal costs may improve adherence. Given the high rate of financial concerns related to medical care in our population, national policies that ensure the affordability of health insurance coverage would help alleviate those stresses. The Affordable Care Act is a step in the right direction since it aims to make wellness and preventive services affordable and accessible by requiring health plans to cover these services and by eliminating cost-sharing. Our study also highlights the need for redesigning of health insurance benefits packages to include incentives for adoption of healthy lifestyle practices. Another important intervention to improve patient and physician knowledge may be the provision of comprehensive survivorship care plans⁴³ by the transplant centers, similar to those that have been developed for breast and colon cancer survivors by ASCO.⁴⁴ Although there is a paucity of data regarding the effectiveness of these plans in improving patient knowledge and adherence to preventive practices, one can assume that providing a diagnostic and treatment summary along with follow-up recommendations that identify the physician who will implement them will improve coordination of care.⁴⁵ A recent study reported that a survivorship care discussion between patients and physicians may have positive effects on some aspects of follow-up care.⁴⁶ Finally, efforts to provide community outreach education and support programs to exploit the "teachable moment"²⁶ provided by the transplant process itself may encourage healthy behaviors. These strategies should be tested in future studies to see if they will result in improved adherence to preventive guidelines, and ultimately lead to improved HRQOL and decreased morbidity and mortality.

Acknowledgments

Grant support: CA18029, CA112631 and HL36444 from the National Institutes of Health

REFERENCES

1. Baker K, Ness K, Steinberger J, et al. Diabetes, hypertension, and cardiovascular events in survivors of hematopoietic cell transplantation: a report from the bone marrow transplantation survivor study. *Blood*. 2007; 109:1765–1772. [PubMed: 17047152]
2. Bhatia S, Francisco L, Carter A, et al. Late mortality after allogeneic hematopoietic cell transplantation and functional status of long-term survivors: report from the Bone Marrow Transplant Survivor Study. *Blood*. 2007; 110:3784–3792. [PubMed: 17671231]
3. Friedman D, Roivo A, Leisenring W, et al. Increased risk of breast cancer among survivors of allogeneic hematopoietic cell transplantation: a report from the FHCRC and the EBMT-Late Effect Working Party. *Blood*. 2008; 111:939–944. [PubMed: 17911386]

