



Published in final edited form as:

J Psychosoc Oncol. 2014 ; 32(1): 1–15. doi:10.1080/07347332.2013.855959.

‘Cancer Sucks,’ and Other Ponderings by Adolescent and Young Adult Cancer Survivors

Brad Zebrack, PhD, MSW, MPH,

University of Michigan School of Social Work, Ann Arbor, MI

Erin E. Kent, PhD, MS,

Office of Cancer Survivorship, National Cancer Institute, National Institutes of Health, Bethesda, MD

Theresa H. M. Keegan, PhD, MS,

Cancer Prevention Institute of California, Fremont, CA and School of Medicine, Stanford University, Stanford, CA

Ikuko Kato, PhD,

Departments of Oncology and Pathology, Wayne State University School of Medicine, Detroit MI

Ashley Wilder Smith, PhD, MPH, and

Outcomes Research Branch, National Cancer Institute, Bethesda, MD

AYA HOPE Study Collaborative Group¹

Abstract

As part of the National Cancer Institute’s AYA HOPE study, 296 AYAs completed an open-ended survey item asking them to describe their medical care or experience with cancer. Patient, provider, and system-level characteristics all appear to influence AYAs’ perceptions of their medical care. Participants attributed levels of satisfaction with care to the availability and communication of information, the management of side-effects, and the expediency and flexibility of treatments. Struggles with health insurance and finances were evident. Findings contribute to a better understanding of AYAs’ cancer treatment experiences and will inform improvements to oncology care for this population.

Keywords

adolescent; young adult; medical care; qualitative research; psychosocial

INTRODUCTION

Adolescents and young adults (AYAs) diagnosed with cancer between the ages of 15 and 39 years confront a unique set of challenges related to the interaction of cancer and its treatment with maturing biological, cognitive, emotional, and social capabilities. The timing of illness

Corresponding author: Brad Zebrack, University of Michigan School of Social Work, 1080 S. University, Ann Arbor, MI 48109-1106, (734) 615-5940, fax (734) 763-3372, zebrack@umich.edu..

¹Rosemary Cress; Gretchen Agha; Mark Cruz; Stephen Schwartz; Martha Shellenberger; Tiffany Janes; Ikuko Kato; Ann Bankowski; Marjorie Stock; Xiao-cheng Wu; Vivien Chen; Bradley Tompkins; Theresa Keegan; Laura Allen; Zinnia Loya; Karen Hussain; Charles Lynch; Michele West; Lori Odle; Ann Hamilton; Jennifer Zelaya; Mary Lo; Urduja Trinidad; Linda Harlan; Ashley Wilder Smith; Jana Eisenstein; Gretchen Keel; Arnold Potosky; Keith Bellizzi; Karen Albritton; Debra Friedman; Michael Link; Brad Zebrack.

The authors wish to thank Laurel Couture and Kara Gottschalk for their contributions to this manuscript.

in their life course often presents distinctive challenges in terms of treatment adherence and symptom management, long term health maintenance, impacts on relationships with family, friends, children and peers, disruption of educational and occupational plans, and challenges to social integration (National Cancer Institute, 2006).

A common trend of clumping adolescents and young adults into either pediatric or older adult populations in psychosocial research has created a gap in understanding the unique experience of AYAs (Haase & Phillips, 2004). Though research specific to AYAs is emerging (Clinton-McHarg, Carey, Sanson-Fisher, Shakeshaft, & Rainbird, 2010; Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Keegan et al., In Press; Zebrack, 2008), this is still a largely understudied group. Recent qualitative studies of AYAs have enhanced our understanding of this population by detailing some of the unique psychosocial issues they face, such as the paradox of being young and diagnosed with a disease that is more prevalent in older adults (Jones et al., 2010; Kent et al., 2012; Miedema, Hamilton, & Easley, 2007; Thompson, Palmer, & Dyson, 2009; Yi & Zebrack, 2010; Zebrack, Chesler, & Kaplan, 2010). While providing a useful approach for identifying important topics for future research, most lack attention to challenges specifically related to medical care. A better understanding of AYAs' experiences with medical care and cancer treatment will inform improvements to oncology care for this population, which demonstrates rates of non-adherence ranging from 27-60% (Butow et al., 2010) and excess risk for psychosocial distress when compared to pediatric and older adult cancer populations (Costanzo, 2009; Mor, Allen, & Malin, 1994; Parker, 2003; Stava, Lopez, & Vassilopoulou-Sellin, 2006).

