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How confident are young adult cancer survivors in managing their survivorship care? A report from the LIVESTRONG™ Survivorship Center of Excellence Network

Jacqueline Casillas^{1,2}, Karen L Syrjala³, Patricia A Ganz^{1,2}, Emy Hammond³, Alfred C Marcus⁴, Kerry M Moss⁵, Catherine M Crespi^{2,6}, Peiyun Lu¹, Mary S McCabe⁷, Jennifer S Ford⁷, Linda A Jacobs⁸, Donna Pucci⁸, Steven C Palmer⁸, Amanda M Termuhlen⁹, Lisa Diller¹⁰, Marci Campbell¹¹, Barbara Jones¹², and Debra L Friedman¹³

¹David Geffen School of Medicine at UCLA, Los Angeles, CA, USA

²Division of Cancer Prevention and Control Research at the UCLA Jonsson Comprehensive Cancer Center, Los Angeles, CA, USA

³Biobehavioral Sciences Department, Fred Hutchinson Cancer Research Center, Seattle, WA, USA

⁴University of Colorado Cancer Center, Denver, CO, USA

⁵Connecticut Children's Medical Center, Hartford, CT, USA

⁶Department of Biostatistics, School of Public Health, University of California, Los Angeles, CA, USA

⁷Memorial Sloan-Kettering Cancer Center Survivorship Program, New York, NY, USA

⁸Abramson Cancer Center, University of Pennsylvania, Philadelphia, PA, USA

⁹The Jonathan Jacques Cancer Center at Miller Children's Hospital and the University of Southern California Keck School of Medicine, Los Angeles, CA USA

¹⁰Dana-Farber Cancer Institute, Boston, MA, USA

¹¹University of North Carolina at Chapel Hill, Lineberger Comprehensive Cancer Center, Chapel Hill, NC, USA

¹²School of Social Work, University of Texas at Austin, Austin, TX, USA

¹³Vanderbilt-Ingram Cancer Center, Department of Pediatrics, Vanderbilt University School of Medicine, Nashville, TN, USA

Abstract

Introduction—This study examined the association between sociodemographic, cancer treatment, and care delivery factors on young adult cancer survivors' confidence in managing their survivorship care.

Corresponding Author: Jacqueline Casillas, MD, MSHS David Geffen School of Medicine at University of California, Los Angeles (UCLA) Department of Pediatrics, Division of Hematology/Oncology 10833 Le Conte Ave. Room A2-410 MDCC, Los Angeles, CA 90095 Phone: 310-794-2474; FAX: 310-825-4552.

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Methods—Survivors aged 18-39 years (n=376) recruited from the LIVESTRONG™ Survivorship Center of Excellence Network sites completed a survey assessing self-reported receipt of survivorship care planning, expectations of their providers, and confidence in managing their survivorship care. Multivariate logistic regression identified characteristics of those reporting low confidence in managing their survivorship care.

Results—Mean age was 28 years; mean interval from diagnosis was 9 ± 8 years. Seventy-one percent reported currently attending an oncology survivorship clinic. Regarding survivorship care planning, 33% did not have copies of their cancer-related medical records, 48% did not have a treatment summary, and 55% had not received a survivorship care plan. Seventy percent identified the oncologist as the most important health care provider for decisions regarding test and treatment decisions, while 10% reported using a “shared-care model” involving both primary care providers and oncologists. Forty-one percent were classified as having low confidence in managing survivorship care. In multivariate analysis, low confidence was associated with non-white ethnicity and lack of a survivorship care plan (both $p < .05$).

Discussion/Conclusion—Findings suggest that provision of survivorship care plans for young adult cancer survivors can be used to improve confidence in managing survivorship care, particularly for ethnic minorities.

Implications for Cancer Survivors—Survivors should consider advocating for receipt of a survivorship care plan as it may facilitate confidence as a consumer of survivorship care.

Keywords

neoplasm; young adult; cancer survivors; delivery of health care; survivorship care plan

Introduction

There are nearly 12 million cancer survivors in the United States (U.S.) including 500,000 young adult survivors of both pediatric and adult malignancies [1, 2]. Cancer survivors have unique health care needs as they transition from active therapy to the survivorship period. A seminal Institute of Medicine (IOM) Report, “From Cancer Patient to Cancer Survivor: Lost in Transition” highlights the need to establish survivorship as a distinct phase of care, as well as to develop and use a written treatment summary and survivorship care plan to guide a survivor’s follow-up care [3, 4]. The “shared-care model” has been proposed as an optimal framework for delivering survivorship care within the U.S. in which the cancer survivor receives care coordinated between the treating oncologist and the primary care provider (PCP) [5-8]. Yet, the health care setting in which survivorship care is delivered varies significantly from survivor to survivor [6, 9]. Furthermore, recent research indicates that survivors and physicians have different expectations when providing survivorship care which can contribute to deficiencies in care [10].

Young adult cancer survivors face several challenges during their transition from cancer patient to cancer survivor. They are at high-risk for medical and psychosocial sequelae from cancer and its treatment [11-16]. Young adult survivors can also experience anxiety due to uncertainty when transitioning from active treatment into the survivorship phase [14, 17]. It is important to understand the health care setting where young adults survivors are receiving their survivorship care given that most are receiving minimal surveillance for these late effects that impact their risk for morbidity and mortality after cancer [18-20]. In addition, given that both oncology and primary care providers can have unique roles when caring for cancer patients with complex medical needs, such as the young adult population, further research aimed at understanding the primary care-subspecialty care interface is an important area of research [21, 22].

