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Journal

Journal of Cancer Survivorship, 8(2)

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Publication Date

2014-06-01

DOI

10.1007/s11764-013-0332-4

Peer reviewed



Published in final edited form as:

J Cancer Surviv. 2014 June ; 8(2): 282–292. doi:10.1007/s11764-013-0332-4.

Medical care in adolescents and young adult cancer survivors: what are the biggest access-related barriers?

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Abstract

Purpose—Adolescent and young adult (AYA) cancer survivors experience barriers to utilizing healthcare, but the determinants of cancer-related medical care of AYAs has not been fully explored.

Methods—We studied factors associated with medical care utilization among 465 AYA cancer survivors in the AYA Health Outcomes and Patient Experience Study (AYA HOPE), a cohort of 15 to 39 year-olds recently diagnosed with germ cell cancer, lymphoma, sarcoma, or acute lymphocytic leukemia. Descriptive statistics and multivariate logistic regression methods were used.

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Results—Most AYA cancer survivors (95%), who were 15–35 months post diagnosis, received medical care in the past 12 months and 17% were undergoing cancer treatment. In multivariate analyses, compared with AYAs with no cancer-related medical visits in the previous year, AYAs receiving cancer-related care were more likely to currently have health insurance (odds ratio (OR) = 4.9; 95% confidence interval (CI): 1.7–13.8) or have had health insurance in the past year (OR= 4.0; 95% CI: 0.99–16.3). Cancer recurrence, lacking employment and negative changes in self-reported general health were associated with ongoing cancer treatment versus other cancer-related medical care. 11% of all AYAs and 25% of AYAs who did not receive medical care in the past 12-months lost health insurance between the initial and follow-up surveys.

Conclusion—AYA cancer survivors with health insurance were much more likely to receive cancer-related medical care than those without insurance.

Implications for Cancer Survivors—Despite the need for post-treatment medical care, lacking health insurance is a barrier to receiving any medical care among AYAs.

Keywords

cancer survivors; adolescent and young adult; health insurance; cancer care

Introduction

Long-term survivors of childhood and adolescent cancer are at an increased risk of developing chronic health conditions and other adverse late effects of treatment, including second cancers, cardiac conditions and psycho-social problems [1–4]. In addition, over 30% of recently treated adolescent and young adult (AYA) cancer survivors 15 to 39 years of age at diagnosis have reported comorbidities that may complicate survivorship [5, 6]. Further, more than half of AYA cancer survivors report having inadequate information about their cancer treatment or appropriate post-treatment medical services, including approaches to surveillance for identifying cancer recurrence [7]. Therefore, a comprehensive healthcare plan that details the transition to survivorship care and incorporates risk-focused education and surveillance based on prior cancer therapy, genetic predisposition, lifestyle behaviors and comorbid conditions is recommended for all AYA survivors of cancer [4, 8].

Lack of adequate health insurance can present a critical barrier to receipt of appropriate healthcare services, particularly for cancer patients with complicated or expensive courses of treatment [9]. In addition, studies of long-term survivors of childhood cancer indicate that lack of insurance negatively affects receipt of appropriate medical care and that cancer survivors have more difficulty obtaining and keeping health insurance compared to their siblings who did not have cancer [8, 10–12]. With uninsurance rates peaking in adolescence and young adulthood [13], AYA cancer survivors may be particularly vulnerable to not receiving cancer survivor-focused medical care. Further, many AYAs are entering the healthcare system at a critical life transition to young adulthood, and with that a transition to new healthcare providers. While many younger adolescents may be treated at a more specialized tertiary care center, including pediatric hospitals, older adolescents are often treated in community-based adult oncology programs [14–16]. As a result, follow-up care for AYAs cancer survivors will likely pose different challenges than survivors of childhood

cancer or cancer survivors diagnosed later in life. One recent study has considered general healthcare access and use among long-term cancer survivors diagnosed across the entire 15 to 39 year age span [17], but no prior studies have addressed this issue in more recently diagnosed AYA cancer survivors. Therefore, using the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study sponsored by the National Cancer Institute (NCI), with support from LIVESTRONG, and conducted by NCI Surveillance, Epidemiology, and End Results (SEER) registries, the aims of this analysis were to 1) determine AYA cancer survivors cancer and non-cancer-related medical care in a 12-month period; and 2) examine socio-demographic and cancer-related factors associated with medical care use among survivors 15–35 months after diagnosis.

Methods

Study Population and Recruitment

Patients were identified through the population-based SEER program cancer registries that cover the geographic areas of Detroit, Michigan; Seattle/Puget Sound, Washington; Los Angeles County, San Francisco/Oakland, Sacramento County, Orange County, California; and the states of Iowa, and Louisiana. As detailed previously [18], eligible cases were 15–39 year old residents of the study areas who were newly diagnosed between July 1, 2007 and October 31, 2008 with the following common, but understudied AYA cancers [19]: invasive, first primary non-Hodgkin lymphoma (NHL), Hodgkin lymphoma (HL), germ cell cancer (e.g., testicular or ovarian), acute lymphocytic leukemia (ALL) or sarcoma, specifically Ewing's sarcoma, osteosarcoma and rhabdomyosarcoma (excluded tumors arising in the central nervous system); those who were not able to read and write English or were diagnosed on autopsy or death certificate were ineligible. Approval for the conduct of this study was obtained by each of the registries' and National Cancer Institute's Institutional Review Boards.

Data Collection

The AYA HOPE study included data from SEER registries, two patient surveys, and medical records. Potential participants were mailed a study packet with multiple follow-up attempts for non-respondents [18]. The self-administered patient survey queried participants about their health status and symptoms 6–14 months after diagnosis, the impact of cancer, quality of life, information and service needs, healthcare delivery and reasons for non-participation in clinical trials (<http://outcomes.cancer.gov/surveys/aya>). A follow-up survey was administered 15–35 months after diagnosis to examine changes in psychosocial, work and quality-of-life outcomes as well as insurance status and medical care utilization. A total of 524 patients completed the initial survey (response rate of 43%) and 465 (88%) of these patients completed the follow-up survey.