4. Landier W, Bhatia S, Eshelman D, et al. Development of risk-based guidelines for pediatric cancer survivors: the Children's Oncology Group Long-Term Follow-Up Guidelines from the Children's Oncology Group Late Effects Committee and Nursing Discipline. *J Clin Oncol*. 2004; 22:4979–4990. [PubMed: 15576413]
5. Leisenring W, Friedman D, Flowers M, Schwartz J, Deeg H. Nonmelanoma skin and mucosal cancers after hematopoietic cell transplantation. *J Clin Oncol*. 2006; 24:1119–1126. [PubMed: 16461782]
6. Leung W, Ahn H, Rose S, et al. A prospective cohort study of late sequelae of pediatric allogeneic hematopoietic stem cell transplantation. *Medicine (Baltimore)*. 2007; 86:215–224. [PubMed: 17632263]
7. Martin P, Counts GJ, Appelbaum F, et al. Life expectancy in patients surviving more than 5 years after hematopoietic cell transplantation. *J Clin Oncol*. 2010; 28:1011–1016. [PubMed: 20065176]
8. Rizzo J, Curtis R, Socié G, et al. Solid cancers after allogeneic hematopoietic cell transplantation. *Blood*. 2009; 113:1175–1183. [PubMed: 18971419]
9. Savani B, Stratton P, Shenoy A, Kozanas E, Goodman S, Barrett A. Increased risk of cervical dysplasia in long-term survivors of allogeneic stem cell transplantation--implications for screening and HPV vaccination. *Biol Blood Marrow Transplant*. 2008; 14:1072–1075. [PubMed: 18721771]
10. Socié G, Cahn J, Carmelo J, et al. Avascular necrosis of bone after allogeneic bone marrow transplantation: analysis of risk factors for 4388 patients by the Société Française de Greffe de Moëlle (SFGM). *Br J Haematol*. 1997; 97:865–870. [PubMed: 9217190]
11. Socié G, Salooja N, Cohen A, et al. Nonmalignant late effects after allogeneic stem cell transplantation. *Blood*. 2003; 101:3373–3385. [PubMed: 12511420]
12. Tichelli A, Bucher C, Rovó A, et al. Premature cardiovascular disease after allogeneic hematopoietic stem-cell transplantation. *Blood*. 2007; 110:3463–3471. [PubMed: 17664354]
13. Rizzo JD, Wingard JR, Tichelli A, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation: joint recommendations of the European Group for Blood and Marrow Transplantation, the Center for International Blood and Marrow Transplant Research, and the American Society of Blood and Marrow Transplantation. *Biol Blood Marrow Transplant*. 2006; 12:138–151. [PubMed: 16443512]
14. Guide to Clinical Preventive Services. Agency for Healthcare Research and Quality: U.S. Preventive Services Task Force (USPSTF). [[Accessed July 17,2009]]. <http://www.ahrq.gov/clinic/uspstfix.htm>.
15. Bishop MM, Lee SJ, Beaumont JL, et al. The preventive health behaviors of long-term survivors of cancer and hematopoietic stem cell transplantation compared with matched controls. *Biol Blood Marrow Transplant*. 2010; 16:207–214. [PubMed: 19781657]
16. Prasad PK, Sun CL, Baker KS, et al. Health care utilization by adult Hispanic long-term survivors of hematopoietic stem cell transplantation: report from the Bone Marrow Transplant Survivor Study. *Cancer*. 2008; 113:2724–2733. [PubMed: 18831512]
17. Shankar SM, Carter A, Sun CL, et al. Health care utilization by adult long-term survivors of hematopoietic cell transplant: report from the Bone Marrow Transplant Survivor Study. *Cancer Epidemiol Biomarkers Prev*. 2007; 16:834–839. [PubMed: 17416780]
18. Ware J Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care*. 1996; 34:220–233. [PubMed: 8628042]
19. Smith RA, Cokkinides V, Brawley OW. Cancer screening in the United States, 2008: a review of current American Cancer Society guidelines and cancer screening issues. *CA Cancer J Clin*. 2008; 58:161–179. [PubMed: 18443206]
20. Williams R. Generalized ordered logit/partial proportional odds models for ordinal dependent variables. *The STATA Journal*. 2006; 6:58–82.
21. National Center for Health Statistics. Health, United States, 2009: With Special Feature on Medical Technology. Hyattsville, MD: 2010.
22. BRFSS Prevalence and Trends Data. Colorectal Cancer Screening/Sigmoidoscopy Nationwide (States and DC and territories); 2008 [Accessed January 21, 2010]. <http://apps.nccd.cdc.gov/brfss/display.asp>.