The IOM recommends that cancer survivors have a treatment summary and survivorship care plan to serve as a roadmap and a communication tool to optimize coordination of care [3, 23-25]. Having a treatment summary and survivorship care plan can serve to increase survivors' confidence in their ability (i.e. self-efficacy) to manage, coordinate, and advocacy for their survivorship care as this document can summarize the cancer treatment received and succinctly outline recommendations of optimal care needed [26]. Interventions to promote self-efficacy have been specifically recommended in the young adult survivor population given the often complex cancer treatment history and need for post-treatment symptom management [27]. Using the survivorship care plan as a tool that can promote self-efficacy and promote patient-centered care is an important area of research as survivors face many difficulties communicating their concerns with their providers [23, 28-30]. Although empirical research on the outcomes and benefits of survivorship care planning is lacking [22, 31], until research confirms or proves the contrary, the IOM assertion that survivorship care plans will improve care for cancer survivors has strong face validity [3, 23, 32].

We used the LIVESTRONG™ Survivorship Center of Excellence (COE) Network to conduct a survey of young adult cancer survivors who received treatment at one of the Network affiliated National Cancer Institute (NCI)-designated Comprehensive Cancer Centers. The study objectives were to: (1) describe the health care settings utilized during the survivorship phase of care; (2) describe the self-reported receipt of survivorship care planning; (3) define survivors' expectations of their providers; and (4) explore characteristics of survivors who report low confidence in managing their survivorship care.

METHODS

Participant Recruitment and Survey

The LIVESTRONG™ Survivorship Center of Excellence Network was created by the Lance Armstrong Foundation among eight cancer centers to increase the effectiveness of survivorship care through research, development of new interventions, and sharing of best practices, as reported previously [33]. The coordinating center for the study was the Fred Hutchinson Cancer Research Center. The Institutional Review Boards of each participating site approved the study. Informed consent was obtained from each participant.

Participants were identified from the survivorship databases at each participating institution. Study eligibility included: current age between 18-39 years of age (using the NCI's definition of a young adult) [34]; diagnosed during the pediatric (0-14 years) or adolescent or young adult years (15 - 39 years), treated for any type of cancer; completed active phase of treatment (i.e. chemotherapy, radiation therapy, and/or surgical resection). Survivors who did not have a recent survivorship visit (i.e. \leq one year) at the participating institution were eligible to participate. Survivors on hormonal therapy, monoclonal antibody therapy (e.g. Rituximab) or imatinib were eligible to participate. Non-English speaking survivors were excluded.

The survey consisted of 57 items organized in six conceptual domains: (1) sociodemographic information which included education completed, race/ethnicity, marital status, health insurance coverage, and household income; (2) cancer diagnosis and treatment which included age at diagnosis, years off cancer therapy, type of cancer, treatments received (chemotherapy, radiation therapy, surgery and/or bone marrow transplant); (3) experiences with doctors which included questions regarding doctors most important in follow-up care related to symptoms, testing, and types of doctors seen for general health care and cancer care; (4) survivor's knowledge and recall of late effects education which included questions regarding late effects topics discussed, doctors who have these discussions, receipt of cancer treatment records, receipt of a treatment summary defined as a

doctor has summarized your cancer medical records, receipt of a written plan or list of recommendations that discusses health care needed after completion of cancer treatment (i.e. survivorship care plan); (5) current health status which included questions regarding overall health status, emotional/psychological health and daily cancer-related stress; and (6) opinions regarding resources for cancer survivors. The survey was developed through an iterative process with investigators at each of the 8 COE sites using interobserver reliability methods [35]. Authors constructed survey items were based on key domains previously published in the survivorship literature on a survivor's knowledge regarding previous cancer treatment and treatment summaries, assessment of health status and health care transitioning of adolescent and young adult survivors [36-39]. Additionally, questions were constructed based on the Health Belief Model to assess the confidence level (i.e. self-efficacy) of survivors to manage their survivorship care. Using the theoretical constructs of the Health Belief Model, survivors perceive themselves to be confident in their ability to manage their survivorship care when they perceive themselves susceptible to the sequelae of an illness (i.e. late effects), understand the seriousness of the illness, and believe the benefits outweigh the barriers or costs [40, 41]. Cues to action (i.e. having medical records, treatment summary and survivorship care plan) are modifying variables that were asked as they influence self-efficacy to manage survivorship care.

We used a convenience sample of survivors who were invited to participate either at their clinic visit or by a mailed invitation letter. Data collection procedures for survey administration included completion of the written survey administered in person if the survivor was in clinic, by returning the written survey in the mail, or via telephone utilizing a trained research assistant. Instructions were included at the beginning of the survey. The survey took approximately 20 minutes to complete.

Statistical Analyses

Self-reported demographic, health care setting characteristics, receipt of survivorship care planning documents, and expectations of health care providers were summarized using descriptive statistics. We classified participants' level of confidence in managing their survivorship care based on their responses to five items scored on a 4-point Likert scale (not at all confident/somewhat confident/confident/very confident): (1) knowledge about cancer treatments received; (2) knowledge about late effects; (3) steps to take for long-term physical effects; (4) steps to take for psychosocial effects; and (5) how long to continue screening for recurrence. Agglomerative hierarchical clustering analyses of these five items using multiple different linkage methods including average linkage, complete linkage and Ward's method consistently identified two clusters of individuals characterized by high and low overall scores. Hence scores on the five items were averaged and participants below and above the midpoint of the scale of 2.5 were classified as low or high confidence, respectively. Bivariate and multivariate logistic regression with low confidence group membership as the dependent variable was used to characterize the association with demographic, medical, receipt of survivorship care planning documents, and health care setting characteristics. Survivorship care planning documents included: (1) copies of cancer treatment records, (2) a treatment summary, and (3) a survivorship care plan during the survivorship period. Health care setting variables were defined as having an oncologist only, primary care provider (PCP) only, other specialist, or using the "shared-care model" (oncology and PCP). Data were analyzed with SAS Statistical software (SAS Version 9, SAS Institute Inc., Cary, NC).