Measures

Cancer histologies were determined from SEER data and verified via medical records. The medical record forms collected information on tumor characteristics and staging, treatment, and serious comorbid conditions, as described previously [6]. Age at diagnosis and gender were obtained from SEER registries. Self-reported race/ethnicity and number of common

symptoms were obtained from the initial survey [7]. Because the number of American Indian /Alaska Natives (AI/AN) (n= 9) was small and their results were most similar to those for Blacks, these two race/ethnicities were collapsed for the multivariable analyses. At the follow-up survey, participants reported their education level, marital status, recurrence and employment status.

At the time of both initial and follow-up surveys, participants were asked about their source of health insurance (employer/school, spouse's employer/school, parent, individual policy, Medicaid/other state programs, Military/Veteran's benefits, COBRA, and any other sources), general health (excellent, very good, good, fair, poor), date of last treatment, their perceived quality of care received since their cancer diagnosis (poor, fair, good, very good, excellent), whether they were currently in treatment, and whether they needed more information (initial survey) or were concerned (follow-up survey) about 13 topics of relevance to AYAs, including cancer recurrence, cancer treatments, financial support, having children, meeting other cancer survivors and talking about their cancer experience. Information need was defined as needing some or much more information or being somewhat or very concerned and summed into low, medium and high information needs. We also considered changes in health insurance, general health, and quality of care from initial to follow-up survey. A positive change was defined as patients who had changed from no insurance to insurance coverage or reported better general health or quality of care (poor, fair, good, very good, excellent); a negative change was defined as a change in the opposite direction.

Outcomes

At the follow-up survey, participants were asked if they had gone to a doctor in the past 12 months, and, if so, to indicate the type/specialty of the physician they saw, and the reasons for their visits. Participants who did not see a doctor were classified as having no medical care and were asked to specify the reasons they did not see a doctor. Because participants could mark multiple reasons for seeing a doctor, we categorized patients into one category using a mutually exclusive, hierarchical approach [8]. In the following order, a cancer-related medical visit included patients who indicated that any visit was for: 1) ongoing cancer treatment; 2) to discuss and/or treat cancer symptoms and side effects; or 3) to receive follow-up tests to check for signs of cancer or other medical problems. On-going cancer treatment was considered separately from other cancer-related medical visits. No cancer-related medical visits included patients with no medical visits or only general medical visits to receive a general physical examination, or treatment for cold/flu or illness other than cancer, injury, or other.

Statistical Analysis

Frequencies and percentages of medical visits, types of doctors seen and reasons for care were described among all AYAs and by status of insurance coverage. Utilization of medical care was described by patient characteristics. Logistic regression analyses were used to assess the associations of socio-demographic and cancer-related factors with cancer-related medical care use (versus no cancer-related medical visits) and ongoing cancer treatment (versus other cancer-related medical visits) in AYAs. Multivariate regression models

included variables significant at $P < 0.05$ in univariate models (e.g., employment, type of cancer, recurrence, self-reported general health, quality of care, health insurance coverage, and level of information needs) or with a priori hypothesis for inclusion (e.g., age at diagnosis, gender, race/ethnicity, education and comorbidities). Stage at diagnosis was not associated with medical care outcomes, and date of last treatment was highly correlated with ongoing cancer care, so these variables were not included in our multivariable models. We also examined the associations between medical care utilization and change of self-reported health insurance coverage, perceived quality of care, and general health from initial to follow-up survey.

All statistical tests were carried out using SAS software version 9.3 (SAS Institute, Cary, North Carolina). All P values reported were two-sided, and those that were <0.05 were considered to be statistically significant.

Results

Types of Medical Visits

Ninety-five percent of the 465 AYAs in our study had received medical care in the past 12 months (Table 1), although AYAs without insurance were much less likely to go to doctors (82%) than those with insurance (97%) in the past 12 months. The majority of AYAs saw primary care physicians or oncologists. The type of physician seen (i.e., oncologist, primary care physician or other type of doctor) did not vary by age group (15–19, 20–29, 30–39) ($P = 0.88$, data not shown). AYAs without insurance generally were less likely to see all types of doctors, particularly oncologists. Most medical care among AYAs was related to receiving follow-up tests (87%) and general physical exams (48%); 17% of AYAs received medical care for ongoing treatment 15–35 months after diagnosis. Among AYAs who did not report a doctor's visit in the past 12 months, the three most common reasons for no care were high cost/no insurance (44%), they felt they did not need follow-up care (40%) or their doctor said they did not need follow-up care (28%) (data not shown).

Medical Visits by Patient Socio-demographic and Cancer-related Factors

Among the 57 AYA's who had no cancer-related medical visits in the past year, a larger percentage were male, of non-Hispanic Black or AI/AN and Hispanic race/ethnicity, unemployed, later from diagnosis, farther from their last treatment, had no health insurance, and had more unmet information needs than those who received cancer-related care (Table 2). AYAs diagnosed with ALL and NHL were more likely to have ongoing cancer treatment. Eleven percent of AYAs overall and 24% who did not receive medical care in the past 12-months lost health insurance between the initial and follow-up surveys.

Multivariate analyses demonstrated that AYAs treated in 2009–2010, versus prior to 2009, were over 5 times more likely to received cancer-related medical care than those reporting no cancer-related medical care (OR= 5.1; 95% CI: 2.0–12.8) (Table 3). AYAs with current health insurance were nearly 5 times more likely to receive cancer-related care than those without health insurance (OR= 4.9; 95% CI: 1.7–13.8). AYAs currently without insurance, but with insurance in the last year, were 4 times more likely to have care-related medical

care (OR= 4.0; 95% CI: 0.99–16.3; borderline significant). AYAs receiving ongoing cancer treatment were more likely to be male, unemployed, have a recurrence, and have ALL (versus HL) than AYAs receiving other cancer-related medical care. AYAs undergoing cancer treatment were somewhat, although not significantly, less likely to have health insurance than AYAs receiving other cancer-related medical care.