The Adolescent and Young Adult Health Outcomes and Patient Experiences (AYA HOPE) Study represents a recent effort to obtain AYA survivors' perspectives on their oncology care and the impact of cancer on their lives (Bellizzi et al., 2012; Harlan et al., 2011). It is the largest and most representative cohort of AYA survivors to date. The purpose of this paper is to report how participants in the AYA HOPE study described their medical care and experiences with cancer.

MATERIALS AND METHODS

Participants and Procedures

Patients were identified through seven National Cancer Institute (NCI) Surveillance, Epidemiology and End-Results (SEER) program cancer registries. Approval for the conduct of this study was obtained by each of the registries and NCI's Institutional Review Boards. Eligible participants were 15-39 years old, residents of the seven SEER catchment areas, and diagnosed between July 1, 2007 and October 31, 2008 with histologically confirmed 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 (tumors arising in the central nervous system were excluded). Those diagnosed on autopsy or death certificate were ineligible for participation.

Among 1208 eligible patients, 524 respondents completed the AYA HOPE mailed survey a median of 11 months (range: 4-22 months) from the date of diagnosis. The survey concluded with an open-ended item in which respondents were asked: "Tell us anything else about your medical care or experience with cancer." The purpose of this question was to ensure that no additional medical or experiential topics were omitted, and to explore needs for future research.

Qualitative data coding and analysis

A deductive approach utilizing an *a priori* cancer survivorship framework (Alfano & Rowland, 2009) informed this analysis. Of 523 surveys (one survey was lost), 296 (57%) contained responses to the open-ended item. Each of the 296 open-ended responses was read and coded by two trained Masters level graduate student research assistants. As described by Miles and Huberman (1994), coding procedures involved examining each individual response, assigning it a one- or two-word label (code) to represent the content of the response, and then organizing it into one of five *a priori* survivorship domains of Medical Care, Side Effects/Symptoms, Psycho-Spiritual, Relationships, and Practical (Table 1) (Alfano & Rowland, 2009). Upon completion of coding, 358 coded responses were distributed across the five survivorship domains. Inter-rater reliability for this procedure was 86%; discrepancies were addressed and discussed by the reviewers in consultation with the lead author (BZ). Through a process of constant comparative analysis (Strauss & Corbin, 1990), the lead author then reorganized coded responses within each survivorship domain to derive sub-themes.

As with much qualitative research, the intent of this analysis was to obtain in-depth and diverse information, and not to quantify the preponderance of experiences (Strauss & Corbin, 1990). The goal was to derive results that cover a wide breadth of topics, generate hypotheses, and inform the design of testable interventions or future research studies, even when just one or two participants comment on a unique aspect of their experience (Denzin & Lincoln, 1998). Therefore, the presentation of quantitative counts of thematic content, or the use of modifiers such as “some” or “a few,” is not intended to suggest dominance of a theme relative to others presented in the analyses. The counts for each domain indicate the number of participants who commented about the impact of cancer on that particular domain.

RESULTS

Descriptive statistics for the entire sample and for those who completed the open-ended question analyzed for this report are summarized in Table 2.

Medical Care Domain (n=131)

Satisfaction with care—Most AYAs expressed satisfaction with the medical care, information, and support they received. Comments reflected gratitude toward “awesome,” “knowledgeable,” “proficient,” “professional,” and “experienced” health care providers and staff, and satisfaction with hospitals and the coordination of their care. Survivors attributed their satisfaction to the availability of information and to staff who helped them make informed decisions about care and manage debilitating side effects. They appreciated instances of “empathy,” “friendliness,” “encouragement,” “special attention,” and “patience.”