Results

Participant Characteristics

As shown in **Table 1**, 376 young adult cancer survivors completed the survey. The mean age at time of survey was 28 years (SD = 5) with 12% of the sample being in the 18-19 year age group, 51% in the 20-29 age group, and 37% in the 30-39 age group. One fourth of the participants were from ethnically diverse backgrounds. One-third had a bachelor's degree and 20% had graduate degrees; the remainder (46%) reported high school graduation or some college. Fifty-four percent of participants had total family incomes at \$60,000 per year or above, and 93% had health insurance.

Diagnostic/Treatment Variables—As shown in **Table 2**, the largest groups of participants were survivors of leukemia/lymphoma (38%), bone and soft tissue sarcomas (14%) and female and male genital system, excluding breast (13%). Six percent reported multiple cancer diagnoses. The mean age at cancer diagnosis was 18 years (SD = 10), ranging from 1-39 years. The mean interval from diagnosis was 9 years (SD = 8) and ranged from less than 2 years (10%), 2-4 years (28%), to 5 or more years (62%) from diagnosis. Fifty-seven percent of respondents were diagnosed under the age of 20. Sixty-one percent received multi-modal cancer therapies and 11% received a bone marrow transplant. Nine percent rated their current overall health status as fair or poor.

Self-Reported Survivorship Clinic Utilization and Receipt of Survivorship Care—As shown in **Table 3**, 71% of participants reported that they currently visit an oncology or survivorship clinic. Forty-five percent reported traveling greater than 30 miles to their oncology/survivorship clinic. Twenty percent of the participants reported no discussion of late effects with their doctors. One-third did not have copies of their medical records and 48% did not have a written treatment summary. More than half (55%) did not have a written survivorship care plan. Nineteen percent reported having none of these three survivorship documents and 26% possessed all three. Participants' report of the roles played by different health care providers in survivorship care can be found in **Table 4**. Most participants indicated that their oncologist played the dominant role in tests and treatment decisions (70%); providing cancer care in the next 6 months (69%); and was most likely to know about or treat symptoms (56%). PCPs scored much lower in these three areas of survivorship care (4%, 10% and 18%, respectively), as did the "shared-care model" (10%, 5% and 6%, respectively). No association was found between interval since cancer diagnosis and the predominant care model ($P = .40$, chi-square test).

Table 5 presents results of bivariate and multivariate logistic regression analyses predicting low confidence in survivors managing their cancer survivorship care. Forty-one percent (155/376) were classified as low confidence using the five-item composite index. Significant bivariate findings were: racial/ethnic minority survivors having higher odds of belonging to the low confidence group, compared to non-Hispanic whites (OR = 1.66, CI = 1.04-2.64); fair or poor self-reported health status respondents having higher odds of being in the low confidence group (OR = 2.20, CI 1.07-4.50); and respondents reporting lack of copies of medical records, a written treatment summary or survivorship care plan having higher odds of low confidence (OR = 1.57, CI = 1.02-2.41; OR = 1.76, CI = 1.16-2.66; and OR = 2.80, CI = 1.81-4.33, respectively). In the multivariate analysis, being an ethnic minority survivor and lacking a survivorship care plan all remained significantly associated with higher odds of being in the low confidence group. The odds ratio for fair/poor health status was essentially unchanged in the multivariate model; however, it was imprecisely estimated due to small sample size.

DISCUSSION

There is a growing population of young adult cancer survivors who require long-term follow-up care to assess for both medical and psychosocial late effects of cancer treatment [4]. This national survey of young adult cancer survivors of both pediatric and adult malignancies describes patterns of post-treatment health care utilization, frequency of receipt of survivorship care planning documents, role expectations of providers, and the relationship between sociodemographic, self-rated health status and post-treatment care patterns with self-reported confidence in cancer survivorship care planning. Through the LIVESTRONG™ Survivorship Center of Excellence Network, we obtained a diverse sample of young adult cancer survivors cared for within a wide variety of tertiary health care settings with different models for delivering survivorship care [33].

There were several notable findings. This sample of young adult cancer survivors had high levels of education, income, and health insurance, along with access to care at an NCI-designated Comprehensive Cancer Center. Nonetheless, a significant proportion of survivors were lacking important documents that could facilitate post-treatment care, specifically, not having copies of cancer treatment medical records, a treatment summary, and a survivorship care plan. Only 26% of survey respondents reported possessing all three survivorship care planning documents which are considered indicative of good quality survivorship care [3]. These findings, however, likely over-represent the proportion of young adult survivors having these survivorship care planning documents, since the majority of young adult survivors do not utilize cancer centers for follow-up and infrequently receive recommended late effects screening based on their previous cancer treatment [42, 43].

The high percentage of survivors not reporting receipt of a survivorship care plan (55%) is particularly concerning. The factors that may account for the lack of receipt of a survivorship care plan include outpatient infrastructure barriers and a focus on screening for cancer recurrence in the outpatient oncology setting rather than on health promotion and disease prevention for survivors [44]. The outpatient infrastructure barriers may include having insufficient time within clinics to prepare for survivorship care discussions. There also may not be the incentive in the outpatient oncology setting to invest the time in developing a survivorship care plan due to lack of adequate insurance reimbursement. Additionally, survivors may not recall receiving a survivorship care plan as this study is using self-reported data, which highlights the complex nature of delivering cancer-related follow-up between the survivor and providers of survivorship care. Deficits in any one area, for example having a survivor who is neither well-informed nor participatory in their survivorship care planning, can ultimately impact on their long-term health outcomes [45]. Research evaluating the most effective communication strategies for delivery of survivorship care plans is an important area of future investigation.