Change of Health and Insurance Status Associated with Cancer-related Medical Care

Changes in health insurance coverage from initial to follow-up survey were not associated with cancer-related medical care utilization in our study (Table 4). However, on-going cancer treatment was associated with a non-significant positive change in quality of care (OR= 2.0; 95% CI: 0.97–4.2) and a significant negative change in self-reported general health compared with other cancer-related medical care (OR= 2.2; 95% CI: 1.1–4.4).

Discussion

In our study of 465 AYA cancer survivors 15–35 months from diagnosis, we found that the majority of AYAs received medical care in the past 12 months. Among those patients who did not receive care, the most commonly reported reasons were high costs, lack of insurance, they felt they did not need follow-up care or their doctor said they did not need follow-up care. Further, AYA cancer survivors without insurance were much less likely to go to the doctor than those with insurance. Notably, 11% of all AYAs and 25% of AYAs who did not receive medical care in the past 12-months lost health insurance between the initial and follow-up surveys. Finally, in multivariate analyses, we demonstrate that having insurance was strongly associated with receiving cancer-related medical care, while having a cancer recurrence, lacking employment and negative changes in self-reported general health were all associated with receiving ongoing cancer treatment. Overall, this study provides important insights into segments of the AYA cancer survivor population that are more likely to forgo medical care in the first few years after diagnosis.

Consistent with our study, cost has been cited as a reason for forgoing medical care in a recent study of long-term, 5-year AYA cancer survivors [17]. Using Behavioral Risk Factor Surveillance System data, AYA cancer survivors were 55% to 67% more likely than non-cancer controls to report foregoing medical care in the past year due to costs, despite similar levels of health insurance [17]. Furthermore, similar to our findings, uninsured survivors reported lower health care use, with more than two-thirds of uninsured survivors having no personal provider or routine medical care [17]. A lack of health insurance has consistently been reported as a barrier to receiving health care [8, 10, 11] in the Childhood Cancer Survivorship Study (CCSS), a study that included 5-year cancer survivors diagnosed before the age of 21 years and ranging in age up to 48 years at time of study [20]. Uninsured childhood cancer survivors were less likely to report a cancer-related or cancer center visit than privately- or publically-insured survivors, with publically-insured survivors using survivor-focused health care at least as often as those with private insurance [11].

During cancer treatment, not having health insurance appears to be less of a barrier to receiving care, as AYA survivors in our study currently undergoing treatment were somewhat less likely to have health insurance coverage than AYAs receiving other cancer-

related medical care. These findings may be a result of hospital-based cancer treatment centers providing care regardless of patient's ability to pay through a combination of charity care or through non-profit organizations that provide financial assistance for patients in active treatment. As expected, currently undergoing treatment was associated with a lack of employment, having a recurrence and a negative change in self-reported health, highlighting the impact treatment has on this age-group [5, 21]. Furthermore, those with ALL were more likely to be undergoing treatment in our study, likely due to the longer treatment regimen for ALL compared to the other cancers in this study. Our results, coupled with studies of long-term childhood and adolescent [8, 10, 11] and AYA [17] cancer survivors, suggest that a lack of health insurance after the completion of treatment is a critical barrier to receiving cancer-related medical care and an important area for intervention so that AYAs get the follow-up care they need. As AYAs are more likely to be uninsured or underinsured [13] compared to children and older adults, future studies should examine best practices for maintenance of health insurance. AYAs may also need help navigating their changing financial status, transition into the education and labor force [22], and accessing resources, such as employer-sponsored health benefits.

The implementation of the measures from the Patient Protection and Affordable Care Act (ACA) of 2010 [23, 24] will likely benefit AYA cancer survivors. ACA allows individuals to stay on their parents' insurance until the age of 26, prohibits rescissions of coverage, eliminates limits on insurance coverage, does not exclude preexisting conditions and expressly prohibits termination of coverage [25]. As over 14% (n=67) of survivors in our study are currently uninsured, the ACA presents important opportunities to extend insurance options and coverage to a population that will require continued medical care [17]. With the state-run insurance exchanges and potential Medicaid expansion by states set for full implementation by 2014 [25, 23], AYA cancer survivors should soon have access to a new array of insurance options to address their chronic health conditions. Therefore, future studies should explore best practices and interventions for informing physicians about and facilitating AYA enrollment in these expanded coverage options in order to improve access to care.

Barriers for survivors to seek medical care go beyond insurance access, and include financial concerns, as found in our study and in long-term AYA cancer survivors [17]. Copayments, high deductibles, lost wages and other out-of-pocket costs, including transportation and childcare costs [26, 27], can be burdensome to AYA survivors, especially when they have debt from attending college or starting a career [28]. In addition to cost, lack of awareness and knowledge about their higher risk for developing chronic complications and other psycho-social factors may also explain access issues for AYA cancer survivors [29, 1, 30]. Therefore additional support, information, and education are needed not only for this high-risk population and their families, but also medical staff and care providers.

Our study expands on previous studies, which focus predominately on general medical care, to provide important information on the utilization of cancer-related medical care in AYA cancer survivors through the recruitment of a large number of participants from cancer registries in the United States. However, the generalizability of our findings may be limited by the requirement that participants read and write English and our response rate of 43% to

the initial survey. While participants in this study were more likely to be female and less likely to be of Hispanic or Black race/ethnicity (versus non-Hispanic white), they did not differ by age, census tract education or median family income, or cancer site from non-participants [18]. Furthermore, respondents to the follow-up survey did not differ from non-respondents on age, gender, race/ethnicity, education, cancer site [18] or health insurance status. Despite this, our findings may underestimate healthcare barriers in the larger AYA cancer survivor population. In addition, because our study considered more recently diagnosed AYAs, 17% of AYAs were receiving medical care for ongoing treatment. Although we were able to compare factors associated with ongoing cancer treatment compared to cancer-related care, it is also critical to understand and improve cancer-related medical care utilization well after diagnosis. We have learned from the CCSS that long-term pediatric and adolescent cancer survivors have an excess risk of chronic health conditions and adverse health outcomes [3, 4], risky health behaviors [31, 32] and poor compliance with medical and dental care [32]. Long-term AYA cancer survivors were also found to have higher prevalences of current smoking, obesity, cardiovascular disease, hypertension, asthma, disability, and poor mental and physical health compared to AYAs without cancer [21], further highlighting the need for close medical surveillance in this population.

