



Published in final edited form as:

*J Cancer Educ.* 2016 September ; 31(3): 430–442. doi:10.1007/s13187-015-0853-9.

## Young Adult Cancer Survivors' Experience with Cancer Treatment and Follow-Up Care and Perceptions of Barriers to Engaging in Recommended Care

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### Abstract

We examined correlates of low engagement in the healthcare system, experiences with survivorship care, barriers to follow-up care, and potential resources for promoting follow-up care among young adult survivors of childhood cancers. We conducted a mixed-method study involving surveys of 106 survivors of childhood cancer aged 18–34 recruited from a university-affiliated children's hospital and an NCI-designated cancer center in the Southeastern USA. Phone-based semistructured interviews were then conducted in a subset of 26. Assessments included health factors, psychosocial factors, healthcare system interaction, and interest in resources to promote engagement in healthcare. Survey participants were on average 22.14(SD=3.16) years old, 50.0 % female, and 77.4 % White. Overall, 46.0 % had attended survivorship clinic, 47.2 % reported receiving a treatment summary, 68.9 % had a primary care provider, and 17.0 % reported no interaction with healthcare in the past 2 years. Correlates of less than annual healthcare provider visits included being older ( $p=0.003$ ), being male ( $p<0.001$ ), lack of insurance ( $p=0.002$ ), and having had chemotherapy ( $p=0.05$ ). Participants reported varied experiences in terms of how health and treatment information was presented, from none or too little to overwhelming or anxiety-provoking amounts. Barriers to engaging in survivorship care included no/limited insurance, time, or transportation; major life changes; anxiety; and difficulty transitioning from pediatrics to adult care. Participants highlighted the need for educational and psychosocial resources, particularly technology-based resources. Multilevel interventions are needed to increase engagement in survivorship care among young adult cancer survivors. Technology-based resources addressing social support and mental well-being are intervention possibilities.

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**Conflict of Interest** The authors declare no conflict of interest.

## Keywords

Survivorship care plans; Transition to survivorship; Young adults; Childhood cancer

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## Introduction

Long-term survival for pediatric cancer has increased to nearly 80 % due to increasing incidence and decreased mortality [1, 2]. The physiological and psychosocial impact of surviving childhood cancer is multifaceted. Survivors of pediatric cancer are at increased risk for health problems including long-term and late medical effects of cancer and treatment [3–8] and for early mortality, often in young adulthood [1, 2]. In addition, the psychosocial impact is immense. A recent review [9] found that families alter roles, responsibilities, and day-to-day functioning to accommodate the needs of children with cancer. In terms of quality of life, one study found that most survivors reported few or no symptoms of distress, although subsets of survivors reported increasing distress over time [10]. However, other research has not found this [11] or found distress was a function of how survivors perceive cancer as impacting their lives [12].

Over the last decade, cancer survivor programs have been formed to address survivorship care. For pediatric cancer patients, follow-up care usually begins 2 years after completion of cancer therapy or 5 years after the initial cancer diagnosis [13]. Most patients are then followed annually. Childhood cancer survivors then typically transition to adult survivorship clinics at 21 years of age. The goals of cancer survivorship care include the treatment of long-term effects, early detection of late effects, and medical treatment of those sequelae [14]. In 2012, the Commission on Cancer (CoC) required accredited cancer centers to issue survivorship care plans (SCPs) posttreatment [15], which includes descriptions of recommended follow-up and surveillance, advice on improving health, and information on employment, insurance, and psychological and support services [16].

Childhood cancer survivors often become lost to follow-up, particularly during the transition to adult survivorship. System-level barriers to survivorship care include difficulties in accessing information, preparation time involved for clinicians, absence of clear guidelines for follow-up care after cancer [17], lack of expertise among providers to address survivorship, limited clinical space [18], and lack of third-party reimbursement [17, 18]. A larger proportion of young adults are uninsured than any other age group in the USA, which is particularly true among young adult cancer survivors [19–21]. During this life period, they are not able to continue coverage under their parents' health insurance beyond the age of 26 [22] or may not have jobs that provide health insurance [23]. In terms of patient-level barriers, young adults are at risk for lack of awareness of and adherence to medical treatment recommendations [24] due to insurance coverage issues [19], avoidance or disengagement in healthcare due to the trauma of cancer [25], increased independence from parents in making medical decisions [19], and high mobility during these transitory years [24].

