Survivorship Care Planning for Young Adults After Cancer Treatment: Understanding Care Patterns and Patient-Reported Outcomes

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Purpose: Young adult survivors (YAS) of cancer experience late effects of treatment similar to older adult survivors (AS). Online health tools such as Internet-based survivorship care plans (SCPs) can provide access to information about late effects and symptom management, but little is known about SCP patterns of use among YAS.

Methods: An Internet-based cross-sectional survey was completed over 24 months. Participants were individuals diagnosed with cancer between 18 and 39 years (YAS, $n=611$) or 40–60 years (AS, $n=1742$), who were 2–20 years postdiagnosis, and who created an Internet-based SCP. Demographics, treatment-related variables, satisfaction with SCP, communication of SCP, and patient-reported late effects (fatigue, neurocognitive, sexual, cardiovascular, pulmonary, or second cancers) were collected.

Results: YAS were primarily female (71%), Caucasian (78%), college educated (65%), and generated the SCP without assistance (76%). YAS reported satisfaction with content (93%) and shared content with providers (71%). A higher proportion of YAS than AS were male (29% vs. 17%, $p<0.001$), lived internationally (23% vs. 17%, $p=0.003$), and endorsed oncologist-led survivorship care (47% vs. 41%, $p=0.001$). YAS reported concerns about neurocognitive performance (56%) and fatigue (50%). Overall, YAS reported equivalent or fewer late effects than AS across all domains.

Conclusions: YAS report high satisfaction with the online SCP, as well as a high symptom burden, although the latter were reported less than for AS.

Keywords: survivorship, internet, survivorship care plan, patient-reported outcomes

Introduction

CANCER DIAGNOSES IN YOUNG ADULTS (between the ages of 18 and 39 years) have steadily increased over the past 25 years, such that there are now ~70,000 new diagnoses in the United States annually.^{1,2} Although improvements in survival rates among this group have not kept pace with those of pediatric and older adult cancer populations,^{3,4} the majority of young adults diagnosed with cancer will become long-term survivors.⁵ Young adult survivors (YAS) are at risk for medical and psychosocial late effects of treatment^{6,7} and report concerns similar to both younger pediatric and older adult survivors (AS).^{8–12} As these late effects may manifest years after cancer therapy, patients require knowledge of and/or screening for late effects as they age.^{13,14}

Unfortunately, many YAS have limited knowledge of these potential health problems related to their cancer treatment and options for management of ongoing symptoms, and over half do not report receiving risk-based cancer-related follow-up care.^{15,16} Despite this, little research has been performed examining the unique needs or engagement of YAS, with most focusing on AS of pediatric cancers.^{17–22}

Survivorship care plans (SCPs), which include information on the possible risk of and surveillance for late effects of treatment, have been described as a potential means of disseminating information to survivors.^{23–27} YAS may not be aware of their treatment-specific risks despite what is perceived as adequate counseling by a medical team because of the multiple personal, social, and medical transitions that they face.^{15,28–31} Medically, YAS transition from on-therapy

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to off-therapy care and oftentimes from oncology to primary care. Simultaneously, young adults are achieving developmental milestones, which may include solidifying plans for education, employment, and family that may necessitate extra flexibility in survivorship care.^{32–35} While SCP implementation has been slow,³⁶ there is a call for better coordination of care for cancer survivors, and Internet-based SCPs may hold particular promise for this group. Thus, the Commission on Cancer (COC) standards and Institute of Medicine (IOM) recommendations include provision of a SCP at the completion of active cancer treatment for all cancer survivors.^{37,38}

There has been some investigation into how subgroups of adult cancer survivors use Internet-based SCPs^{24,25} with evidence of feasibility, improvements in perceived knowledge, and increased satisfaction with care.³⁹ However, YAS use of Internet-based SCPs, and their satisfaction with such tools, are poorly understood, as are patient-reported late effects in this population. The aims of this study are to compare the characteristics and experience of YAS versus AS using Internet-based SCPs and to compare patient-reported outcomes, encompassing various late effects of cancer therapy, reported by YAS to other AS through an Internet-based SCP mechanism.

Methods

This is a descriptive cross-sectional study examining the experience of YAS use of Internet-based SCPs over a 24-month interval (January 1, 2010 to December 31, 2012). We describe demographics, treatment characteristics, experience of users, and patient-reported late effects of therapy. IRB approval was obtained before any data collection.