The findings of our study suggest that AYA cancer survivors covered by health insurance within the first few years after diagnosis were more likely to receive cancer-related medical care than those without health insurance. Furthermore, although the number of patients reporting a decision to forgo medical care was small, cost and anxiety influenced their medical care decisions. AYAs have historically been a highly uninsured population and 11% lost insurance during the course of our study. Given the need for comprehensive surveillance and medical care to reduce the long-term health and psychosocial challenges, the lack of adequate health insurance presents a critical barrier to receipt of necessary medical care. Future studies should consider best practices and interventions for increasing health insurance enrollment with the expansion of the ACA in the coming years as well as encouraging ongoing health promotion and surveillance care among AYA cancer survivors.

Acknowledgments

AYA HOPE Study Collaborative Group

California Cancer Registry/Public Health Institute (Sacramento, CA): Rosemary Cress, DrPH (P.I.); Gretchen Agha; Mark Cruz

Fred Hutchinson Cancer Research Center (Seattle, WA): Stephen M. Schwartz, Ph.D. (P.I.); Martha Shellenberger; Tiffany Janes

Karmanos Cancer Center (Detroit, MI): Ikuko Kato, M.D., Ph.D. (P.I.); Ann Bankowski; Marjorie Stock

Louisiana State University (New Orleans, LA): Xiao-cheng Wu, M.D., MPH (P.I.); Vivien Chen; Bradley Tompkins

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Supported by National Cancer Institute contracts N01-PC-54402, N01-PC-54404, N01-PC-35136, N01-PC-35139, N01-PC-35142, N01-PC-35143, N01-PC-35145.

References

1. Zeltzer LK, Lu Q, Leisenring W, Tsao JC, Recklitis C, Armstrong G, et al. Psychosocial outcomes and health-related quality of life in adult childhood cancer survivors: a report from the childhood cancer survivor study. *Cancer Epidemiol Biomarkers Prev.* 2008; 17(2):435–46. 17/2/435 [pii] . EPI-07-2541. 10.1158/1055-9965 [PubMed: 18268128]
2. Hudson MM, Mertens AC, Yasui Y, Hobbie W, Chen H, Gurney JG, et al. Health status of adult long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *JAMA.* 2003; 290(12):1583–92. 290/12/1583 [pii]. 10.1001/jama.290.12.1583 [PubMed: 14506117]
3. 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. 355/15/1572 [pii]. 10.1056/NEJMsa060185 [PubMed: 17035650]
4. Oeffinger KC, Tonorezos ES. The cancer is over, now what?: Understanding risk, changing outcomes. *Cancer.* 2011; 117(10 Suppl):2250–7. 10.1002/cncr.26051 [PubMed: 21523742]
5. Parsons HM, Harlan LC, Lynch CF, Hamilton AS, Wu XC, Kato I, et al. Impact of cancer on work and education among adolescent and young adult cancer survivors. *J Clin Oncol.* 2012; 30(19): 2393–400. JCO.2011.39.6333 [pii]. 10.1200/JCO.2011.39.6333 [PubMed: 22614977]
6. Parsons HM, Harlan LC, Seibel NL, Stevens JL, Keegan TH. Clinical trial participation and time to treatment among adolescents and young adults with cancer: does age at diagnosis or insurance make a difference? *J Clin Oncol.* 2011; 29(30):4045–53. JCO.2011.36.2954 [pii]. 10.1200/JCO.2011.36.2954 [PubMed: 21931022]
7. Keegan TH, Lichtensztajn DY, Kato I, Kent EE, Wu XC, West MM, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *J Cancer Surviv.* 2012; 6(3):239–50. 10.1007/s11764-012-0219-9 [PubMed: 22457219]
8. Nathan PC, Greenberg ML, Ness KK, Hudson MM, Mertens AC, Mahoney MC, 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. 26/27/4401 [pii]. 10.1200/JCO.2008.16.9607 [PubMed: 18802152]
9. Ward E, Halpern M, Schrag N, Cokkinides V, DeSantis C, Bandi P, et al. Association of insurance with cancer care utilization and outcomes. *CA Cancer J Clin.* 2008; 58(1):9–31. CA.2007.0011 [pii]. 10.3322/CA.2007.0011 [PubMed: 18096863]
10. 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. [PubMed: 15053285]
11. Casillas J, Castellino SM, Hudson MM, Mertens AC, Lima IS, Liu Q, et al. Impact of insurance type on survivor-focused and general preventive health care utilization in adult survivors of childhood cancer: the Childhood Cancer Survivor Study (CCSS). *Cancer.* 2011; 117(9):1966–75. 10.1002/cncr.25688 [PubMed: 21509774]
12. Park ER, Li FP, Liu Y, Emmons KM, Ablin A, Robison LL, et al. Health insurance coverage in survivors of childhood cancer: the Childhood Cancer Survivor Study. *Journal of Clinical Oncology.* 2005; 23(36):9187–97. [PubMed: 16361621]