This study used a mixed-method approach to examine correlates of low engagement in the healthcare system (i.e., less than annual doctor visits), experiences with survivorship care, barriers to follow-up care, and potential resources for promoting follow-up care among

young adult survivors of childhood cancer. We used the Health Belief Model (HBM) [26] to address these aims in the context of an explanatory sequential mixed-method study [27]. Per HBM, patient perceptions of health and threat of disease and barriers in a patient's social or cultural environment influence whether a patient will engage in health-promoting or treatment behaviors, such as medical compliance [28].

## Methods

### Participants and Procedures

The Institutional Review Board approved this study, IRB# 00055570. An explanatory sequential mixed-method approach was used, as this approach allows for in-depth exploration of quantitative findings through the use of subsequent qualitative interviews [27]. In Fall 2012, young adult survivors of childhood cancers were recruited from the medical records of a university-affiliated children's hospital and a National Cancer Institute-designated cancer center in the Southeastern USA. Eligibility requirements included being diagnosed with cancer before age 18 and being between 18 and 34 years old. Research staff mailed packets including a consent form and the survey. Of the 594 patients identified who had phone numbers on record, 225 had nonworking numbers, 53 had incorrect phone numbers, 99 were unable to be reached via phone, ten were ineligible (i.e., too old, disability), six were deceased, five were unable to be reached (i.e., family member declined on their behalf, lived internationally), and five declined participation. Of the 191 packets mailed, 106 (55.5 %) were completed. A sample size of 106 participants allows for 80 % power in logistic regression analyses at the  $\alpha=0.05$  level (per Stata program command powerlog). Survey participants were compensated \$40.

The survey included a question regarding their willingness to be contacted for a follow-up study involving a telephone-based semistructured interview. Of the 106 participants, 60.4 % ( $n=64/106$ ) provided permission. In Spring 2013, we recruited a subset of 26 survey participants with a range of cancer types and engagement with the healthcare system to participate in semistructured interviews.

### Quantitative Survey

The survey assessed sociodemographics, psychosocial factors, health-related factors, interactions with the healthcare system, and interest in resources to promote engagement in the healthcare system.

#### Measures

**Sociodemographic Characteristics:** We assessed age, gender, race/ethnicity, relationship/marital status, employment status, college attendance, parental education (as a proxy for socioeconomic status), and healthcare coverage.

**Health-Related Factors:** We assessed type of cancer, year of cancer diagnosis, whether their treatment included chemotherapy, surgery, and/or radiation, and other health problems (e.g., second cancer, diabetes, hypertension, and reproductive issues).

**Psychosocial Factors:** Participants completed the Patient Health Questionnaire — nine items (PHQ-9) [29], which is a nine-item assessment of depressive symptoms (e.g., feeling depressed and little interest). Each of the items is scored 0 to 3, providing a 0 to 27 severity score. A score of 10 or more indicates moderate depressive symptoms. Cronbach’s alpha in this study was 0.89.

Perceived social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS) [30], which is a valid 12-item measure comprising three subscales: support from friends, family, and significant others. There are four items per subscale, each with response options ranging from 1=“Very strongly disagree” to 7=“Very strongly agree.” Higher scores indicate higher levels of perceived support, and a sum of the three scales yields a summary score. Cronbach’s alpha in the current study was 0.93, 0.95, and 0.96 for family, friends, and significant other, respectively.

Particularly focusing on the HBM constructs of perceived threat and severity, we asked, “How concerned are you about your health? Do you ever feel uncertain about your health? Do you worry that your cancer will come back? How likely is it you’ll develop a health problem related to cancer/treatment? How painful do you remember cancer treatment being?” with response options of 0=almost never/not at all to 4=almost always/extremely.

**Interaction With the Healthcare System and Interest in Resources:** Table 2 lists a range of questions assessing interactions with the healthcare systems. We also asked about the likelihood of going to see a healthcare provider for a variety of reasons, with response options of 0=very unlikely to 4=very likely. We asked about a range of barriers to going to a survivorship clinic. Finally, we assessed interest in various resources (listed in Table 2) with response options of 0=not at all interested to 4=very interested.