“The people who provided the medical care helped me by providing me with the information and the support I needed.”

“The rad-onc physician worked around my busy schedule during school and made my preferred treatment time a priority.”

“My doctors presented me with the options of radiation, chemo, or observation. I was able to make an informed decision considering my life plans, family plans, and future treatment options.”

Dissatisfaction with care—Dissatisfaction with care also emerged, particularly around a lack of information about drug effects and protocols, alternative treatment options,

complementary and alternative medicine, and appropriate follow-up care upon completion of therapy. Expressions of dissatisfaction also were attributable to delays in the initial cancer diagnosis, despite AYAs reporting health concerns and repeated visits to doctors.

“Almost a year before I was diagnosed I went to my [primary care physician] because I felt something in my testicle. He said it was nothing. A few months later I returned because I was throwing up blood and fainting. He said it was nothing and that it was all ‘in my head,’ to ‘watch TV,’ that I was ‘ok.’ A few months later I was found with cancer, testicular cancer, and it had spread to both my lungs and kidney. So, because some careless doctor, I lost a kidney, a testicle, underwent two major lung surgeries, and lost half of one lung.”

Several respondents expressed dissatisfaction with how they were informed about their cancer diagnosis (e.g., over the telephone) and about experiences in which they perceived a lack of empathy or compassion from providers or other hospital staff.

“My diagnosis was given to me on my cell phone while I was in line at the post office - by a doctor that I had never seen before and was substituting for my primary care doctor. To this day I have never met this man in person and I continue to be greatly disappointed by the way in which my diagnosis was handled. It was impersonal, careless, and a breach of proper protocol. I still cannot remember how I got home that day.”

Some AYAs complained about the physical environment for treatment being inappropriate for their age, including receiving treatment at youth-oriented children’s hospitals or in adult-oriented facilities comprised of mostly elderly patients. Some described difficult or confusing experiences around the coordination of their care within hospitals or across health care providers.

“I have to call various offices to get my different blood tests, scans, and X-rays. Sometimes they do not follow up and it takes a while to get them set up. There does not seem to be any sort of coordination and I often see my doctor without all of the results being in.”

Side Effects and Symptoms Domain (n=45)

Respondents reported persistent physical side effects that they attributed to cancer treatment, including: nausea, depression, fatigue, headaches, dizziness, weight loss, pain and neuropathy, sexual dysfunction, early menopausal symptoms, gestational diabetes, blood clots, dehydration, shingles, breathing difficulties, accelerated heart rate, disfigurement, lymphedema, weight gain, infections, pneumonia, seizures, gag reflex, anxiety, and treatment-related infertility. They often attributed a poor mental health state to these treatment-related symptoms. Some described how side effects limited their ability to work or to attend support groups.

“I reacted so strongly to the side effects of my chemo that I really wasn’t able to live day to day without assistance of my spouse. During this time I did suffer from depression, and I wasn’t able to go to a support group or see someone because of my side effects.”

A few respondents stated that they did not have side effects or else that side effects were minimized thanks to availability of medications.

“My treatment was very easy with new anti-nausea medication and never being in the hospital for more than a week.”

Psychological-Spiritual Domain (n=120)

Comments reflected negative emotions and on-going struggles and fears related to cancer. Several AYAs remonstrated: “cancer sucks.” Others detailed specific struggles around managing distress and emotions related to cancer, treatment, and fears of recurrence. Participants expressed struggles around efforts to (re)-establish or maintain a sense of normalcy in their lives. Several indicated co-occurring struggles with alcohol and drugs. Some survivors were particularly challenged by loss: lost jobs, lost friends, lost hair.

“The only real toll that has been taken has been a mental toll, as I am pissed at the universe and angry with my lack of motivation and energy.”

“Since being diagnosed I have not slept well, I feel depressed, scared, and constantly have a feeling of wanting to be home with my family. I was very social before and now I don’t do much.”