Survivorship care plan

YAS used an interactive, Internet-based tool designed to create tailored SCPs. The care plan generator is a free Internet-based service maintained at The Abramson Cancer Center of the University of Pennsylvania and available at www.oncolife.org. Patients were not recruited for this study, but rather decided to engage with the tool voluntarily after encountering it on the Internet. At our center, and many others, we encourage patients to utilize the tool as part of survivorship care. The tool is also hosted on several websites dedicated to cancer care and cancer survivorship. Finally, the tool will appear on an Internet search for “survivorship care plan.” To utilize the tool, a survivor answers questions regarding demographics, cancer diagnosis, and various aspects of cancer treatments received. Based on the answers to these questions, each patient receives an individualized SCP, which includes information on the recommended surveillance for late effects of chemotherapy, radiation, or surgeries in addition to general health maintenance guidelines, general cancer screening, financial and social aspects of survivorship care, and lists of cancer-related resources. Guidelines embedded in the care plan are evidence or consensus based and written in simple patient-friendly language. Because data were obtained only for voluntary participants, no clear “nonparticipant” group existed as part of this study.

Details of the care plan format have been previously described.²³ Briefly, the tool is publicly accessible and available in English and Spanish. It is designed for entry of diagnosis

and treatments by a survivor, family member, or provider and, on average, takes less than 10 minutes to complete. All questions provide a checklist of options listed as potential surgeries, type and sites of radiotherapy, and chemotherapy/biologic medications. Medications listed include both generic and trademark names, as well as acronyms/initials and typical treatment regimens. The SCP generator may be used initially or updated at any point during or after treatment and thus may be used by patients themselves, medical oncology providers, radiation oncologists, specialized survivorship clinics, or primary care clinicians. Since its initiation, the care plan tool has evolved steadily to include patient-reported outcomes on late and long-term toxicities of treatment.⁴⁰ Institutional Review Board approval was obtained and all recommended procedures followed before and during execution of this study.

Study population

Inclusion criteria for the YAS cohort included patients diagnosed between 18 and 39 years. The AS cohort included those diagnosed between 40 and 60 years of age. The age range for YAS is defined according to National Cancer Institute (NCI) definition of adolescent and young adult oncology (15–39 years) with the exclusion of adolescent patients (age 15–17.99 years), who were not eligible to use this tool.⁴¹ Similarly, the age range for AS was defined to exclude those patients who would be classified as either YAS or geriatric oncology survivors (i.e., >65 years) based on NCI definitions. All patients were at least 2 years from their cancer diagnosis. Exclusion criteria included patients who indicated living with metastatic disease to avoid reporting outcomes that might be due to current therapy or progressive disease, as opposed to long term or late effects.

Measures

Demographic, treatment-related, and current survivorship care information was collected during creation of the care plan. Demographic information collected included age, gender, educational achievement, distance to cancer center, living area (urban, rural, suburban), and country of origin. Treatment information included age at diagnosis, cancer type, presence of associated genetic syndrome, and type of treatments received. Methods of cancer follow-up care were assessed through questions about self-motivated versus provider-initiated use and current survivorship provider discipline. A survey 1 month after completion and review of SCP assessed satisfaction with plan content and whether SCP was shared with a survivor's healthcare team. Satisfaction was assessed by a Likert-type scale rating the information provided as poor, fair, good, very good, or excellent and was dichotomized into poor/fair and good to excellent for analyses. Communication of plan to healthcare team was assessed by a single item asking “Did you share your results with any member of your healthcare team?” and reported as dichotomous “yes” or “no” response.

Patient-reported late effects were collected for any survivor filling out a SCP independently (without healthcare provider assistance). To account for heterogeneity of disease processes and treatment, the total number of queries concerning patient-reported late effects varied depending on diagnosis and treatments received. For example, if a patient

received an anthracycline as a chemotherapeutic agent, questions about cardiovascular toxicity would be asked. Answer choices for each individual late effect were “yes,” “no,” and “I don’t know.” For the purpose of this study, six late-effect categories were predefined: fatigue, neurocognitive, sexual, cardiovascular, pulmonary, and secondary malignancy. Each item contains a grouping of questions related to that late effect (Appendix Table A1).