**Data Analysis**—Bivariate analyses were conducted comparing those who had seen a healthcare provider at least annually in the past 2 years versus those who had not using Chi-squared tests for categorical variables and independent samples *t* tests for continuous variables. We then developed a binary logistic regression model, using backward stepwise entry of factors associated with annual healthcare provider interaction per the bivariate analyses at  $p < 0.10$ . SPSS 21.0 was used; statistical significance was set at  $\alpha = 0.05$  for all tests.

### Qualitative Semistructured Interviews

Participants were compensated with an \$80 gift card for participating in the interviews, which were telephone-based, were audiorecorded, and lasted about 60 minutes. Prior to beginning the structured interviews, participants provided verbal consent. A trained interviewer (the second author) facilitated the interviews.

**Measures**—Drawing from HBM, the discussion guide focused on patient perceptions of health and threat of disease and barriers in a patient’s social or cultural environment. Specifically, the discussion covered: (1) experiences with cancer and follow-up care; (2) knowledge of recommended follow-up care, perceptions of need of care, and sources of

information; (3) barriers to follow-up care; and (4) potential resources to address those barriers.

**Data Analysis**—Qualitative data were analyzed according to standard principles [31] and using NVivo 10.0 (QSR International, Cambridge, MA). Transcripts were independently reviewed by the first and second authors and an MPH graduate student to generate preliminary codes. They then refined the definition of primary (i.e., major topics explored) and secondary codes (i.e., recurrent themes within these topics) and independently coded each transcript. The independently coded transcripts were compared and consensus for coding was reached. Two independent coders then coded all interviews using the refined coding tree. Upon completion, and two coders came to a consensus about coding in disagreement. The final codes were then used for analysis. Themes were identified, and representative quotes were selected.

## Results

### Quantitative Survey

Table 1 provides survey participant characteristics, and Table 2 provides psychosocial factors. Regarding experiences with healthcare providers and other factors (see Table 2), 46.0 % had attended survivorship clinic, 47.2 % reported receiving a treatment summary, 68.9 % reported having a primary care physician (PCP) currently, and 17.0 % reported no interaction with a healthcare provider in the past 2 years, with an additional 14.0 % (n=14) reporting only seeing a provider once. In bivariate analyses, factors associated with seeing a doctor less than once a year in the past 2 years at the  $p < 0.10$  level included being older ( $p = 0.05$ ), being male ( $p = 0.002$ ), not being employed ( $p = 0.008$ ), lack of insurance ( $p = 0.02$ ), and having chemotherapy ( $p = 0.04$ ) as part of treatment. Interestingly, none of the perceived threat or severity-related factors (e.g., concern about health) were associated with seeing a doctor less than annually, and the only barrier associated with this outcome was moving ( $p = 0.035$ ). In the multivariate regression, factors included in the model predicting less than annual healthcare provider visits included being older (OR=1.35; CI 1.11, 1.63;  $p = 0.003$ ), being male (OR=0.09; CI 0.03, 0.35;  $p < 0.001$ ), lack of insurance (OR=0.04; CI 0.01, 0.33;  $p = 0.002$ ), and having chemotherapy (OR=5.73; CI 0.98, 40.30;  $p = 0.05$ ; Nagelkerke  $R$ -squared=0.41).

Participants reported a range of providers seen, with the most common being a PCP (50.0 %). The majority (63.2 %) reported that, during their last clinic visit, a provider discussed any symptoms related to their cancer, with less than half reporting that they promoted adherence to care recommendations (44.3 %), interest in reproduction (42.5 %), social support (39.6 %), and mental health issues (49.1 %). The most common barrier to engaging in cancer survivorship that participants reported was time management due to college attendance (34.3 %). In this sample, 20.8 % lived more than 100 miles from where they received treatment. Regarding interest in resources, they were most interested in engaging with an online network with other young adult cancer survivors.