Even though post-treatment survivorship care is a recognized distinct phase of oncology care, providing survivorship care plans appears to be a work-in-progress in the oncology setting based on our findings. In addition to considering provider roles, efforts to increase cancer survivorship care planning should also examine patient-related barriers. These barriers may include cancer stigma, avoidance and lack of awareness of the need for late effects discussions and survivorship visits [6, 36, 37, 46-49]. Young adults may not want to have survivorship discussions with their oncologists or other providers of care as they seek to return to “a normal life” and integrate with their peers [24, 50]. Future research should explore the impact psychosocial issues may have on the discussions and receipt of survivorship care planning in young adult survivors.

This is the first study to our knowledge to identify the positive effect that survivorship care plans can have on young adults in preparing them to be confident consumers of survivorship care. The finding that the lack of a survivorship care plan is associated with higher odds of being in a low confidence group of survivors adds to the growing body of literature within medical oncology discussing how survivorship care plans can promote optimal care by functioning as an efficient communication method among providers [25, 51]. Survivorship care plans seem to prepare survivors to be more self-assured in being their own health advocates. There have been several national efforts to improve the dissemination of survivorship care plans in the medical oncology setting, including the development of survivorship care plan templates for use by providers or survivors [52-55]. Future research should explore the use of different strategies for delivering survivorship care plans and whether they improve confidence and health promotion actions in young adult survivors.

There is an evolving area of research seeking to understand how survivorship care plans are used by survivors and health care providers to coordinate and improve survivorship care. While survivors in this study report that oncologists have the primary role for cancer-related care and symptom management, prior research has demonstrated that the majority of survivors are seen in the community medical setting during the young adult years [42]. Given the multiple settings in which young adult survivors can receive care, survivorship care plans should delineate and clarify providers' responsibilities in survivorship care management [10]. It is difficult, however, to implement effective communication technologies when providers are practicing within different health care settings, including the primary care office, community-based oncology office, academic center, and/or cancer center [56]. As a result of this fragmentation of care and poorly coordinated health care system, young adult survivors are often left responsible for coordinating their own care, from active cancer treatment to off-therapy, between their different providers of care. Our findings suggest that these survivors do not endorse the "shared-care model" with involvement of both the oncologist and primary care physicians in managing their health care needs. Instead they rely on their oncologist for symptom management and testing and treatment decisions [6]. The lack of transition by young adult survivors in this study from the oncology to the primary care setting may originate from the lack of awareness that survivors have non-cancer related health needs [57] and/or a strong therapeutic relationship with the oncology team.

Also noteworthy are the health care factors that did not predict low confidence in managing survivorship care, including whether the survivor is currently visiting an oncology or survivorship clinic or other models of care delivery including the "shared-care model" or PCP only. Age at diagnosis and current age were also not statistically significant predictors in either the bivariate or multivariate models. Given these findings, there is no single model of care that conveys advantages in promoting cancer survivor self-confidence, as long as survivorship care plans are prepared and shared with survivors.

Lastly, an important significant finding is that ethnic minorities were a high-risk group for low confidence in managing their survivorship care. This result reinforces previous research demonstrating significant disparities by race/ethnicity and language in cancer survivors' views of quality of care [58]. In colon cancer survivors, problems with coordination of care and access to care have been found to be significantly more common for African-Americans, Asian/Pacific Islanders and non-English speaking whites. Other exploratory studies have found limited understanding and misperceptions of cancer risks in minority populations. In African-American men, participants recommended community-based health education or word-of mouth education from their peers to improve their cancer risk knowledge [59]. Qualitative research in minority breast cancer survivors has found that survivorship care plans have the potential to serve as a health-enhancing tool by decreasing

anxiety following the completion of treatment, increasing the use of late effects screenings, and increasing confidence in discussing health concerns with their PCP [60]. Given our findings, future research exploring interventions to improve the awareness of the need for survivorship care planning within diverse populations of young adults is an important area of investigation.

There are study limitations that should be considered in the interpretation of these results. A convenience sample was obtained from NCI-designated Comprehensive Cancer Centers across the U.S. and we cannot be certain of the generalizability of our findings. Sampling bias, as a result of the challenges of tracing lost-to follow-up young adult cancer survivors, is a recognized challenge in young adult survivorship research as this population is very mobile due to their life transitions [61, 62]. The sample also included a significant percentage of survivors with higher socioeconomic resources. This may lead to overestimation of the rates of reported survivorship confidence as these participants had access to cancer centers, which specialize in survivorship care. Taken together, these study limitations could restrict the generalizability of the findings, which may yield overestimates of survivor self-confidence in managing their survivorship care. Conversely, there is also the limitation of using self-reported data for the measurement of receiving late effects counseling. The oncology literature has shown disagreement between self-reported information and medical record information concerning knowledge of cancer diagnosis with a significant proportion not adequately recalling even their cancer diagnosis [63, 64]. However, given that the young adult survivor is the center of the patient-clinician relationship, it is important to have a clear understanding of what they report knowing about their cancer diagnosis and treatment. If discrepancies are identified, targeted educational interventions can be developed to improve the survivorship care that young adult survivors receive.