13. Adams SH, Newacheck PW, Park MJ, Brindis CD, Irwin CE Jr. Health insurance across vulnerable ages: patterns and disparities from adolescence to the early 30s. *Pediatrics*. 2007; 119(5):e1033–9. 10.1542/peds.2006-1730 [PubMed: 17473076]
14. Pollock BH. Where adolescents and young adults with cancer receive their care: does it matter? *J Clin Oncol*. 2007; 25(29):4522–3. 25/29/4522 [pii]. 10.1200/JCO.2007.12.1715 [PubMed: 17925546]
15. Albritton KH, Wiggins CH, Nelson HE, Weeks JC. Site of oncologic specialty care for older adolescents in Utah. *J Clin Oncol*. 2007; 25(29):4616–21. 25/29/4616 [pii]. 10.1200/JCO.2006.08.4103 [PubMed: 17925557]
16. Howell DL, Ward KC, Austin HD, Young JL, Woods WG. Access to pediatric cancer care by age, race, and diagnosis, and outcomes of cancer treatment in pediatric and adolescent patients in the state of Georgia. *J Clin Oncol*. 2007; 25(29):4610–5. 25/29/4610 [pii]. 10.1200/JCO.2006.07.6992 [PubMed: 17925556]
17. Kirchhoff AC, Lyles CR, Fluchel M, Wright J, Leisenring W. Limitations in health care access and utilization among long-term survivors of adolescent and young adult cancer. *Cancer*. 2012; 118(23):5964–72. 10.1002/cncr.27537 [PubMed: 23007632]
18. Harlan LC, Lynch CF, Keegan TH, Hamilton AS, Wu XC, Kato I, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *J Cancer Surviv*. 2011; 5(3):305–14. 10.1007/s11764-011-0173-y [PubMed: 21274648]
19. National Cancer Institute. Report of the Adolescent and Young Adult Oncology Progress Review Group. Bethesda: National Cancer Institute; 2006. Closing the gap: research and care imperatives for adolescents and young adults with cancer.
20. Robison LL, Mertens AC, Boice JD, Breslow NE, Donaldson SS, Green DM, et al. Study design and cohort characteristics of the Childhood Cancer Survivor Study: a multi-institutional collaborative project. *Med Pediatr Oncol*. 2002; 38(4):229–39. [pii]. 10.1002/mpo.1316 [PubMed: 11920786]
21. Tai E, Buchanan N, Townsend J, Fairley T, Moore A, Richardson LC. Health status of adolescent and young adult cancer survivors. *Cancer*. 2012; 118(19):4884–91. 10.1002/cncr.27445 [PubMed: 22688896]
22. Nicholson JL, Collins SR, Mahato B, Gould E, Schoen C, Rustgi SD. Rite of passage? Why young adults become uninsured and how new policies can help, 2009 update. *Issue Brief (Commonw Fund)*. 2009; 64:1–20. [PubMed: 19658271]
23. Wolfson J, Ruccione K, Reaman GH. Health care reform 2010: expected favorable impact on childhood cancer patients and survivors. *Cancer J*. 2010; 16(6):554–62. 00130404-201011000-00002 [pii]. 10.1097/PPO.0b013e3181f6ee83 [PubMed: 21131785]
24. Bleyer A, Ulrich C, Martin S. Young adults, cancer, health insurance, socioeconomic status, and the Patient Protection and Affordable Care Act. *Cancer*. 2012; 118(24):6018–21. 10.1002/cncr.27685 [PubMed: 22736148]
25. Moy B, Polite BN, Halpern MT, Stranne SK, Winer EP, Wollins DS, et al. American Society of Clinical Oncology policy statement: opportunities in the patient protection and affordable care act to reduce cancer care disparities. *J Clin Oncol*. 2011; 29(28):3816–24. JCO.2011.35.8903 [pii]. 10.1200/JCO.2011.35.8903 [PubMed: 21810680]
26. Brown, ML.; Yabroff, KR. Economic impact of cancer in the United States. In: Schottenfeld, DFJJ., editor. *Cancer Epidemiology and Prevention*. 3. New York, NY: Oxford Univ; 2006. p. 202-14.
27. Gruber J, Perry I. Will the Affordable Care Act make health insurance affordable? *Issue Brief (Commonw Fund)*. 2011; 2:1–15. [PubMed: 21539012]
28. Nicholson JL, Collins SR. Young, uninsured, and seeking change: health coverage of young adults and their views on health reform. Findings from the Commonwealth fund Survey of Young Adults (2009). *Issue Brief (Commonw Fund)*. 2009; 73:1–22. [PubMed: 20183947]
29. Green DM. Late effects of treatment for cancer during childhood and adolescence. *Curr Probl Cancer*. 2003; 27(3):127–42. S014702720300028X [pii]. [PubMed: 12748582]

30. 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):982–90.10.1002/pon.1650 [PubMed: 20017115]
31. Klosky JL, Howell CR, Li Z, Foster RH, Mertens AC, Robison LL, et al. Risky health behavior among adolescents in the childhood cancer survivor study cohort. *J Pediatr Psychol*. 2012; 37(6): 634–46. jss046 [pii]. 10.1093/jpepsy/jss046 [PubMed: 22427699]
32. 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. JCO.2008.21.1441 [pii]. 10.1200/JCO.2008.21.1441 [PubMed: 19255308]

Table 1

Number (n) and frequency (%) of medical visits in the previous 12-month period among adolescent and young adult cancer survivors.

Medical visits	n (N = 465)	%
Medical visits in the Last 12 Months		
No	25	5.4
Yes	440	94.6
Health insurance in the last 12 months		
No	69	14.8
Yes	390	83.9
Missing	6	1.3
Medical visits in the last 12 months among AYAs without health insurance		(% out of 69)
No	12	17.4
Yes	57	82.6
Medical visits in the last 12 months among AYAs with health insurance		(% out of 390)
No	13	3.3
Yes	377	96.7
Type of doctors seen*		(% out of 440)
Medical Oncologist or Hematologist	287	65.2
Primary Care	280	63.6
Obstetrician/Gynecologist	79	18.0
Urologist	71	16.1
Surgeon	66	15.0
Radiation Oncologist	56	12.7
Psychiatrist	28	6.4
Pediatric oncologist	28	6.4
Orthopedic Physician	24	5.5
Other	86	19.8
Don't Know	6	1.4
Type of doctors seen † among AYAs without health insurance		(% out of 57)
Oncologists	33	57.9
Primary care physicians	32	56.1
Other doctors	32	56.1
Type of doctors seen † among AYAs with health insurance		(% out of 377)
Oncologists	287	76.1
Primary care physicians	245	65.0
Other doctors	228	60.5
Reasons for care*		(% out of 440)
Follow-up Tests	382	86.8
General Physical Exam	212	48.2
Non-cancer Illness	142	32.3

Medical visits	n (N = 465)	%
Discuss or Treat Symptoms	87	19.8
Ongoing Treatment	75	17.0
Injury	51	11.6
Other	75	17.0

* Respondents could indicate more than one type of provider and reasons for care

† Oncologists include pediatric oncologist, medical oncologist/hematologist, or radiation oncologist; Other doctors include surgeon, urologist, obstetrician/gynecologist, orthopedic physician, psychiatrist, and other doctors

Table 2

Percentage of adolescent and young adult cancer survivors who reported the following types of outpatient medical visits in a 12-month period by socio-demographic and cancer-related factors.