23. Mayer DK, Terrin NC, Menon U, et al. Screening practices in cancer survivors. *J Cancer Surviv.* 2007; 1:17–26. [PubMed: 18648941]
24. Trask PC, Rabin C, Rogers ML, et al. Cancer screening practices among cancer survivors. *Am J Prev Med.* 2005; 28:351–356. [PubMed: 15831340]
25. Earle CC, Burstein HJ, Winer EP, Weeks JC. Quality of non-breast cancer health maintenance among elderly breast cancer survivors. *J Clin Oncol.* 2003; 21:1447–1451. [PubMed: 12697865]
26. Ganz PA. A teachable moment for oncologists: cancer survivors, 10 million strong and growing! *J Clin Oncol.* 2005; 23:5458–5460. [PubMed: 16043826]
27. Nathan PC, Greenberg ML, Ness KK, et al. Medical care in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol.* 2008; 26:4401–4409. [PubMed: 18802152]
28. Yeazel MW, Oeffinger KC, Gurney JG, et al. The cancer screening practices of adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Cancer.* 2004; 100:631–640. [PubMed: 14745882]
29. Earle CC, Neville BA. Under use of necessary care among cancer survivors. *Cancer.* 2004; 101:1712–1719. [PubMed: 15386307]
30. Henderson TO, Hlubocky FJ, Wroblewski KE, Diller L, Daugherty CK. Physician preferences and knowledge gaps regarding the care of childhood cancer survivors: a mailed survey of pediatric oncologists. *J Clin Oncol.* 2010; 28:878–883. [PubMed: 20038717]
31. Buchmueller TC, Grumbach K, Kronick R, Kahn JG. The effect of health insurance on medical care utilization and implications for insurance expansion: a review of the literature. *Med Care Res Rev.* 2005; 62:3–30. [PubMed: 15643027]
32. Weissman JS, Epstein AM. The insurance gap: does it make a difference? *Annu Rev Public Health.* 1993; 14:243–270. [PubMed: 8323589]
33. Braveman P, Schaaf VM, Egerter S, Bennett T, Schechter W. Insurance-related differences in the risk of ruptured appendix. *N Engl J Med.* 1994; 331:444–449. [PubMed: 7880234]
34. American College of Physicians. White Paper. American College of Physicians; Philadelphia: 2000. No Health Insurance? It's Enough to Make You Sick—Scientific Research Linking the Lack of Health Coverage to Poor Health.
35. Institute of Medicine. Care without Coverage; Too Little, Too Late. National Academy Press; Washington, D.C.: 2002.
36. Rahimi AR, Spertus JA, Reid KJ, Bernheim SM, Krumholz HM. Financial barriers to health care and outcomes after acute myocardial infarction. *JAMA.* 2007; 297:1063–1072. [PubMed: 17356027]
37. Weaver K, Rowland J, Bellizzi K, Aziz N. Forgoing medical care because of cost: assessing disparities in healthcare access among cancer survivors living in the United States. *Cancer.* 2010; 116:3493–3504. [PubMed: 20549763]
38. National Center for Health Statistics Health, United States, 2008 With Chartbook. Hyattsville, MD: 2009. p. 100
39. Oeffinger K, Mertens A, Hudson M, et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Ann Fam Med.* 2004; 2:61–70. [PubMed: 15053285]
40. Crowne D, Marlowe D. A new scale of social desirability independent of psychopathology. *J Consult Psychol.* 1960; 24:349–354. [PubMed: 13813058]
41. Kristiansen C, Harding C. The social desirability of preventive health behavior. *Public Health Rep.* 1984; 99:384–388. [PubMed: 6431487]
42. Toobert D, Hampson S, Glasgow R. The summary of diabetes self-care activities measure: results from 7 studies and a revised scale. *Diabetes Care.* 2000; 23:943–950. [PubMed: 10895844]
43. Hoffman B, Stovall E. Survivorship perspectives and advocacy. *J Clin Oncol.* 2006; 24:5154–5159. [PubMed: 17093279]
44. American Society of Clinical Oncology. ASCO Chemotherapy Treatment Plan and Summary. [Accessed on May 30,2010]. <http://www.asco.org/treatmentsummary>.

45. Lin J, Donehower R. Make quality cancer survivorship care possible in the era of workforce shortage. *J Oncol Pract*. 2010; 6:52–53. [PubMed: 20539735]
46. Cheung W, Neville B, Earle C. Associations among cancer survivorship discussions, patient and physician expectations, and receipt of follow-up care. *J Clin Oncol*. 2010; 28:2577–2583. [PubMed: 20406932]