While AYAs described debilitations and life disruptions attributable to cancer, they also described positive attitudes, beliefs, feelings, or experiences that have emerged from the cancer experience. For some survivors, the end of treatment was emphasized as a time of unexpected feelings of anger, sadness, and feeling depressed. For others, fears and feelings of hope or sadness were accompanied by recognition of having something to live for, a sense of purpose in life, or an opportunity for personal transformation, growth, and empowerment. Personal feelings of empowerment were often accompanied by feelings of vulnerability.

“It was a devastating experience. Especially chemo days. But it changed my life. I became more positive, more health conscious. I exercise more. It allowed me to look at life differently. But every day I think about it and I seem very scared that it may return and I may not be strong enough to fight again!!!”

“Cancer makes you slow down, forces you to rely on others, changes the way you look at your body, and makes you reevaluate your life. It is challenging and humbling, but like any hardship it is a chance to learn about yourself or reaffirm things you already knew, your friends and family, and about the things we take for granted, our health, mortality, others.”

Relationships Domain (n=15)

Some survivors identified relationships with family and friends, church, God, and other cancer survivors as primary sources of inspiration, support, and positive outcomes, but others did not. Respondents described instances in which family members or friends acted as if nothing was happening, did not express interest in learning about their cancer, or were unwilling to talk about their feelings. Some attributed stressful family dynamics, including separation or divorce from a spouse, to cancer.

“I lost a lot of people who were very close to me. I disappeared for a couple months and when I finally returned, everything was not the same. The people who knew my situation did not know how to approach me. I felt they had no idea who I was, and I wasn’t too sure if they really cared.”

“My spouse did not express any interest in learning about my cancer. He was and is unwilling to talk with me about my feelings or my fears.”

Not all AYAs, however, valued or needed support from others and preferred to deal with cancer by themselves.

“This is something that I did not expect to deal with. I did not feel sorry for myself during this crazy experience. I dealt with this ordeal mostly by myself. I did not want help.”

Practical Domain (n=55)

Health insurance and financial burden—Many participants reported on the financial problems due to their cancer experience, and some indicated that their health insurance was inadequate, often not reimbursing for incurred medical expenses.

“My insurance does not cover injections. I needed one that cost \$1300. I had to pay with my credit card. Every time I went for chemo treatment I had to pay. I didn’t qualify for state programs because of my age, the type of cancer I had, and it’s a very scary time for me, and then you have to add the stress of dealing with insurances. It was very hard.”

Most of the survivors who described health insurance troubles attributed financial problems, frustrations, and fears about future financial debt to lacking or having inadequate health insurance. They indicated that their financial burdens were compounded by lost compensation due to missing work or an inability to obtain employment after the end of treatment. In some cases, sporadic insurance coverage precluded or limited survivors’ use of medical care services.

“I had no insurance coverage at first. Then when I got it, it was good, but I lost it later when I stopped working. I have continual issues with health care coverage. I am missing follow-up appointments now because I can’t afford them. There is no real point in getting checked because it is unaffordable to treat if cancer is there.”

Survivors also expressed frustration at the complexity and inflexibility of health insurance, social security, or other disability benefits programs

“I was working at an internship out of my home state when I was diagnosed. Because of this, I went to the nearest hospital, not my standard hospital. My insurance refused to pay because I had not seen my GP doctor, even though I was not even in my home state at the time.”

“Without warning, the insurance informed me that I had reached the life time maximum of one million dollars under the policy. Currently I have more than \$70,000 of outstanding claims for which I am sure the service providers will start to request payment. How do I deal with this situation? How do I handle the fact that due to the insurance company not informing us, in a timely manner, that the coverage was nearing the cap, we could have taken the proper steps to prevent this issue?”

School/work/life disruptions—When unable to integrate cancer care and day-to-day life activities, many found that having to choose treatment over school/work or family matters was distressing.