	All AYAs N = 465 (%)		Cancer-related medical visit		No cancer-related medical visit	
	All cancer-related care N = 408 (%)	Ongoing cancer treatment N = 75 (%)	Other cancer-related care N = 333 (%)	No cancer-related medical visit N = 57 (%)		
Socio-demographic and cancer-related factors						
Age at diagnosis						
15–19	58 (14.2%)	18 (24.0%)	40 (12.0%)	~		
20–29	168 (41.2%)	30 (40.0%)	138 (41.4%)	27 (47.4%)		
30–39	182 (44.7%)	27 (36.0%)	155 (46.5%)	26 (45.6%)		
Gender						
Male	246 (60.3%)	43 (57.3%)	203 (61.0%)	41 (71.9%)		
Female	178 (38.3%)	32 (42.7%)	130 (39.0%)	16 (28.1%)		
Race/ethnicity						
Non-Hispanic white	248 (60.8%)	42 (56.0%)	206 (61.9%)	29 (50.9%)		
Non-Hispanic Black and AI/AN *	40 (9.8%)	10 (13.3%)	30 (9.0%)	8 (14.0%)		
Hispanic	78 (19.1%)	14 (18.7%)	64 (19.2%)	17 (29.8%)		
Non-Hispanic Asian/Pacific Islander	42 (10.3%)	9 (12.0%)	33 (9.9%)	~		
Education						
High school or less	154 (37.7%)	35 (46.7%)	119 (35.7%)	25 (43.9%)		
Some college or associate degree	104 (25.5%)	13 (17.3%)	91 (27.3%)	13 (22.8%)		
College graduate or post-graduate	150 (36.8%)	27 (36.0%)	123 (36.9%)	19 (33.3%)		
Employment						
Unemployed	60 (14.7%)	25 (33.3%)	35 (10.5%)	11 (19.3%)		
Part-time working/studying	78 (19.1%)	9 (12.0%)	69 (20.7%)	14 (24.6%)		
Full-time working/studying	241 (59.1%)	30 (40.0%)	211 (63.4%)	25 (43.9%)		
Other/Unknown	36 (7.7%)	11 (14.7%)	18 (5.4%)	7 (12.3%)		
Marital Status						
Married	188 (46.1%)	22 (29.3%)	166 (49.8%)	26 (45.6%)		
Not married	251 (54.0%)	53 (70.7%)	167 (50.2%)	31 (54.4%)		
Time from diagnosis to follow-up survey receipt						
15–23 months	189 (46.3%)	39 (52.0%)	150 (45.0%)	17 (29.8%)		

Socio-demographic and cancer-related factors		All AYAs N = 465 (%)	All cancer-related care N = 408 (%)	Cancer-related medical visit Ongoing cancer treatment N = 75 (%)	Other cancer-related care N = 333 (%)	No cancer-related medical visit N = 57 (%)
25–35 months		259 (55.7%)	219 (53.7%)	36 (48.0%)	183 (55.0%)	40 (70.2%)
Date of last treatment						
Before 2009		311 (66.9%)	261 (64.0%)	5 (6.7%)	256 (76.9%)	50 (87.7%)
2009–2010		154 (33.1%)	147 (36.0%)	70 (93.3%)	77 (23.1%)	7 (12.3%)
Type of cancer						
Hodgkin Lymphoma		18 (3.9%)	17 (4.2%)	13 (17.3%)	~	~
Germ Cell Cancer		181 (38.9%)	156 (38.2%)	14 (18.7%)	142 (42.6%)	25 (43.9%)
Acute Lymphoblastic Leukemia		130 (28.0%)	112 (27.5%)	18 (24.0%)	94 (28.2%)	18 (31.6%)
Non-Hodgkin Lymphoma		113 (24.3%)	101 (24.8%)	20 (26.7%)	81 (24.3%)	12 (21.1%)
Sarcoma		23 (4.9%)	22 (5.4%)	10 (13.3%)	12 (3.6%)	~
Stage at diagnosis						
I		181 (38.9%)	154 (37.7%)	15 (20.0%)	139 (41.7%)	27 (47.4%)
II		115 (24.7%)	103 (25.2%)	15 (20.0%)	88 (26.4%)	12 (21.1%)
III		66 (14.2%)	54 (13.2%)	12 (16.0%)	42 (12.6%)	12 (21.1%)
IV		60 (12.9%)	56 (13.7%)	14 (18.7%)	42 (12.6%)	~
Unknown/missing		25 (5.4%)	24 (5.9%)	6 (8.0%)	18 (5.4%)	~
Unstaged (acute lymphoblastic leukemia)		18 (3.9%)	17 (4.2%)	13 (17.3%)	~	~
Total number of comorbidities						
0		309 (66.5%)	272 (66.7%)	50 (66.7%)	222 (66.7%)	37 (64.9%)
1		78 (16.8%)	68 (16.7%)	11 (14.7%)	57 (17.1%)	10 (17.5%)
2		33 (7.1%)	28 (6.9%)	8 (10.7%)	20 (6.0%)	5 (8.8%)
3+		16 (3.4%)	13 (3.2%)	~	12 (3.6%)	~
Unknown		29 (6.2%)	27 (6.6%)	5 (6.7%)	22 (6.6%)	~
Recurrence						
Yes		32 (6.9%)	31 (7.6%)	19 (25.3%)	12 (3.6%)	~
No		390 (83.9%)	341 (83.6%)	42 (56.0%)	299 (89.8%)	49 (86.0%)
Unknown/Missing		43 (9.2%)	36 (8.8%)	14 (18.7%)	22 (6.6%)	7 (12.3%)
Self-reported general health						
Excellent/Very good/Good		392 (84.3%)	343 (84.1%)	52 (69.3%)	291 (87.4%)	49 (86.0%)
Poor/Fair		73 (15.7%)	65 (15.9%)	23 (30.7%)	42 (12.6%)	8 (14.0%)