Analytic plan

Demographic, treatment, and care plan use patterns are reported using descriptive statistics, including frequency

counts with percentages and mean with standard deviations as appropriate. YAS were compared with AS using t-tests for continuous variables and chi-square tests for categorical variables. For patient-reported late effects of therapy, frequencies of patients who endorse any of six predefined late effects were compared between groups.

Results

The data from care plans created for YAS ($n=611$) are reported. AS ($n=1742$) who filled out a SCP over the same time period are reported as a comparison group. YAS were primarily female (70.8%), white (78.2%), and college educated

TABLE 1. DEMOGRAPHIC-, DISEASE-, AND TREATMENT-RELATED VARIABLES

	YAS ($n=611$)	AS ($n=1742$)	p
Gender			
Male	179 (29.3)	289 (16.5)	<0.001
Female	432 (70.8)	1453 (83.4)	
Race			
White	478 (78.2)	1479 (85.6)	<0.001
African American	37 (6.6)	83 (4.7)	
Asian	25 (4.1)	70 (4.0)	
Hispanic/Latino	20 (3.3)	66 (3.8)	
Mixed race/other	32 (5.1)	44 (2.5)	
Highest level of education			
Grade school	11 (1.8)	26 (1.5)	0.115
High school	66 (11.1)	190 (11.4)	
Some college	133 (22.4)	412 (24.8)	
College degree	245 (41.2)	609 (36.7)	
Graduate school	139 (23.4)	422 (25.4)	
Distance to cancer center			
Greater than 20 miles	212 (34.7)	591 (33.9)	0.730
Less than 20 miles	399 (65.3)	1151 (66.1)	
Living area			
Urban	275 (45.0)	565 (32.4)	<0.001
Suburban	270 (44.2)	837 (48.1)	
Rural	66 (11.7)	340 (19.5)	
Country of origin			0.050
United States	470 (76.9)	1443 (82.9)	
Canada	38 (6.2)	92 (5.3)	
Great Britain	35 (5.7)	117 (6.7)	
Australia	15 (2.4)	21 (1.2)	
Mexico	5 (0.8)	6 (0.3)	
Other	48 (7.8)	63 (3.6)	
Plans created in Spanish	28 (4.6)	26 (1.5)	<0.001
Diagnosis age, years, mean (SD)	28.2 (6.9)	49.0 (5.8)	<0.001
Current age, years, mean (SD)	33.3 (6.5)	53.3 (5.9)	<0.001
Time since diagnosis, years, mean (SD)	5.1 (3.8)	4.2 (2.9)	<0.001
Associated genetic syndrome	54 (8.8)	136 (7.8)	0.421
Diagnoses (in order of frequency)	Breast (22.4%)	Breast (54.9%)	
	Hodgkin's (16.4%)	Colon cancer (4.5%)	
	Testicular (10.0%)	Lymphoma (5.2%)	
	Lymphoma (8.5%)	Head/neck (4.0%)	
	Thyroid (3.3%)	Ovarian (2.3%)	
	Sarcoma (3.4%)	Prostate (2.1%)	
Received chemotherapy	626 (86)	1416 (79)	<0.001
Received radiation	725 (53.5)	1079 (60.5)	0.001
Had surgery	568 (78.3)	1576 (88.3)	<0.001
Had bone marrow transplant	57 (7.8)	51 (2.8)	<0.001

Values are reported as numbers (percentages). Missing values ($n=100$ for education question) are excluded from percentage calculations. AS, adult survivors; SD, standard deviation; YAS, young adult survivors.