“I cannot plan my life. I can work a little, but then cancer comes back. Then I go through a hardship with money, child care. You don’t only have to worry about your health, you have to worry about kids. Who’s gonna put them on the bus? Will you be alone and so sick you cannot get out of bed and have to send your kids off because you cannot see about them? Also are you gonna be able to pay your light bill, or mortgage all in the same month? And the doctors tell you not to get stressed.”

Related to distress were expressions of, and challenges related to, an inability to get one’s life back on track or back to normal after cancer.

“I cannot believe what’s happened to me. My career in sports, which I spent my whole life, since age 6-1/2 – has been wrecked. And I’m not trying to pick up the pieces.”

DISCUSSION

In this study, the largest population-based survey of AYAs to date (Harlan, et al., 2011), AYAs diagnosed with cancer described both positive and negative experiences, often simultaneously, with the medical care they received. They also described ways in which cancer affected them in other key cancer survivorship domains. These patient-centered perspectives illuminated AYAs’ preferences and needs, which is essential information for developing standards of care (Patient-Centered Outcomes Research Institute, 2012) and for meeting national priorities for patient-centered outcomes research (Selby, Beal, & Frank, 2012).

Consistent with prior study (Zebrack, et al., 2010), many AYAs expressed satisfaction with the medical care, information, and support they received, and attributed their satisfaction to the availability of information, the management of side-effects, and expediency and flexibility of treatments. AYAs reporting dissatisfaction with their care cited lack of information about treatments and follow-up care, poor communication with health care providers, and delays in diagnosis as contributing factors. AYAs’ satisfaction with care appeared to be associated with being disease-free or free from debilitating side effects, a finding consistent with prior research demonstrating a positive association between health care satisfaction and the alleviation of symptoms or resolution of disease (Skarstein, Dahl, Laading, & Fossa, 2002). Conversely, negative comments about care in the current study were often associated with disease set-backs, recurrences, and treatment-related symptoms. These findings suggest that symptom management and health promotion during and after treatment are critical to being satisfied with oncologic care, and to AYAs’ mental health.

AYAs’ reports of delays in their cancer diagnosis are particularly concerning and consistent with retrospective analyses of epidemiological data suggesting that AYAs may be at greater risk for delays in diagnosis than other age groups (Bleyer, 2002; Pollock, Krischer, & Vietti, 1991). The delays in diagnosis for AYAs may be attributable to patient-level factors, such as still-maturing cognitive function and ability to regulate emotions, or a tendency to question authority and rely on peers for information and support, all of which are normative aspects of development for this population (Arnett, 2000). AYAs also may mistrust or at least be skeptical of oncology care providers after experiencing frustration or anger at physicians who minimized their pre-diagnosis symptoms or told them they were “too young to have cancer” (Kent, et al., 2012; Zebrack, et al., 2010). These provider-level factors -- failure to initially attribute clinical symptoms to cancer, or poor communication exchanges between AYAs and providers -- may contribute to delays in diagnosis. The skepticism or mistrust resulting from delays in diagnosis may contribute to poor adherence to therapy (Butow, et al., 2010). Lastly, system- or institutional-level factors (including inadequate health insurance) could contribute to delays in diagnosis or subsequent adherence to therapy, particularly if pediatric or adult-care settings do not provide age-appropriate materials or resources, or staff lack training in the provision of psychosocial support for this age group. Future research is needed to elucidate patient, provider, and institutional/system-level characteristics associated with elapsed time from the AYAs’ first expression of symptoms to eventual cancer diagnosis.

AYAs detailed both positive and negative psychological and relational aspects of having had cancer, as quantified previously in this cohort (Bellizzi, et al., 2012). In many instances, the same individuals expressed both positive and negative experiences. For example, statements reflected AYAs’ experiences of distress and struggle to maintain or achieve some sense of

normalcy in their lives, while also recognizing that they have something to live for, such as caring for young children. In terms of relationships, AYAs reported inspiration and support but also situations in which expectations of support from family or friends were met by denial of, or disinterest in, their condition or feelings. These findings suggest that interventions intended to facilitate psychosocial adaptation should include programmatic components that alleviate distress but also promote potential for positive growth and successful achievement of normative developmental tasks (e.g., vocational rehabilitation, social re-integration and involvement). Research is needed to evaluate the extent to which psychosocial interventions reduce distress and facilitate involvement with friends and intimate others, educational achievement, and gainful employment for AYAs.