In conclusion, lacking survivorship care plans was associated with higher risk of reporting low self-confidence in managing cancer survivorship care. Non-white race/ethnicity is an independent risk factor for reporting low confidence in managing survivorship care. These findings suggest that interventions to increase provision of survivorship care plans for young adult cancer survivors should be tested to potentially improve confidence in managing survivorship care, particularly for ethnic minorities.

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References

1. Altekruse, SF.; Kosary, CL.; Rapcho, M.; Neyman, N.; Aminou, R.; Waldron, W., et al. SEER Cancer Statistics Review, 1975–2007. National Cancer Institute; Bethesda, MD: 2010. Available from: http://seer.cancer.gov/csr/1975_2007/, based on November 2009 SEER data submission, posted to the SEER web site
2. National Cancer Institute Cancer Control and Population Sciences. Estimated U.S. Cancer Prevalence. 2010. Available from: <http://cancercontrol.cancer.gov/ocs/prevalence/prevalence.html>
3. Committee on Cancer Survivorship: Improving Care and Quality of Life, and National Cancer Policy Board. From cancer patient to cancer survivor: lost in transition. Hewitt, M.; Sheldon, G.; Stovall, E., editors. The National Academies Press; Washington, DC: 2005.
4. Ganz PA. Survivorship: adult cancer survivors. *Prim Care*. 2009; 36(4):721–41. [PubMed: 19913184]

5. Nielsen J, Palshof T, Mainz J, Jensen A, Olesen F. Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. *Qual Saf Health Care*. 2003; 12(4):263–72. [PubMed: 12897359]
6. Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol*. 2006; 24(32): 5117–24. [PubMed: 17093273]
7. Pritchard, P.; Hughes, J. *Shared care the future imperative?*. Royal Society of Medicine Press; London, England: 1995.
8. Braun T, Hagen N, Smith C, Summers N. Oncologists and family physicians. Using a standardized letter to improve communication. *Can Fam Physician*. 2003; 49:882–6. [PubMed: 12901484]
9. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*. 2011; 117(10 Suppl):2329–34. [PubMed: 21523754]
10. Cheung WY, Neville BA, Cameron DB, Cook EF, Earle CC. Comparisons of patient and physician expectations for cancer survivorship care. *J Clin Oncol*. 2009; 27(15):2489–95. [PubMed: 19332716]
11. Crom DB, Lensing SY, Rai SN, Snider MA, Cash DK, Hudson MM. Marriage, employment, and health insurance in adult survivors of childhood cancer. *J Cancer Surviv*. 2007; 1(3):237–45. [PubMed: 18648974]
12. Maltaris T, Boehm D, Dittrich R, Seufert R, Koelbl H. Reproduction beyond cancer: A message of hope for young women. *Gynecologic Oncology*. 2006; 103(3):1109–21. [PubMed: 16996582]
13. Mertens AC, Liu Q, Neglia JP, Wasilewski K, Leisenring W, Armstrong GT, et al. Cause-specific late mortality among 5-year survivors of childhood cancer: the childhood cancer survivor study. *J Natl Cancer Inst*. 2008; 100(19):1368–79. [PubMed: 18812549]
14. Odo R, Potter C. Understanding the needs of young adult cancer survivors: a clinical perspective. *Oncology (Williston Park)*. 2009; 23(23-7(11 Suppl Nurse Ed):33.
15. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006; 355(15):1572–82. [PubMed: 17035650]
16. Schover LR. Psychosocial aspects of infertility and decisions about reproduction in young cancer survivors: a review. *Med Pediatr Oncol*. 1999; 33(1):53–9. [PubMed: 10401498]
17. Duffey-Lind EC, O'Holleran E, Healey M, Vettese M, Diller L, Park ER. Transitioning to survivorship: a pilot study. *J Pediatr Oncol Nurs*. 2006; 23(6):335–43. [PubMed: 17035624]
18. Rowland JH, Hewitt M, Ganz PA. Cancer survivorship: a new challenge in delivering quality cancer care. *J Clin Oncol*. 2006; 24(32):5101–4. [PubMed: 17093270]
19. Landier W. Survivorship care: essential components and models of delivery. *Oncology (Williston Park)*. 2009; 23(4):46–53. [PubMed: 19856598]
20. Ayanian JZ, Jacobsen PB. Enhancing research on cancer survivors. *J Clin Oncol*. 2006; 24(32): 5149–53. [PubMed: 17093278]
21. Klabunde CN, Ambs A, Keating NL, He Y, Doucette WR, Tisnado D, et al. The role of primary care physicians in cancer care. *J Gen Intern Med*. 2009; 24(9):1029–36. PMID: 2726889. [PubMed: 19597893]
22. Earle CC. Long term care planning for cancer survivors: a health services research agenda. *J Cancer Surviv*. 2007; 1(1):64–74. [PubMed: 18648946]
23. Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *J Clin Oncol*. 2006; 24(32):5112–6. [PubMed: 17093272]
24. Ganz PA, Casillas J, Hahn EE. Ensuring quality care for cancer survivors: implementing the survivorship care plan. *Semin Oncol Nurs*. 2008; 24(3):208–17. [PubMed: 18687267]
25. Jacobs LA, Palmer SC, Schwartz LA, DeMichele A, Mao JJ, Carver J, et al. Adult cancer survivorship: evolution, research, and planning care. *CA Cancer J Clin*. 2009; 59(6):391–410. [PubMed: 19897841]
26. Wiljer D, Urowitz S, Frasca E, Nyhof-Young J, Secord S, Walton T, et al. The role of a clinician-led reflective interview on improving self-efficacy in breast cancer survivors: a pilot study. *J Cancer Educ*. 2010; 25(3):457–63. [PubMed: 20383675]