(62.9%). There was a higher proportion of YAS than AS who were male and of non-white race ($p < 0.001$). Although the care plan generator is available internationally, the majority of YAS who generated plans were from the United States (77.3%), lived in urban/suburban settings (89.1%) less than 20 miles from their cancer center (65.3%). A higher proportion of YAS than AS were found to live internationally (23% vs. 17%, $\chi^2 = 9.49$, $p = 0.050$) and create their plans in Spanish (4.6% vs. 1.5%, $\chi^2 = 19.26$, $p < 0.001$). The mean age of survivors in the YAS group was 33.3 years with a mean age at diagnosis of 28.2 years. The most common diagnoses represented in YAS were: breast cancer, Hodgkin's lymphoma, testicular cancer, non-Hodgkin's lymphoma, thyroid cancer, and sarcomas. A higher proportion of YAS versus AS received chemotherapy (86% vs. 79%, $\chi^2 = 16.5$, $p < 0.001$) or underwent bone marrow transplant (7.8% vs. 2.8%, $\chi^2 = 10.2$, $p < 0.001$). A higher proportion of AS received radiation (60.5% vs. 53.5%, $\chi^2 = 31.3$, $p < 0.001$) and reported prior surgery related to their cancer diagnosis (88.3% vs. 78.3%, $\chi^2 = 58.2$, $p < 0.001$). YAS were modestly, although significantly farther in time from diagnosis than AS (5.22 years vs. 4.47 years, $p < 0.001$). Demographic, disease-, and treatment-related data are summarized in Table 1.

Experience with survivorship care and SCPs was similar between YAS and AS. A greater proportion of YAS than AS were receiving oncologist-led survivorship (46.5% vs. 40.9%, $\chi^2 = 18.5$, $p < 0.001$) care as opposed to care led by primary care providers, but less than one quarter of survivors in either group had ever received a formal summary of the treatment they received. Survivors filled out their own care plans, as opposed to receiving healthcare provider-initiated plans, in the majority of cases (76.2% in YAS and 77.3% in AS, $\chi^2 = 0.82$, $p = 0.365$). Similarly, the survivors in both groups endorsed satisfaction with care plan content (92.7% of YAS and 89.7% of AS, $\chi^2 = 1.03$, $p = 0.309$) and had shared their SCP with a member of their healthcare team (70.9% of YAS and 73.2% of AS, $\chi^2 = 0.26$, $p = 0.607$). Receipt of survivorship care and care plan usage are summarized in Table 2.

Patient-reported late effects were common in both groups, with fatigue and neurocognitive concerns being the most common late effects in both YAS (50% and 56% respectively) and AS (53% and 58% respectively). On the contrary,

few (<5%) of survivors in either group reported cardiovascular late effects or secondary malignancy. A similar proportion of YAS compared with AS reported issues with fatigue, secondary malignancies, or sexual side effects in men. Fewer YAS than AS reported issues with neurocognitive, pulmonary, cardiovascular, or female sexual late effects ($p < 0.01$). To further delineate the differences in patient-reported late effects between YAS and AS, late effects were compared between YAS and AS with common diagnoses (i.e., breast cancer and non-Hodgkin's lymphoma). YAS with a breast cancer history reported significantly more concerns with fatigue compared with AS with breast cancer history (91% vs. 54%, $\chi^2 = 23.4$, $p < 0.001$). YAS and AS of non-Hodgkin's lymphoma reported similar proportions of late effects across each domain, except cardiovascular issues (8% vs. 0%, $\chi^2 = 6.31$, $p = 0.012$) and female sexual side effects (49% vs. 23%, $\chi^2 = 6.4$, $p = 0.012$), both of which were more prevalent in AS. Patient-reported late effects are summarized in Table 3.

Discussion

Survivors of young adult cancers are an understudied and underserved group of patients, compared with older and younger individuals with cancer, across the cancer trajectory from diagnosis through survivorship.^{7,10} Data indicate that survivors are not receiving formal treatment summaries or care plans and thus, YAS, a prime group to explore use of Internet-based SCPs, because of their care transitions, social transitions, years of survivor care, and need for self-management.^{42,43}

This study is the first to report on the use of Internet-based SCPs by survivors of young adult cancers (diagnosed at ages 18–39). In this study, the experience of YAS with Internet-based SCPs is demonstrated to be feasible for a diverse group self-motivated YAS. As has been shown previously,^{25,39} survivors tend to be highly satisfied with Internet-based care plans, and use these plans as to aid in communicating with their providers. Internet-based SCPs may have particular importance for engaging select groups of YAS as compared with survivors of other adult cancers who used Internet-based SCPs over the same time period, a higher proportion of YAS were male, of minority status, and live outside the United States.⁴⁴