Table 1

Respondent and Non-Respondent characteristics

	Respondents	Non-respondents	P-value [†]
Number, %	1549 (51)	1517 (49)	
Current age, median years (range)	54.5 (18.2–81.8)	47.4 (18.0–82.3)	<0.001
Age at transplant, median years (range)	42.2 (0.9–73.8)	32.6 (1.2–71.2)	<0.001
White, n (%)	1379 (95)	1275 (93)	0.01
Missing or unknown	95	139	
Hispanic or Latino, n (%)	35 (2)	87 (6)	<0.001
Missing or unknown	47	54	
Male, n (%)	796 (51)	876 (58)	<0.001
Transplant type, n (%)			0.001
Autologous	415 (27)	343 (23)	
Related	748 (48)	837 (55)	
Unrelated	386 (25)	337 (22)	
Diagnosis, n (%)			<0.001
Chronic leukemia	429 (28)	422 (28)	
Acute leukemia	352 (23)	453 (30)	
Lymphoma	282 (18)	239 (16)	
Multiple myeloma	121 (8)	66 (4)	
Myelodysplastic syndrome	170 (11)	109 (7)	
Aplastic anemia	92 (6)	118 (8)	
Solid tumor	53 (4)	54 (4)	
Other heme	19 (1)	33 (2)	
Other	14 (1)	8 (1)	
Missing	17	15	
Post transplant relapse, n (%)	181 (12)	157 (10)	0.24
Disease risk, n (%)			0.005
Low	599 (40)	664 (45)	
Intermediate	604 (40)	514 (35)	
High	308 (20)	284 (19)	
Missing	38	55	
Graft source, n (%)			<0.001
Peripheral blood	682 (44)	536 (35)	
Bone marrow	866 (56)	975 (64)	
Umbilical cord blood	1 (<1)	6 (<1)	

	Respondents	Non-respondents	P-value [‡]
Myeloablative conditioning, n (%)	1424 (92)	1449 (96)	<0.001
Missing	1	7	
Time since transplant, median years (range)	11.0 (2.6–38.0)	13.1 (2.5–36.7)	<0.001
Time since last seen at FHCRC, median years (range)	8.0 (0–37.0)	10.4 (0–35.3)	<0.001
Chronic GVHD, among allogeneic patients, n (%)	748 (66)	731 (62)	0.064

[‡]Two-sided p-values from Wilcoxon rank sum tests for continuous variables and from Chi-square tests for categorical variables.

Table 2

Current health status

Characteristics	n (%)
General health	
Excellent	288 (19)
Very good	547 (36)
Good	477 (31)
Fair	188 (12)
Poor	29 (2)
Missing	20
Karnofsky performance status(self-reported)	
100%	753 (49)
90%	436 (28)
80%	152 (10)
≤ 70%	192 (13)
Missing	16
Work status	
Full time work outside the home	627 (41)
Full time school	43 (3)
Part time work outside the home	192 (12)
Part time school	14 (1)
Work at home	125 (8)
Retired	421 (27)
None of these	117 (8)
Missing	10
Ability to do usual job, housework or school work	
Yes, doing this without limitation	851 (56)
Yes, but limited a little	415 (27)
Yes, but limited a lot	167 (11)
No, unable to do these things	84 (6)
Missing	32
Number of physician appointments during the last 3 months	
None	367 (24)
1	522 (34)
2	256 (17)
3 or more	381 (25)
Current chronic GVHD ^I	
No	815 (72)
Yes	245 (22)

Characteristics	n (%)
Don't know	66 (6)
GVHD medications currently taken (allogeneic only)	
None	932 (83)
At least one of the following:	202 (17)
Corticosteroids	106 (10)
Cyclosporine or tacrolimus	84 (7)
Mycophenolate mofetil	31 (3)
Sirolimus	24 (2)

¹ GVHD = graft-vs.-host disease

Table 3
Adherence to recommended preventive care. Shaded boxes indicate compliance with recommended guidelines