Respondents described their health insurance as inadequate and suggested that significant financial problems resulted from the burden of having to pay for unreimbursed drugs, prostheses, medical equipment, or infertility services. In some cases financial problems were compounded by missing work, being unable to obtain employment, or by employment that did not include health insurance benefits. Indeed, young adults represent the largest uninsured proportion of the US population (Adams, Newacheck, Park, Brindis, & Irwin, 2007). Some AYAs indicated that lacking health insurance was a serious barrier to maintaining on-going medical follow-up and surveillance. The financial burden associated with cancer may be especially significant and long-lasting for AYAs, as the impact can damage credit and subsequent ability to buy a home or start a business.

This study's strengths include recruitment of a large number of participants from SEER cancer registries across the United States that enumerate all newly diagnosed cancers. Survey respondents did not differ from non-respondents by age, census tract education, or median family income, or cancer site (Harlan, et al., 2011). However, the generalizability of our findings may be limited somewhat by a modest response rate of 43%. Only half of all respondents completed the open-ended item. Participants who are limited in English writing literacy or who are less apt to express emotional feelings, particularly in writing, may have been less likely to respond to the open-ended item. Furthermore, the wording of the open-ended question, which emphasized medical care, may explain the predominance of responses coded and organized into the medical care domain, and may have precluded respondents from detailing other ways in which cancer affected other aspects of their lives (e.g., relationships).

CONCLUSION

The findings reported here improve our understanding of how cancer affects AYAs, and can be used in formulating targeted questions for future investigations. This information will be useful in clinics to systematically assess the impact of cancer on the lives of AYAs. Based on our findings, targeted questions for future research may include: What is occurring in clinical encounters between AYAs and health providers that either prohibit or promote AYA's involvement in their own care and follow-up? What specific instructions should be given to AYA patients by their primary care providers for follow-up? Are there cognitive or financial issues that prevent AYAs from complying with medical care instructions? To what extent are cost factors and lack of insurance contributing to lack of adequate medical care and follow-up or adherence among AYAs? To enhance oncology care for the AYA population, future studies need to focus on the extent to which patient, provider, and system-level factors serve as either barriers or promoters of adequate health service availability, accessibility, and utilization.

Acknowledgments

This article is a US Government work and, as such, is in the public domain in the United States of America. Authors report no financial disclosures. This work supported by contracts N01-PC-35136, N01-PC-35139, N01-PC-35142, N01-PC-35143, N01-PC-35145, N01-PC-54402, N01-PC-54404.