TABLE 2. SURVIVORSHIP CARE AND CARE PLAN USAGE

	YAS (n = 611)	AS (n = 1742)	p
Care model used for survivor care			
Oncologist	284 (46.5)	712 (40.9)	<0.001
Primary care physician	132 (21.6)	306 (17.6)	
Shared care	165 (27.0)	627 (36.0)	
Other	30 (4.9)	97 (5.6)	
Treatment summary received			
Yes	126 (20.6)	286 (16.4)	0.067
No	408 (66.8)	1255 (72.0)	
Do not know	77 (12.6)	200 (11.5)	
Self-motivated use	466 (76.2)	1346 (77.3)	0.365
Satisfied with information in plan ^a	126/136 (92.7)	428/477 (89.7)	0.309
Shared SCP with member of healthcare team ^a	90/127 (70.9)	330/451 (73.2)	0.607

^aDenominator given when different than total sample. Represents number of participants who responded to 1-month follow-up survey. SCP, survivorship care plan.

TABLE 3. PATIENT REPORTED LATE EFFECTS OF CANCER THERAPY

<i>Patient-reported late effect</i>	<i>YAS</i>	<i>AS</i>	<i>p</i>
Fatigue	156/277 (56)	443/769 (58)	0.719
Neurocognitive	243/485 (50)	776/1226 (63)	<0.001
Cardiovascular	4/402 (1)	106/1209 (1.4)	0.50
Pulmonary	65/200 (33)	78/167 (47)	0.005
Second cancer	16/454 (4)	36/233 (3)	0.501
Female sexual	178/377 (47)	714/1237 (58)	<0.001
Male sexual	19/143 (13)	36/233 (15)	0.564
	<i>YAS of breast cancer</i>	<i>AS of breast cancer</i>	
Fatigue	84/92 (91)	262/478 (54)	<0.001
Neurocognitive	99/165 (60)	457/680 (67)	0.080
Cardiovascular	0/167 (0)	3/779 (0.4)	0.503
Pulmonary	11/15 (73)	34/51 (66)	0.962
Second cancer	0/114 (0)	16/814 (2)	0.131
Female sexual	68/124 (54.8)	531/859 (61.8)	0.137
	<i>YAS of lymphoma</i>	<i>AS of lymphoma</i>	
Fatigue	21/49 (42)	31/52 (60)	0.092
Neurocognitive	21/49 (42)	40/76 (53)	0.402
Cardiovascular	0/44 (0)	5/64 (8)	0.012
Pulmonary	8/19 (42)	5/13 (38)	0.266
Second cancer	0/44 (0)	0/67 (0)	n/a
Female sexual	8/35 (23)	29/59 (49)	0.012
Male sexual	2/14 (14)	4/27 (15)	0.964

Denominator varies by number of participants presented with question based on treatment-related risk of late effect.

Regarding treatment, a higher proportion of YAS who used the resource were treated with chemotherapy and bone marrow transplant. YAS, especially those with high treatment intensity will require more years of ongoing survivorship care as well as personalized screening for late effects and subsequent malignancy. Regarding care model used for survivorship care, the majority of YAS who used this resource report remaining under the care of their primary oncologist at the time of Internet-based SCP creation. This is interesting as the majority of survivors had not previously received a formal treatment summary or care plan. This Internet-based SCP may be used by providers as well as patients to generate SCPs. Creating a SCP during clinical encounters may also be a way for institutions to satisfy requirements for SCP distribution for accreditation purposes.

The fact that a large proportion of YAS are remaining under the care of their primary oncologist, even years posttherapy, calls to attention the need to continue to improve transitions back to primary care providers. Primary care practices, equipped with necessary information about the need for heightened surveillance and symptom management to care for survivors, may provide a more appropriate venue to care for long-term survivors.⁴⁵ Specifically, even in patients reporting traditionally difficult to treat late effects of therapy (fatigue and neurocognitive issues), the validation and recommendations made through the care plan

were highly satisfactory to survivors, which may be useful information to primary care providers managing these patients and symptoms. Finally, while a similar proportion of survivors report of late effects in both groups, it should be noted that YAS were significantly younger at the time of study indicating a higher symptom burden over time for these survivors.