## Qualitative Semistructured Interviews

Qualitative interview participants were on average 21.73(SD=2.96) years of age, 53.8 % ( $n=14$ ) female, 100.0 % ( $n=26$ ) non-Hispanic, 84.6 % ( $n=22$ ) White, 26.9 % ( $n=7$ ) married or living with a partner, 38.5 % ( $n=10$ ) employed at least part-time, and 42.3 % ( $n=11$ ) were college students. In terms of cancer diagnosis, our sample had the following: Hodgkin's lymphoma ( $n=7$ ), non-Hodgkin's lymphoma ( $n=2$ ), acute lymphoblastic leukemia ( $n=4$ ), sarcoma ( $n=6$ ), thyroid cancer ( $n=3$ ), and other ( $n=4$ ). Average time since diagnosis was 6.69(SD=3.08) years.

**Experiences with Cancer and Care**—Table 3 (supplementary online material) summarizes major qualitative themes and representative sample quotes for each theme. One major theme was being informed about their diagnosis, treatment plan, and recommended follow-up care. Some reported being well informed of their diagnosis and treatment, while others reported not being informed of their diagnosis and treatment. Many participants reported that parents acted as gatekeepers to information.

Major themes regarding the physical impact of cancer included feeling sick, reproductive issues, and changes in physical appearance (air loss and weight gain/loss). Themes regarding the social impact of cancer were the impact on the family, difficulty keeping up with friends, social isolation, and social stigma. Participants reported social support from medical professionals. Regarding the psychological impact of cancer, themes included shock due to age/prior health, difficulty processing diagnosis, depression/anxiety, guilt, a sense of having lost time, a sense of loss due to reproductive issues, concern about recurrence, and the impact of medication on emotions. Positive themes included pride that they overcame an immense challenge and gratitude for those that treated and/or supported them. Finally, they reported major academic implications including academic delay due to missing school.

**Experiences with Follow-up Care**—In relation to receiving a SCP, some participants reported that there was too little information presented to them, whereas others reported overwhelming amounts of information. A couple also reported that there was a lack of information provided about day-to-day health implications; the focus was rather on the most severe medical implications. Many commented on the importance of personalized information and in setting expectations about how their cancer and treatment would affect them and their future. Participants also expressed their confidence in survivorship clinic given their expertise and specialization.

**Barriers to Engaging in Follow-up Care**—Major barriers were limited/no insurance coverage, time, transportation, life changes, such as starting a family, going to college, location/moving, and changes in social support. Many indicated not wanting to continue medical care in order to avoid anxiety-provoking information regarding their health or to not be reminded about their history with cancer. Finally, many spoke about the difficulty of transitioning from pediatrics to adult care in terms of both the loss of continuity of care with providers with whom they had a relationship and the logistics of transitioning.

**Potential Resources for Promoting Follow-up Care**—Participants highlighted the need for educational materials in many forms. There were several suggestions for using technology (e.g., using email to remind participants of upcoming appointments and to facilitate communication with providers and automated scheduling). They also mentioned the potential utility of blogging or message boards to promote education and support, as well as internet forums or social networks of young adult cancer survivors to provide support, in-person support groups, and counselors (e.g., peer counselors and therapists).

## Discussion

This mixed-method study was drawn from HBM and provided novel data regarding young adult cancer survivors' experiences with cancer, treatment, and survivorship care, barriers to follow-up care, and potential resources for promoting follow-up. Currently, participants reported being somewhat concerned about their health, feeling somewhat uncertain about their health, and somewhat worried that their cancer will come back, indicating the long-standing psychological toll of childhood cancer. They also reported a range of barriers to engaging in the recommended follow-up care. Interestingly, our quantitative analyses indicated that none of the HBM constructs, specifically the perceived threat, severity, or barriers items, were associated with seeing a healthcare provider annually. As such, the qualitative interviews were important in terms of providing a greater basis for understanding the range of experiences of this population and providing important insights regarding how barriers to follow-up care might be addressed.