Socio-demographic and cancer-related factors	All AYAs				Cancer-related medical visit		No cancer-related medical visit	
	N = 465 (%)	All cancer-related care N = 408 (%)	Ongoing cancer treatment N = 75 (%)	Other cancer-related care N = 333 (%)	N = 57 (%)			
Total number of symptoms reported in past 4 weeks								
0	80 (17.2%)	71 (17.4%)	8 (10.7%)	63 (18.9%)	9 (15.8%)			
1–2	155 (33.3%)	135 (33.1%)	19 (25.3%)	116 (34.8%)	20 (35.1%)			
3–4	101 (21.7%)	90 (22.1%)	18 (24.0%)	72 (21.6%)	11 (19.3%)			
5+	129 (27.7%)	112 (27.5%)	30 (40.0%)	82 (24.6%)	17 (29.8%)			
Self-reported quality of care								
Excellent/Very good	392 (84.3%)	348 (85.3%)	60 (80.0%)	288 (86.5%)	44 (77.2%)			
Poor/Fair/Good	73 (15.7%)	60 (14.7%)	15 (20.0%)	45 (13.5%)	13 (22.8%)			
Health insurance coverage								
No insurance coverage currently and last year	27 (5.8%)	17 (4.2%)	6 (8.0%)	11 (3.3%)	10 (17.5%)			
No insurance coverage currently but had insurance last year	40 (8.6%)	34 (8.3%)	3 (4.0%)	31 (9.3%)	6 (10.5%)			
Have insurance coverage currently	390 (83.9%)	351 (86.0%)	63 (84.0%)	288 (86.5%)	39 (68.4%)			
Unknown/Missing	8 (1.7%)	6 (1.5%)	~	~	~			
Level of information needs[†]								
Low (0–3 total unmet information needs)	145 (31.2%)	133 (32.6%)	16 (21.3%)	117 (35.1%)	12 (21.1%)			
Medium (4–8 total unmet information needs)	175 (37.6%)	149 (36.5%)	32 (42.7%)	117 (35.1%)	26 (45.6%)			
High (9–13 total unmet information needs)	145 (31.2%)	126 (30.9%)	27 (36.0%)	99 (29.7%)	19 (33.3%)			
Change of health insurance coverage[‡]								
No change	388 (83.4%)	343 (84.1%)	62 (82.7%)	281 (84.4%)	~			
Positive change	15 (3.2%)	13 (3.2%)	~	10 (3.0%)	45 (78.9%)			
Negative change	51 (11.0%)	43 (10.5%)	7 (9.3%)	36 (10.8%)	~			
Unknown/Missing	11 (2.4%)	9 (2.2%)	~	6 (1.8%)	8 (14.0%)			
Change of self-reported quality of care[§]								
No change	264 (56.8%)	233 (57.1%)	35 (46.7%)	198 (59.5%)	31 (54.4%)			
Positive change	106 (22.8%)	90 (22.1%)	21 (28.0%)	69 (20.7%)	16 (28.1%)			
Negative change	95 (20.4%)	85 (20.8%)	19 (25.3%)	66 (19.8%)	10 (17.5%)			
Change of self-reported general health[§]								
No change	227 (48.8%)	196 (48.0%)	32 (42.7%)	164 (49.2%)	31 (54.4%)			
Positive change	109 (23.4%)	98 (24.0%)	16 (21.3%)	82 (24.6%)	11 (19.3%)			

Socio-demographic and cancer-related factors	All AYAs		Cancer-related medical visit		No cancer-related medical visit	
	N = 465 (%)	N = 408 (%)	Ongoing cancer treatment N = 75 (%)	Other cancer-related care N = 333 (%)	Other cancer-related care N = 333 (%)	No cancer-related medical visit N = 57 (%)
Negative change	129 (27.7%)	114 (27.9%)	27 (36.0%)	87 (26.1%)	87 (26.1%)	15 (26.3%)

~ Data suppressed because less than 5 patients

* AI/AN: American Indian /Alaska Natives

† The survey question regarding information need differs between the baseline and follow-up survey. In the baseline survey patients were asked “At this time, do you feel you need more information about any of the following?” and possible responses were “I have enough information”, “I need some more information”, “I need much more information”, and “Does not apply”. In the follow-up survey patients were asked “How concerned are you about each of the following?” and possible responses were “Not at all concerned”, “A little concerned”, “Somewhat concerned”, and “Very concerned”. Unmet needs are defined as survey responses in the baseline survey “I need some more information” and “I need much more information” and in the follow-up survey as “Somewhat concerned” and “Very concerned”. Met needs are defined as survey responses in the baseline survey “I have enough information” and “Does not apply” and in the follow-up survey as “Not at all concerned” and “A little concerned”. Based on a total of 13 questions of information needs, we defined 0–3, 4–8, and 9–14 unmet information needs as ‘Low’, ‘Medium’, and ‘High’ level of information needs respectively.

‡ A positive change from baseline to follow-up was defined as patients who had changed from no insurance to insurance coverage; a negative change was defined as a change in the opposite direction.

§ A positive change from baseline to follow-up was defined as patients who reported better general health or quality of care (poor, fair, good, very good, excellent); a negative change was defined as a change in the opposite direction.