		Time since last tested, n (%)						
		N eligible	Less than 1 year	1–2 years	3+ years	Never	Do not recall	Missing
	Asymptomatic target population and Recommended frequency or testing							
	Recommended preventive care used to determine adherence rate							
Recommended preventive care used to determine adherence rate	Tooth cleaning and dental exam	1549	1229 (81)	164 (11)	114 (7)	7 (1)	11 (1)	24
	Thyroid blood test	1549	578 (39)	160 (11)	122 (8)	187 (12)	452 (30)	50
	Blood pressure test	1549	1401 (92)	61 (4)	15 (1)	17 (1)	29 (2)	26
	Cholesterol test	1287	918 (73)	170 (13)	64 (5)	25 (2)	85 (7)	25
	Stool occult blood test	997	235 (25)	162 (17)	219 (23)	119 (13)	212 (22)	50
	Colonoscopy or sigmoidoscopy	997	201 (21)	202 (21)	383 (40)	122 (13)	58 (6)	31
	Skin exam by professional	1549	705 (47)	205 (14)	237 (16)	188 (12)	174 (12)	40
	Skin exam by patient or family	1549	883 (59)	83 (6)	72 (5)	287 (19)	168 (11)	56
	Gynecologic exam	753	488 (66)	150 (20)	73 (10)	7 (1)	22 (3)	13
	Pap smear	753	472 (64)	151 (20)	88 (12)	12 (2)	18 (2)	12
Additional preventive care testing not considered in adherence rate	Breast examination	753	558 (76)	120 (16)	41 (6)	8 (1)	12 (2)	14
	Mammogram	641	457 (73)	107 (17)	39 (6)	13 (2)	7 (1)	18
	Eye exam	1549	897 (59)	401 (26)	198 (13)	15 (1)	14 (1)	24
	Bone density test – women	753	257 (35)	211 (29)	159 (22)	54 (7)	48 (7)	24
	Bone density test – men	796	118 (15)	115 (15)	198 (26)	195 (25)	140 (18)	30
	Prostate specific antigen	796	309 (39)	112 (14)	60 (8)	137 (17)	169 (21)	9
	Digital rectal exam	796	242 (31)	144 (19)	155 (20)	142 (18)	89 (12)	24

Source:

¹ Rizzo JD et al, BBMT 2006; 12: 138–151

² Agency for Healthcare Research and Quality, US Preventive Services Task Force (USPSTF), <http://www.ahrq.gov/clinic/uspstfix.htm>

³ Smith RA et al, *CA Cancer J Clin*. 2008; 58: 161–179

Table 4

Patient participation in preventive health care

Characteristics	n (%)
Interest in health maintenance programs	
None	199 (13)
At least one of the following:	1313 (87)
Annual one day clinic visit to prevent health problems	364 (24)
Mailed information annually about recommended tests	965 (64)
Yearly telephone call to discuss recommended tests	408 (27)
Mailed reminders when you are due for recommended tests	683 (45)
Missing	37
Keeps records of medical tests and results	930 (61)
Missing	30
Knowledge of recommended tests for transplant survivors	
Yes	418 (27)
No, but would like to know	702 (46)
No, rely on doctor to know	401 (26)
Missing	28
Willingness to participate in a study to determine the best ways to help survivors maintain their health	
Yes, definitely	652 (43)
Yes, probably	591 (39)
No	268 (18)
Missing	38
Breast self examination – optional for women over 20 ³ (n=805)	
Regularly (once a month)	232 (31)
Occasionally	360 (49)
Rarely or never	146 (20)
Missing	15
Testicular self examination – annually for men ³ ; not recommended by USPSTF ² (n=869)	
Regularly (once a month)	140 (19)
Occasionally	259 (35)
Rarely or never	343 (46)
Missing	54

¹ Rizzo JD et al, BBMT 2006; 12: 138–151

² Agency for Healthcare Research and Quality, US Preventive Services Task Force (USPSTF). <http://www.ahrq.gov/clinic/uspstfix.htm>