27. Zebrack B, Hamilton R, Smith AW. Psychosocial outcomes and service use among young adults with cancer. *Semin Oncol*. 2009; 36(5):468–77. [PubMed: 19835742]
28. Roundtree AK, Giordano SH, Price A, Suarez-Almazor ME. Problems in transition and quality of care: perspectives of breast cancer survivors. *Support Care Cancer*. 2010
29. Royak-Schaler R, Passmore SR, Gadalla S, Hoy MK, Zhan M, Tkaczuk K, et al. Exploring patient-physician communication in breast cancer care for African American women following primary treatment. *Oncol Nurs Forum*. 2008; 35(5):836–43. [PubMed: 18765331]
30. Arora NK. Importance of patient-centered care in enhancing patient well-being: a cancer survivor's perspective. *Qual Life Res*. 2009; 18(1):1–4. [PubMed: 19005778]
31. Faul LA, Shibata D, Townsend I, Jacobsen PB. Improving survivorship care for patients with colorectal cancer. *Cancer Control*. 2010; 17(1):35–43. [PubMed: 20010517]
32. Lichtenfeld L. Cancer care and survivorship planning: promises and challenges. *J Oncol Pract*. 2009; 5(3):116–8. PMID: 2790677. [PubMed: 20856749]
33. Shapiro CL, McCabe MS, Syrjala KL, Friedman D, Jacobs LA, Ganz PA, et al. The LIVESTRONG Survivorship Center of Excellence Network. *J Cancer Surviv*. 2009; 3(1):4–11. [PubMed: 19169829]
34. US Department of Health and Human Resources. National Institutes of Health. National Cancer Institute. LIVESTRONG Young Adult Alliance. Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer. 2006. NIH Publication No. 06-6067 Available from: http://planning.cancer.gov/library/AYAO_PRG_Report_2006_FINAL.pdf
35. Litwin, MS. *How To Measure Survey Reliability And Validity*. Sage; Thousand Oaks: 1995.
36. Kadan-Lottick NS, Robison LL, Gurney JG, Neglia JP, Yasui Y, Hayashi R, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *JAMA*. 2002; 287(14):1832–90. [PubMed: 11939869]
37. Casillas J, Kahn KL, Doose M, Landier W, Bhatia S, Hernandez J, et al. Transitioning childhood cancer survivors to adult-centered healthcare: insights from parents, adolescent, and young adult survivors. *Psychooncology*. 2010; 19(9):982–90. [PubMed: 20017115]
38. 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(3):220–33. [PubMed: 8628042]
39. Bashore L. Childhood and adolescent cancer survivors' knowledge of their disease and effects of treatment. *J Pediatr Oncol Nurs*. 2004; 21(2):98–102. [PubMed: 15125553]
40. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the health belief model. *Health Educ Q*. 1988; 15(2):175–83. [PubMed: 3378902]
41. Nutbeam, D.; Harris, E. *Theory in a nutshell: a practical guide to health promotion theories*. McGraw-Hill Australia Pty Ltd; Australia: 2004.
42. Oeffinger KC, Mertens AC, Hudson MM, Gurney JG, Casillas J, Chen H, et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Ann Fam Med*. 2004; 2(1):61–70. PMID: 1466633. [PubMed: 15053285]
43. Nathan PC, Ford JS, Henderson TO, Hudson MM, Emmons KM, Casillas JN, et al. Health behaviors, medical care, and interventions to promote healthy living in the Childhood Cancer Survivor Study cohort. *J Clin Oncol*. 2009; 27(14):2363–73. PMID: 2738646. [PubMed: 19255308]
44. Cheung WY, Neville BA, Earle CC. Associations among cancer survivorship discussions, patient and physician expectations, and receipt of follow-up care. *J Clin Oncol*. 2010; 28(15):2577–83. [PubMed: 20406932]
45. Epstein, R.; Street, RJ. *Patient-centered communication in cancer care: promoting healing and reducing suffering*. U.S. Department of Health and Human Services; Bethesda, MD: 2007. monograph on the internet Available from: http://outcomes.cancer.gov/areas/pcc/communication/pcc_monograph.pdf
46. Henderson TO, Friedman DL, Meadows AT. Childhood cancer survivors: transition to adult-focused risk-based care. *Pediatrics*. 2010; 126(1):129–36. [PubMed: 20547645]