Table 3

Socio-demographic and cancer-related factors associated with cancer-related medical visits (versus no cancer-related medical visit) and an ongoing cancer treatment (versus other cancer-related medical visit) in the previous 12-month period in adolescent and young adult cancer survivors.

Socio-demographic and cancer-related factors	Cancer related medical visits vs. No cancer-related medical visits OR* (95% CI) †	Ongoing cancer treatment vs. Other cancer-related medical visits OR (95% CI) *
Age at diagnosis		
15–19	2.39 (0.68–8.43)	2.33 (0.85–6.42)
20–29	1.00 (0.52–1.92)	1.33 (0.64–2.74)
30–39	1.00 (reference)	1.00 (reference)
Gender		
Male	1.00 (reference)	1.00 (reference)
Female	1.81 (0.85–3.87)	0.74 (0.36–1.54)
Race/ethnicity		
Non-Hispanic white	1.00 (reference)	1.00 (reference)
Non-Hispanic Black and AI/AN ‡	0.40 (0.14–1.11)	0.95 (0.33–2.74)
Hispanic	0.58 (0.26–1.28)	0.67 (0.27–1.66)
Non-Hispanic Asian/Pacific Islander	1.40 (0.36–5.48)	0.70 (0.26–1.93)
Education		
High school or less	0.79 (0.38–1.67)	0.84 (0.39–1.82)
Some college or associate degree	1.09 (0.48–2.50)	0.55 (0.23–1.31)
College graduate or post-graduate	1.00 (reference)	1.00 (reference)
Employment		
Unemployed/Other	1.00 (reference)	1.00 (reference)
Part-time working/studying	1.15 (0.45–2.94)	0.33 (0.12–0.90)
Full-time working/studying	1.86 (0.82–4.21)	0.39 (0.18–0.85)
Date of last treatment		
Before 2009	1.00 (reference)	§
2009–2010	5.07 (2.01–12.8)	
Type of cancer		
Hodgkin Lymphoma	1.00 (reference)	1.00 (reference)
Germ Cell Cancer	1.83 (0.80–4.17)	0.46 (0.18–1.18)
Acute Lymphoblastic Leukemia	1.58 (0.16–15.5)	17.4 (4.14–73.0)
Non-Hodgkin Lymphoma	1.69 (0.68–4.15)	1.12 (0.48–2.64)
Sarcoma	2.49 (0.27–22.8)	2.73 (0.79–9.39)
Recurrence		
Yes/Unknown/Missing	1.00 (reference)	1.00 (reference)
No	0.76 (0.28–2.05)	0.17 (0.08–0.38)
Total number of comorbidities		
0	1.00 (reference)	1.00 (reference)
1	0.95 (0.40–2.26)	0.62 (0.25–1.56)
2	0.99 (0.32–3.12)	2.16 (0.70–6.65)

Socio-demographic and cancer-related factors	Cancer related medical visits vs. No cancer-related medical visits OR* (95% CI) †	Ongoing cancer treatment vs. Other cancer-related medical visits OR (95% CI) *
3+	0.76 (0.17–3.49)	0.16 (0.01–1.99)
Unknown	2.09 (0.40–10.9)	1.83 (0.54–6.22)
Self-reported quality of care		
Excellent/Very good	1.00 (reference)	1.00 (reference)
Poor/Fair/Good	0.53 (0.23–1.21)	0.87 (0.36–2.11)
Self-reported general health		
Excellent/Very good/Good	1.00 (reference)	1.00 (reference)
Poor/Fair	1.52 (0.59–3.88)	1.61 (0.69–3.75)
Health insurance coverage		
No insurance coverage currently and last year	1.00 (reference)	1.00 (reference)
No insurance coverage currently but had insurance last year	4.01 (0.99–16.3)	0.17 (0.03–1.06)
Have insurance coverage currently	4.88 (1.72–13.8)	0.34 (0.10–1.19)
Level of information needs		
Low (0–3 total unmet information needs)	1.00 (reference)	1.00 (reference)
Medium (4–8 total unmet information needs)	0.50 (0.23–1.09)	1.32 (0.58–2.98)
High (9–13 total unmet information needs)	0.74 (0.30–1.84)	0.98 (0.39–2.42)

* OR= odds ratio. Multivariate logistic regression models were adjusted for all variables presented in the table.

† AI/AN: American Indian /Alaska Natives

§ Variable not included in the model.

Table 4

Change of status associated with cancer-related medical care (versus non-cancer related care or no care) and an ongoing cancer treatment (versus other cancer-related care) in the previous 12-month period in adolescent and young adult cancer survivors.

Change of status	Cancer-related medical visits vs. No cancer-related medical visits OR* (95% CI) †	Ongoing cancer treatment vs. Other cancer-related medical care OR (95% CI) ‡
Change of health insurance coverage ‡		
No change	1.00 (reference)	1.00 (reference)
Positive change	0.97 (0.20–4.80)	0.48 (0.08–2.85)
Negative change	0.81 (0.34–1.90)	1.09 (0.41–2.92)
Change of self-reported quality of care §		
No change	1.00 (reference)	1.00 (reference)
Positive change	0.81 (0.41–1.61)	2.00 (0.97–4.13)
Negative change	1.22 (0.55–2.72)	1.12 (0.51–2.47)
Change of self-reported general health §		
No change	1.00 (reference)	1.00 (reference)
Positive change	1.37 (0.65–2.92)	1.22 (0.56–2.67)
Negative change	1.26 (0.63–2.52)	2.15 (1.05–4.38)

* OR= odds ratio.

† Multivariate logistic regression models were adjusted for age at diagnosis, gender, race/ethnicity, education, employment, recurrence and comorbidities.

‡ A positive change from baseline to follow-up was defined as patients who had changed from no insurance to insurance coverage; a negative change was defined as a change in the opposite direction.

§ A positive change from baseline to follow-up was defined as patients who reported better general health or quality of care (poor, fair, good, very good, excellent); a negative change was defined as a change in the opposite direction.