This study has some limitations. First, participants were a select group of patients who found and voluntarily chose to use the SCP generator on the Internet and may be looking for guidance on symptom management and thus the satisfaction with the tool may not be generalizable to all survivors. Because data were available only for survivors who voluntarily utilized the tool, no “nonparticipant” group is available for analysis or comparison. Comparative studies would be useful and represent a future area of study for our group. Survivors who used this resource were more often female, of nonminority status, and college educated. The prominence of this demographic group may be driven by the need for relative affluence to access the Internet, although the tool is free of charge to use. It also may reflect a relative comfort with technology among certain YAS, as well as greater willingness to seek information on the Internet by some groups compared with others. Despite these limitations, understanding use patterns is very useful even as generalizability continues to be explored. Second, while the questions asked are tailored to treatments received, they do not discern whether symptoms reported are late effects of cancer and cancer treatment or effects of aging. All of the late effects are patient self-report. While not confirmed by medical records, these data allow for understanding the symptoms that are most pertinent to survivors.

Cancer survivors of all ages are seeking out information about their cancer history and risk for late effects of therapy through the web.⁴⁶ The number of YAS willing to report late effects of treatment through this mechanism indicates that SCPs may be a feasible method of obtaining patient-reported late effects from YAS and providing information on late effects to YAS. At our center, we continue to work on methods to incorporate SCPs into care of all survivors, in particular YAS, and many survivor subpopulations rely heavily on this and other Internet tools. High proportions of YAS who used the SCP reported ongoing issues with symptoms in many domains even years, posttreatment, and high satisfaction with SCP content related to their ongoing care. While overall, YAS reported fewer late effects than AS, the proportion of patients reporting ongoing symptoms, particularly concerning fatigue and neurocognitive late effects even 2 years and greater posttherapy, is alarming and reiterates the need for evaluation of all cancer survivors.⁴⁷ As we strive to implement the use of SCPs with all cancer survivors, this study elucidates the current experience with Internet-based SCPs among self-motivated survivors. Understanding and optimizing the use of SCPs to relay information and capture patient-reported outcomes can be a valuable tool for patients and providers to address late effects of therapy that are most burdensome to them, while informing ongoing surveillance for potential life-altering complications of therapy. Future research should focus on using SCPs as communication tools between patients, oncologists, and primary care and feasibility of providing Internet-based SCPs to all patients.