REFERENCES

- Adams SH, Newacheck PW, Park MJ, Brindis CD, Irwin CE. Health insurance across vulnerable ages: patterns and disparities from adolescence to the early 30s. *Pediatrics*. 2007; 119(5):1033–1039. [PubMed: 17473109]
- Alfano, CM.; Rowland, JH. The experience of survival for patients: Psychosocial Adjustment. In: Miller, SM.; Bowen, DJ.; Croyle, RT.; Rowland, JH., editors. *Handbook of Cancer Control and Behavioral Science: A Resource for Researchers, Practitioners, and Policymakers*. American Psychological Association; Washington, DC: 2009. p. 413-430.
- Arnett JJ. Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*. 2000; 55(5):469–480. [PubMed: 10842426]
- Bellizzi KM, Smith AW, Schmidt S, Keegan THM, Zebrack B, Lynch CF, et al. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*. 2012 In press.
- Bleyer WA. Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Medical and Pediatric Oncology*. 2002; 38(1):1–10. [PubMed: 11835231]
- Butow PN, Palmer S, Pai A, Goodenough B, Luckett T, King M. Review of adherence-related issues in adolescents and young adults with cancer. *Journal of Clinical Oncology*. 2010; 28(32):4800–4809. [PubMed: 20212260]
- Clinton-McHarg T, Carey M, Sanson-Fisher R, Shakeshaft A, Rainbird K. Measuring the psychosocial health of adolescent and young adult (AYA) cancer survivors: a critical review. *Health and Quality of Life Outcomes*. 2010; 8:25. [PubMed: 20205922]
- Costanzo ES, Ryff CD, Singer BH. Psychosocial adjustment among cancer survivors: Findings from a national survey of health and well-being. *Health Psychology*. 2009; 28(2):147–156. [PubMed: 19290706]
- Denzin, NK.; Lincoln, YS. *Collecting and Interpreting Qualitative Materials*. Sage Publications; Thousand Oaks, CA: 1998.
- Dyson GJ, Thompson K, Palmer S, Thomas DM, Schofield P. The relationship between unmet needs and distress amongst young people with cancer. *Supportive Care in Cancer*. 2012; 20:75–85. [PubMed: 21311915]
- Haase JE, Phillips CR. The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing*. 2004; 21(3):145–149. [PubMed: 15296043]
- Harlan LC, Lynch CF, Keegan THM, Hamilton AS, Wu X, Kato I, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *Journal of Cancer Survivorship*. 2011; 5:305–314. [PubMed: 21274648]
- Jones BL, Volker DL, Vinajeras Y, Butros L, Fitchpatrick C, Rossetto K. The meaning of surviving cancer for Latino adolescents and emerging young adults. *Cancer Nursing*. 2010; 33(1):74–81. [PubMed: 19926975]
- Keegan THM, Lichtensztajn D, Kato I, Kent E, Wu X, West MM, et al. Unmet adolescent and young adult cancer survivors information and service needs: A population-based cancer registry study. *Journal of Cancer Survivorship: Research and Practice*. (In Press).
- Kent E, Parry C, Montoya MJ, Sender LS, Morris RA, Anton-Culver H. ‘You’re too young for this’: Adolescent and young adult perspectives on cancer survivorship. *Journal of Psychosocial Oncology*. 2012; 30(2):260–279. [PubMed: 22416959]
- Miedema B, Hamilton R, Easley J. From ‘invincibility’ to ‘normalcy’: coping strategies of young adults during the cancer journey. *Palliative and Supportive Care*. 2007; 5(1):41–49. [PubMed: 17461370]

- Miles, MB.; Huberman, AM. *Qualitative data analysis: A sourcebook of new methods*. 2nd edition. Sage Publications; Thousand Oaks: 1994.
- Mor V, Allen S, Malin M. The psychosocial impact of cancer on older versus younger patients and their families. *Cancer*. 1994; 74:2118–2127. [PubMed: 8087779]
- National Cancer Institute. *A report of the Adolescent and Young Adult Oncology Program Review Group*. Bethesda: 2006. Closing the gap: Research and care imperatives for adolescents and young adults with cancer.
- Parker PA, Baile WF, De Moor C, Cohen L. Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psycho-Oncology*. 2003; 12:183–193. [PubMed: 12619150]
- Patient-Centered Outcomes Research Institute (PCORI). Methodological standards and patient-centeredness in comparative effectiveness research: The PCORI perspective. *Journal of the American Medical Association*. 2012; 307(15):1636–1640. [PubMed: 22511692]
- Pollock BH, Krischer JP, Vietti TJ. Interval between symptom onset and diagnosis of pediatric solid tumors. *Journal of Pediatrics*. 1991; 119:725–732. [PubMed: 1941378]
- Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *Journal of the American Medical Association*. 2012; 307(15):1583–1584. [PubMed: 22511682]
- Skarstein J, Dahl AA, Laading J, Fossa SD. 'Patient satisfaction' in hospitalized cancer patients. *Acta Oncol*. 2002; 41(7-8):639–645. [PubMed: 14651208]
- Stava CJ, Lopez A, Vassilopoulou-Sellin R. Health profiles of younger and older breast cancer survivors. *Cancer*. 2006; 107(8):1752–1759. [PubMed: 16967441]
- Strauss, A.; Corbin, J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Sage; London: 1990.
- Thompson K, Palmer S, Dyson GJ. Adolescents and young adults: issues in transition from active therapy into follow-up care. *European Journal of Cancer*. 2009; 13(3):207–212.
- Yi J, Zebrack B. Self-Portraits of Families with Young Adult Cancer Survivors: Using Photovoice. *Journal of Psychosocial Oncology*. 2010; 28(3):219–243. [PubMed: 20432114]
- Zebrack B, Chesler M, Kaplan S. To Foster Healing Among Adolescents and Young Adults with Cancer: What helps? What hurts? *Supportive Care in Cancer*. 2010; 18(1):131–135. [PubMed: 19690897]
- Zebrack BJ. Information and service needs for young adult cancer patients. *Supportive Care in Cancer*. 2008; 16:1353–1360. [PubMed: 18386075]