47. Mertens AC, Cotter KL, Foster BM, Zebrack BJ, Hudson MM, Eshelman D, et al. Improving health care for adult survivors of childhood cancer: recommendations from a delphi panel of health policy experts. *Health Policy*. 2004; 69(2):169–78. [PubMed: 15212864]
48. Oeffinger KC, Eshelman DA, Tomlinson GE, Buchanan GR. Programs for adult survivors of childhood cancer. *J Clin Oncol*. 1998; 16(8):2864–7. [PubMed: 9704740]
49. Zebrack BJ, Eshelman DA, Hudson MM, Mertens AC, Cotter KL, Foster BM, et al. Health care for childhood cancer survivors: insights and perspectives from a Delphi panel of young adult survivors of childhood cancer. *Cancer*. 2004; 100(4):843–50. [PubMed: 14770443]
50. Enskar K, Bertero C. Young adult survivors of childhood cancer; experiences affecting self-image, relationships, and present life. *Cancer Nurs*. 2010; 33(1):E18–24. [PubMed: 19926973]
51. Mor-Shalom M, Hahn EE, Casillas J, Ganz PA. Do survivorship care plans make a difference? The primary care physician perspective. *J Oncol Pract*. in press.
52. American Society of Clinical Oncology. ASCO cancer treatment summaries. 2009. Available from: <http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries>
53. National Coalition for Cancer Survivorship. UCLA Cancer Survivorship Center. WellPoint Inc.. Genentech. Journey Forward: Guiding survivors as they move ahead. 2010. Available from: www.journeyforward.org
54. Penn Medicine's OncoLink. LIVESTRONG Care Plan. 2010. Available from: <http://www.livestrongcareplan.org>
55. Texas Children's Cancer Center and Hematology Service. Passport for Care. 2010. Available from: http://www.txccc.org/content.cfm?menu_id=128
56. Gagnon MP, Légaré F, Labrecque M, Frémont P, Pluye P, Gagnon J, et al. Interventions for promoting information and communication technologies adoption in healthcare professional. *Cochrane Database Syst Rev*. 2009
57. Thompson K, Palmer S, Dyson G. Adolescents & young adults: issues in transition from active therapy into follow-up care. *Eur J Oncol Nurs*. 2009; 13(3):207–12. [PubMed: 19539526]
58. Ayanian JZ, Zaslavsky AM, Guadagnoli E, Fuchs CS, Yost KJ, Creech CM, et al. Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language. *J Clin Oncol*. 2005; 23(27):6576–86. [PubMed: 16116149]
59. Friedman DB, Corwin SJ, Dominick GM, Rose ID. African American men's understanding and perceptions about prostate cancer: why multiple dimensions of health literacy are important in cancer communication. *J Community Health*. 2009; 34(5):449–60. [PubMed: 19517223]
60. Burg MA, Lopez ED, Dailey A, Keller ME, Prendergast B. The potential of survivorship care plans in primary care follow-up of minority breast cancer patients. *J Gen Intern Med*. 2009; 24(Suppl 2):S467–71. PMID: 2763149. [PubMed: 19838852]
61. Tercyak KP, Donze JR, Prahlad S, Mosher RB, Shad AT. Identifying, recruiting, and enrolling adolescent survivors of childhood cancer into a randomized controlled trial of health promotion: preliminary experiences in the Survivor Health and Resilience Education (SHARE) Program. *J Pediatr Psychol*. 2006; 31(3):252–61. [PubMed: 15758194]
62. Mertens AC, Walls RS, Taylor L, Mitby PA, Whitton J, Inskip PD, et al. Characteristics of childhood cancer survivors predicted their successful tracing. *J Clin Epidemiol*. 2004; 57(9):933–44. [PubMed: 15504636]
63. Nord C, Mykletun A, Fossa SD. Cancer patients' awareness about their diagnosis: a population-based study. *J Public Health Med*. 2003; 25(4):313–7. [PubMed: 14747590]
64. Manjer J, Merlo J, Berglund G. Validity of self-reported information on cancer: determinants of under- and over-reporting. *Eur J Epidemiol*. 2004; 19(3):239–47. [PubMed: 15117117]

Table 1

Participant Characteristics (N = 376)

Characteristic	No.	%
Gender		
Male	173	46
Female	203	54
Race/ethnicity		
Non-Hispanic/Latino white	278	74
Hispanic/Latino	30	8
Asian	23	6
Black	12	3
Mixed race/ethnicity	32	9
Not reported	1	0.3
Age at survey, Yrs, mean \pm SD	28 \pm 5	
18-19	44	12
20-29	192	51
30-39	139	37
Not reported	1	0.3
Annual household income		
< \$20,000	48	13
\$20,000-\$39,999	35	9
\$40,000-\$59,999	46	12
\$60,000 and higher	205	54
Not reported	44	12
Education		
High school or some college	173	46
Bachelor's degree	123	33
Graduate or professional degree	77	20
Not reported	3	1
Marital status		
Single	234	62
Divorced/widowed	11	3
Married	120	32
Not reported	11	3
Health insurance		
Private insurance	313	83
Public insurance	39	10
None	14	4
Not reported	12	3

Table 2

Clinical Characteristics of the Participants and Their Self-Reported Health Status

Characteristic	No.	%
Cancer diagnosis		
Leukemia	77	20
Lymphoma (Hodgkin and non-Hodgkin)	69	18
Bone/soft-tissue sarcoma	53	14
Testicular	44	12
Brain/central nervous system	22	6
Breast	17	5
Thyroid	16	4
Kidney	14	4
Neuroblastoma	8	2
Melanoma	8	2
Colon	5	1
Cervical/ovarian/germ cell	5	1
Head and neck	3	1
Other diagnosis	12	3
Multiple diagnoses indicated by respondent	23	6
Cancer treatments received		
Chemotherapy only	50	13
Surgery only	48	13
Radiation only	3	1
Chemotherapy and surgery	86	23
Chemotherapy and radiation	38	10
Surgery and radiation	27	7
Chemotherapy, surgery and radiation	80	21
Bone marrow transplant (with or without other therapies)	42	11
Not reported	2	0.5
Age at cancer diagnosis, Yrs, mean \pm SD		
	18 \pm 10	
5 and younger	54	14
6-10	27	7
11-14	48	13
15-19	87	23
20-29	102	27
30-39	56	15
Not reported	2	0.5
Interval from diagnosis, Yrs, mean \pm SD		
	9 \pm 8	
Less than 2	37	10
2-4	106	28
5-9	100	27
10 or more	130	35

Characteristic	No.	%
Not reported	3	1
Current overall health status		
Excellent	74	20
Very good	172	45
Good	99	26
Fair or poor	34	9
Not reported	2	0.5

Table 3

Self-Reported Survivorship Clinic Utilization, Receipt of Late Effects Counseling, and Receipt of Survivorship Care Planning Documents