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References

- Bleyer A, O'Leary M, Barr R, Reiss LAG. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975–2000 (NIH Pub. No. 06-5767). Bethesda, MD: National Cancer Institute; 2006.
- NIH National Cancer Institute Statistics. Accessed at February 1, 2017 from: www.cancer.gov/types/aya.
- Keegan TH, Reis LA, Barr RD, et al. Comparison of cancer survival trends in the United States of adolescents and young adults with those in children and older adults. *Cancer*. 2016;122(7):1009–16.
- Tai E, Pollack L, Townsend J, et al. Differences in non-Hodgkin lymphoma survival between young adults and children. *Arch Pediatr Adolesc Med*. 2010;164(3):218–24.
- NIH National Cancer Institute Statistics. Accessed at February 1, 2017 from: www.cancer.gov/research/progress/snapshots/adolescent-young-adult
- Lee JS, DuBois SG, Coccia PF, et al. Increased risk of second malignant neoplasms in adolescents and young adults with cancer. *Cancer*. 2016;122(1):116–23.
- National Cancer Institute, LIVESTRONG Young Adult Alliance. Closing the gap: research and care imperative for adolescents and young adults with cancer. Report of the Adolescent and Young Adult Oncology Progress Review Group. National Institutes of Health Publication Number 06-6067, Bethesda, MD, 2006.
- Kazak AE, Derosa BW, Schwartz LA, et al. Psychological outcomes and health beliefs in adolescent and young adult survivors of childhood cancer and controls. *J Clin Oncol*. 2010;28(12):2002–7.
- Pendley JS, Dahlquist LM, Dreyer Z. Body image and psychosocial adjustment in adolescent cancer survivors. *J Pediatr Psychol*. 1997;22(1):29–43.
- Nass SJ, Beaupin LK, Demark-Wahnefried W, et al. Identifying and addressing the needs of adolescents and young adults with cancer: summary of an Institute of Medicine Workshop. *Oncologist*. 2015;20(2):186–95.
- Richardson R, Nelson M, Meeke K. Young adult survivors of childhood cancer: attending to emerging medical and psychosocial needs. *J Pediatr Oncol Nurs*. 1999;16(3):136–44.
- Zebrack B, Hamilton R, Smith AR. Psychosocial outcomes and service use among young adults with cancer. *Semin Oncol*. 2009;36(5):468–77.
- Bleyer A. The adolescent and young adult gap in cancer care and outcome. *Curr Probl Pediatr Adolesc Health Care*. 2005;35(5):182–17.
- Bleyer A. Young adult oncology: the patients and their survival challenges. *CA Cancer J Clin*. 2007;57(4):242–55.
- Kadan-Lottick NS, Robinson LL, Gurney JG, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *JAMA*. 2002;287(14):1832–9.
- 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(27):4401–9.
- Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355:1572–82.
- Henderson TO, Friedman DL, Meadows AT. Childhood cancer survivors: transition to adult-focused risk-based care. *Pediatrics*. 2010;126:129–36.
- Laverdiere C, Liu Q, Yasui Y. Long-term outcomes in survivors of neuroblastoma: a report from the Childhood Cancer Survivor Study. *J Natl Cancer Inst*. 2009;101(16):1121–40.
- Stuber ML, Meeske KA, Krull KR, et al. Prevalence and predictors of posttraumatic stress disorder in adult survivors of childhood cancer. *Pediatrics*. 2010;125:1124–34.
- Castellino SM, Geiger AM, Mertens AC. Morbidity and mortality in long-term survivors of Hodgkin lymphoma: a report from the Childhood Cancer Survivor Study. *Blood*. 2011;117(6):1806–16.
- Keegan TH, Lichtensztain DY, Kato I, et al. Unmet adolescent and young adult cancer survivor information and service needs: a population-based cancer registry study. *J Cancer Surviv*. 2012;6(3):239–50.
- Hill-Kayser CE, Vachani C, Hampshire MK, et al. An Internet tool for creation of cancer survivorship care plans for survivors and health care providers: design, implementation, use and user satisfaction. *J Med Internet Res*. 2009;11(3):e39.
- Hill-Kayser CE, Vachani C, Hampshire MK, et al. Utilization of Internet-based survivorship care plans by lung cancer survivors. *Clin Lung Cancer*. 2009;10(5):347–52.
- Hill-Kayser CE, Vachani C, Hampshire MK, Metz JM. High level use and satisfaction with Internet-based breast cancer survivorship care plans. *Breast J*. 2012;18(1):97–9.
- Brennan ME, Gormally JF, Butow P, et al. Survivorship care plans in cancer: a systematic review of care plan outcomes. *Br J Cancer*. 2014;111(10):1899–908.
- Shalom MM, Hahn EE, Casillas J, Ganz PA. Do survivorship care plans make a difference? A primary care provider perspective. *J Oncol Pract*. 2011;7(5):314–8.
- Bashore L. Childhood and adolescent cancer survivor knowledge of their disease and effects of treatment. *J Pediatr Oncol Nurs*. 2004;21(2):98–102.
- Henderson TO, Hlubocky FJ, Wroblewski KE, et al. Physician preferences and knowledge gaps regarding the care of childhood cancer survivors: a mailed survey of pediatric oncologists. *J Clin Oncol*. 2010;28(5):878–83.
- Nathan PC, Daugherty CK, Wroblewski KE, et al. Family physician preferences and knowledge gaps regarding the care of adolescent and young adult survivors of childhood cancer. *J Cancer Surviv*. 2013;7(3):275–82.
- Suh E, Daugherty CK, Wroblewski K, et al. General internists' preferences and knowledge about the care of adult survivors of childhood cancer: a cross-sectional survey. *Ann Intern Med*. 2014;160(1):11–17.
- Albritton K, Bleyer WA. The management of cancer in the older adolescent. *Eur J Cancer*. 2003;39(18):2584–99.
- Evan EE, Zeltzer LK. Psychosocial dimensions of cancer in adolescents and young adults. *Cancer*. 2006;107(7):1663–71.
- Haase JE, Phillips CR. The adolescent/young adult experience. *J Pediatric Oncol Nurs*. 2004;21:145–9.