Table 1**Five survivorship domains (Alfano & Rowland, 2009) for organizing coded data.**

<p>MEDICAL CARE: Ongoing medical follow-up and health planning</p> <p>SIDE EFFECTS/SYMPTOMS: Persistent physical effects of cancer and treatment</p> <p>PSYCHO-SPIRITUAL: Residual psychological and spiritual effects of illness</p> <p>RELATIONSHIPS: Altered social and interpersonal relationships</p> <p>PRACTICAL: Impact of cancer on employment, insurance, other economic effects, child care, transportation</p>

Table 2

Sample descriptives.

	All n=523	Q39 Respondents n=296
	n(%)	n(%)
Age at Diagnosis		
15-19	66(12.6)	36(12.2)
20-24	92(17.6)	48(16.2)
25-29	134(25.6)	84(28.4)
30-34	116(22.2)	66(22.3)
35+	115(22.0)	62(20.9)
Age at Survey		
15-19	50(9.6)	25(8.4)
20-24	88(16.8)	44(14.9)
25-29	126(24.1)	81(27.4)
30-34	124(23.7)	76(25.7)
35+	135(25.8)	70(23.6)
Sex		
Male	331(63.3)	192(64.9)
Female	192(36.7)	104(35.1)
Race/Ethnicity		
Hispanic	108(20.7)	67(22.6)
White	310(59.3)	166(56.1)
Black	45(8.6)	28(9.5)
Other	60(11.5)	35(11.8)
Education		
High School or Less	149(28.5)	77(26.0)
At Least Some College	373(71.3)	219(74.0)
Marital Status		
Married	219(41.9)	122(41.2)
Not Married	303(57.9)	173(58.4)
Has children under 18		
No	316(60.4)	184(62.2)
Yes	207(39.6)	112(37.8)
Time since diagnosis with no health insurance coverage		
No	435(83.2)	244(82.4)
Yes	75(14.3)	48(16.2)
I don't know	5(1.0)	3(1.0)
Cancer Site		
Acute Lymphoblastic Leukemia	21(4.0)	10(3.4)
Germ Cell Cancer	204(39.0)	122(41.2)
Hodgkin Lymphoma	142(27.2)	83(28.0)
Non-Hodgkin Lymphoma	131(25.0)	68(23.0)
Sarcoma	25(4.8)	13(4.4)
SEER AJCC Stage		
Stage I	206(39.4)	122(41.2)
Stage II	127(24.3)	71(24.0)
Stage III	73(14.0)	41(13.9)
Stage IV	66(12.6)	37(12.5)
N/A	28(5.4)	16(5.4)
Unknown	23(4.4)	9(3.0)
Treatment		
No/Unknown Treatment	16(3.1)	7(2.4)
Surgery only	60(11.5)	35(11.8)
Radiation	52(9.9)	29(9.8)
Chemotherapy	249(47.6)	147(49.7)
Radiation and Chemo	121(23.1)	66(22.3)
Currently receiving treatment (self-report)		
No	419(80.1)	243(82.1)
Yes	91(17.4)	43(14.5)

Not all figures total 100% due to missing data.