³ Smith RA et al, *CA Cancer J Clin*. 2008; 58: 161–179

Table 5

Insurance status and concern about medical costs

Characteristics	n (%)
Medical insurance*	
Medical insurance	1153 (74)
Medicare/Medicaid	457 (30)
VA	75 (5)
Other	152 (10)
None	24 (2)
Denied coverage because of cancer or cancer treatment	154 (11)
Missing	163
Availability of employee group medical coverage is an important reason why work at current job	471 (37)
Missing	274
Cost of medical care has caused	
No change in use of medical care	1121 (74)
At least one of the following:	392 (26)
Cut back on the prescribed medications taken	158 (10)
Not purchased a prescription medication	166 (11)
Avoided making appointments to see physician	226 (15)
Not used a medically related service such as physical therapy	193 (13)
Not had a medical test performed	187 (12)
Missing	37-4
Worried that expenses will reach the limit and the insurance company will stop paying	368 (25)
Missing	57
Insurance company has already stopped paying because cap exceeded	19 (1)
Missing	69
Filed bankruptcy because of medical expenses	40 (3)
Missing	46

* may have multiple insurance types, sum > 100%

Multivariable proportional odds regression models for ordinal categories of adherence to recommended preventive care, two cutpoints used: <50%*:

Table 6

	Common OR	(95% CI)	p-value
Male	2.81	(2.27, 3.49)	<0.001
Autologous transplant	1.69	(1.30, 2.19)	0.001
Concerns about medical costs	1.48	(1.15, 1.89)	0.002
Time since transplant			
<5 years	1.0	--	-
5–9.9 years	0.88	(0.63, 1.22)	0.44
10–14.9 years	1.08	(0.71, 1.64)	0.58
15 years or more	1.42	(1.03, 1.94)	0.02
Non-White	1.90	(1.21, 3.00)	0.006
Physical Function < –1 STD	1.43	(1.11, 1.85)	0.006
No CGVHD	1.80	(1.29, 2.50)	<0.001
Lack of Knowledge	2.00	(1.57, 2.56)	<0.001

	<75% Compliance			<50% Compliance		
	OR	(95% CI)	p-value	OR	(95% CI)	p-value
Current Age						
≥65 years	1.0	--	-	1.0	--	-
55–64.9 years	0.98	(0.71, 1.36)	0.92	1.08	(0.72, 1.63)	0.69
40–54.9 years	0.47	(0.32, 0.69)	<0.001	1.25	(0.78, 2.00)	0.36
<40 years	1.08	(0.71, 1.64)	0.71	2.14	(1.32, 3.47)	0.002

Abbreviations: STD = standard deviation, GVHD = graft versus host disease, OR = Odds Ratio, CI = Confidence Interval.

Table 7

Multivariable logistic regressions for concern about medical costs and lack of knowledge about recommended tests

Dependent variable	Covariates	OR	(95% CI)	p-value ^a	p-value ^b
Concern about medical cost	Physical functioning				
	< -1 STD	2.68	(2.03, 3.53)		<0.001
	Mental functioning				
	< -1 STD	2.32	(1.65, 3.27)		<0.001
	Age				
	65 or older	1.0	-	-	<0.001
	50–64.9	2.42	(1.57, 3.74)	<0.001	
	40–49.9	3.98	(2.50, 6.36)	<0.001	
	<40	3.10	(1.88, 5.14)	<0.001	
	Male	0.64	(0.50, 0.82)		<0.001
Lack of knowledge about recommended tests for survivors	No chronic GVHD	1.40	(0.98, 2.00)		0.06
	Male	1.44	(1.13, 1.83)		0.003
	No chronic GVHD	1.46	(1.05, 2.03)		0.03
	Autologous transplant	1.54	(1.13, 2.11)		0.007
	Time since Transplant				
	<5 years	1.0	-	-	<0.001
	5–9.9 years	0.92	(0.64, 1.32)	0.65	
	10–14.9 years	0.79	(0.54, 1.14)	0.20	
	15 years or more	1.62	(1.12, 2.34)	0.010	
	Non-white	1.90	(1.02, 3.54)		0.042
	Age 65 or older	1.41	(1.01, 1.97)		0.043

Abbreviations: STD = standard deviation, GVHD = graft versus host disease, OR = Odds Ratio, CI = Confidence Interval.

^aCategory specific p-value from Wald test shown where different from overall variable level p-value.^bGlobal p-value for covariate.