	No.	%
Currently go to oncology/survivorship clinic	265	71
Frequency of visits to oncology/survivorship clinic (among the 265 participants currently attending)		
More than once a year	128	48
Every 1-2 years	125	47
Less frequently	12	5
Doctor has discussed late or chronic effects of cancer treatment		
Yes	288	77
No	74	20
Not reported	14	4
Have copies of medical records		
Yes	248	66
No	125	33
Not reported	3	1
Have written treatment summary		
Yes	191	51
No	179	48
Not reported	6	2
Have written cancer survivorship follow-up care plan		
Yes	163	43
No	208	55
Not reported	5	1
Number of these above 3 items in possession		
0	71	19
1	104	28
2	105	28
3	96	26

Table 4

Participants' Reports of Health Care Provider Roles in Survivorship Care

	Doctor Most Important for Test/Treatment Decisions N (%)	Doctor in Charge of Cancer Care for Next 6 Months N (%)	Doctor Most Likely to Know About or Treat Symptoms N (%)
Shared-Care (Both PCP and Oncologist)	38 (10)	18 (5)	23 (6)
Oncologist Only	265 (70)	258 (69)	211 (56)
PCP Only	16 (4)	38 (10)	69 (18)
Other Subspecialty	56 (15)	56 (15)	56 (15)
Not Reported	1 (0.3)	6 (2)	17 (5)

Table 5
Odds Ratios for Membership in Low Confidence Group by Participant Characteristics

Characteristics	Percentage in Low Confidence Group % (n/N)	Bivariate logistic regression OR (95% CI)	P	Multivariate logistic regression OR (95% CI)	P
Sociodemographic factors					
Gender					
Male	38 (67/176)	0.83 (0.55-1.25)	.36	0.83 (0.51-1.35)	.44
Female	43 (88/203)	1.00		1.00	
Race/ethnicity					
Minority	51 (49/97)	1.66 (1.04-2.64)	.03	2.29 (1.30-4.02)	.004
Non-Hispanic white	38 (106/278)	1.00		1.00	
Education					
Bachelor's or higher	42 (83/200)	1.02 (0.67-1.54)	.93	0.94 (0.54-1.66)	.84
Some college or less	41 (71/173)	1.00		1.00	
Age at survey					
18-29	42 (58/139)	1.03 (0.67-1.57)	.91	0.88 (0.47-1.66)	.70
30-39	41 (97/236)	1.00		1.00	
Health insurance status					
Private	40 (124/311)	0.88 (0.30-2.61)	.38	2.80 (0.65-12.1)	.50
Public	51 (20/39)	1.40 (0.41-4.81)	.34	4.29 (0.87-21.2)	.08
None (reference)	43 (6/14)	1.00		1.00	
Cancer treatment variables					
Age at cancer diagnosis					
20-39	44 (69/158)	1.21 (0.80-1.85)	.35	0.99 (0.43-2.30)	.99
19 years or less	39 (84/216)	1.00		1.00	
Interval since diagnosis					
10 years or more	39 (51/130)	0.92 (0.57-1.49)	.73	1.03 (0.48-2.22)	.93
5-9 years	43 (43/100)	1.07 (0.64-1.80)	.79	1.10 (0.60-2.04)	.75
0-4 years	41 (59/143)	1.00		1.00	
Diagnosis					
Leukemia/lymphoma	39 (57/146)	0.86 (0.57-1.32)	.49	0.80 (0.46-1.38)	.42
Solid tumors	43 (98/230)	1.00		1.00	

Characteristics	Percentage in Low Confidence Group	Bivariate logistic regression OR (95% CI)	P	Multivariate logistic regression OR (95% CI)	P
Treatment received					
Multiple treatments (chemo, radiation, surg)	40 (93/231)	0.87 (0.54-1.40)	.75	0.91 (0.51-1.63)	.79
Bone marrow transplant (w/ or w/o other tx)	40 (14/42)	0.88 (0.42-1.83)	.86	0.98 (0.40-2.40)	.96
Single treatment	44 (44/101)	1.00		1.00	
Current health status					
Overall health status					
Fair/poor	59 (20/34)	2.20 (1.07-4.50)	.03	2.23 (0.92-5.40)	.08
Excellent/very good/good	36 (134/340)	1.00		1.00	
Receipt of Survivorship Care Planning Documents					
Have copies of medical records					
No	48 (62/128)	1.57 (1.02-2.41)	.04	1.31 (0.78-2.19)	.31
Yes	38 (93/248)	1.00		1.00	
Have written treatment summary					
No	48 (89/185)	1.76 (1.16-2.66)	.008	1.41 (0.82-2.44)	.22
Yes	35 (66/191)	1.00		1.00	
Have follow-up survivorship care plan					
No	52 (110/213)	2.80 (1.81-4.33)	<.001	2.65 (1.52-4.61)	.001
Yes	28 (45/163)	1.00		1.00	
Currently go to oncology/survivorship clinic					
No	45 (49/110)	1.22 (0.78-1.92)	.38	0.91 (0.53-1.58)	.75
Yes	40 (105/265)	1.00		1.00	
Care model*					
Oncologist only	40 (106/264)	0.92 (0.48-1.74)	.25	0.99 (0.48-2.05)	.98
Primary care provider only	54 (13/24)	1.62 (0.60-4.38)	.23	2.21 (0.68-7.15)	.19
Other subspecialty	27 (7/26)	0.50 (0.18-1.44)	.20	0.40 (0.11-1.43)	.16
Shared-care (both oncologist and PCP)	42 (19/45)	1.00		1.00	

* Care model variable is based on which doctor is reported as most important for test/treatment decisions.