35. Shama W, Lucchetta S. Psychosocial issues of the adolescent cancer patient and the development of the Teenage Outreach Program (TOP). *J Psychosoc Oncol*. 2007;25(3):99–112.
36. Stricker CT, Jacobs LA, Risendal B, et al. Survivorship care planning after the institute of medicine recommendations: how are we faring? *J Cancer Surviv*. 2011;5(4):358–70.
37. Cancer Program Standards 2012: Ensuring Patient-Centered Care. Commission on Cancer V1.2.1, August, 2012.
38. Hewitt M, Greenfield S, Stoval E. From cancer patient to cancer survivor: lost in transition. Washington, DC: National Academies Press; 2005.
39. Palmer SC, Stricker CT, Panzer SL, et al. Outcomes and satisfaction after delivery of a breast cancer survivorship care plan: results of a multicenter trial. *J Oncol Pract*. 2015;11(2):e222–9.
40. Grover S, Hill-Kayser CE, Vachani C, et al. Patient reported late effects of gynecological cancer treatment. *Gynecol Oncol*. 2012;124(3):399–403.
41. National Cancer Institute. Adolescent and Young Adults with Cancer. <https://www.cancer.gov/types/aya> (last accessed March 15, 2018).
42. Shliakhsitsava K, Romero SAD, Whitcomb BW, et al. Age cancer treatment are related to receiving treatment summaries and survivorship care plans in female young adult cancer survivors. *J Adolesc Young Adult Oncol*. 2017;6(4):573–8.
43. Casillas J, Syrjala KL, Ganz PA, et al. How confident are young adult cancer survivors in managing their survivorship care? A report from the LIVESTRONG™ Survivorship Center of Excellence Network. *J Cancer Surviv*. 2011;5(4):371–81.
44. Hill-Kayser C, Vachani C, Hampshire MK, et al. World-wide use of Internet-based survivorship care plans. *Eur Oncol*. 2010;6(2):10–13.
45. Oeffinger KC, Argenbright KE, Levitt GA, et al. Models of cancer survivorship health care: moving forward. *Am Soc Clin Oncol Educ Book*. 2014;205–13.
46. Finney Rutten LJ, Agunwamba AA, Wilson P, et al. Cancer-related information seeking among cancer survivor: trends over a decade 2003–2013. *J Cancer Educ*. 2016;31(2):348–57.
47. Kadan-Lottick NS, Zeltzer LK, Liu Q. Neurocognitive functioning in adult survivors of childhood non-central nervous system cancers. *J Natl Cancer Inst*. 2010;102(12):881–93.

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APPENDIX TABLE A1. ITEMS USED TO ASSESS PATIENT-REPORTED LATE EFFECTS AND EXAMPLES OF TREATMENT WHICH TRIGGERED ASSESSMENT

<i>Patient-reported late effect</i>	<i>Item(s) included</i>	<i>Example of treatment(s) received</i>
Fatigue	Are you experiencing fatigue (overwhelming physical, mental, or emotional exhaustion)? Have you been diagnosed with a learning disability or memory issue	All patients with chemotherapy or radiation Cranial radiation Cytarabine Methotrexate Ifosfamide
Neurocognitive	Are you concerned about cognitive changes, such as memory loss, difficulty with short-term memory, concentration or learning new skills	
Cardiovascular	Have you been diagnosed with myocardial infarction, hypertension, angina, heart failure, cardiomyopathy, arrhythmia, or left ventricular dysfunction	Anthracycline Herceptin Chest radiation
Pulmonary	Have you been diagnosed with lung disease or lung fibrosis	Bleomycin, lomustine Lung radiation
Second cancer	Have you been diagnosed with a second cancer, breast cancer, thyroid cancer, bladder cancer, or AML/MDS. (Did not include skin cancer)	Etoposide, ifosfamide, anthracyclines Radiation
Female sexual	Have you experienced sexual changes or concerns, including vaginal dryness, painful intercourse, decreased desire	Surgeries: hysterectomy, oophorectomy Pelvic radiation Cyclophosphamide
Male sexual	Have developed erectile dysfunction or required medical intervention to achieve an erection Have you experienced retrograde ejaculation or dry ejaculation	Prostatectomy Testicular cancer Retroperitoneal dissection of lymph nodes Pelvic radiation Cyclophosphamide

AML, acute myeloid leukemia; MDS, myelodysplastic syndrome.