Regarding engagement in healthcare, roughly two thirds of survey participants reported having a PCP currently, and of the range of providers seen, the most common was a PCP. However, a 2010–2011 survey of US and Canadian family physicians found that only a quarter felt comfortable providing care to pediatric cancer survivors and less than a fifth correctly identifying recommended surveillance for several conditions [32]. Current results indicated that nearly one fifth of participants reported no interaction with a healthcare provider in the past 2 years, in line with previous research [33, 34]. Factors predicting less than annual healthcare provider visits included being older, being male, lack of insurance, and having chemotherapy, potentially indicating that older survivors may have additional responsibilities due to family or career and that insurance issues become problematic as these young adults are no longer eligible for insurance coverage under their parents' plan. Also, males are less likely to engage in the healthcare system [35]. While the majority had a provider discuss symptoms related to their cancer during their last clinical encounter, less than half reported that they promoted adherence to care recommendations or assessed issues related to reproduction, social support, and mental health, highlighting an important gap in care [33].

Less than half of survey participants had attended survivorship clinic (46.0 %) or reported receiving a treatment summary (47.2 %), which is similar to prior findings [34]. Major barriers included limited/no insurance coverage, limited time, transportation, and life changes, such as starting a family, going to college, location/moving, and changes in social support were important barriers, which align with prior research [19, 24]. Moreover, many reported difficulty transitioning from pediatrics to adult care in terms of both the loss of

continuity of care with providers with whom they had a relationship and the logistics of transitioning. These barriers are difficult to alter on an individual level, and thus, access to care must be addressed at an institutional level. In addition, many participants indicated not wanting to continue medical care in order to avoid anxiety-provoking health-related information or reminders about their history with cancer, consistent with prior findings [25, 36]. This barrier may be a prime intervention target posttreatment.

Regarding interest in resources, technology-based resources were popular. Participants suggested blogging or message boards to promote education and support, as well as internet forums or social networks of young adult cancer survivors to provide support [37]. Recent research has leveraged online tools to address these issues with some promise [38]. They also suggested automated reminders regarding appointments and the potential appeal of having in-person support groups and counselors.

Finally, participants reported a host of cancer-related physical, social, psychological, and academic implications. They reported the engagement of the healthcare team in addressing not only the physical but also the psychosocial aspects of cancer. At the time of data collection, one fifth or survey participants reported significant symptoms of depression compared to 6.8 % in the general population [39]. The impact of depressive symptoms on self-care may be an important consideration within this population.

## Limitations

Limitations include the recruitment for this study being limited to those with whom we had current addresses and telephone numbers and the sample being drawn exclusively from one children's hospital and one cancer center, limiting generalizability to other parts of the country or to other groups of young adult cancer survivors. Self-report of prior health behaviors and other concepts covered in this study is also a limitation.

## Conclusions

Efforts and resources to increase engagement in survivorship care among young adult survivors of childhood cancer are necessary. Addressing system- and individual-level barriers to survivorship care is necessary. Participants suggested technology-based resources for increasing access to care, particularly resources related to social support and psychological well-being.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

This work was supported by the Georgia Cancer Coalition (PI: Berg), the National Cancer Institute (PI: Berg; 5K07CA139114), the Emory Egleston Children's Research Center (PI: Esiashvili), and the Winship Cancer Institute Kennedy Survivorship Award (PI: Berg)

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**Table 1**

## Participant sociodemographic and health-related characteristics

Variable	N (%) or M (SD), N=106
<i>Sociodemographics</i>	
Age (SD)	22.14 (3.16)
Gender (%)	
Male	53 (50.0)
Female	53 (50.0)
Ethnicity (%)	
Hispanic or Latino	5 (4.7)
Not Hispanic or Latino	101 (95.3)
Race (%) <sup>a</sup>	
White	82 (77.4)
Black	21 (19.8)
Other	1 (0.9)
Relationship status (%)	
Married	13 (12.3)
Never been married	87 (82.1)
Living with significant other	6 (5.7)
Employment status (%) <sup>a</sup>	
Employed full time	24 (22.6)
Employed part-time	11 (10.4)
Student	50 (47.2)
Unemployed	7 (6.6)
Unable to work or disabled	3 (2.8)
Other	11 (10.4)
Current college attendance (%) <sup>a</sup>	
Not attending	50 (47.2)
Two-year technical or community college	12 (11.3)
Four-year university	37 (34.9)
Graduate school	6 (5.7)
Parental education (%) <sup>a</sup>	
Less than high school	2 (1.9)
High school diploma or GED	19 (17.9)
Some college but no degree	14 (13.2)
Associates degree	11 (10.4)
Bachelor's degree	30 (28.3)
Graduate or doctoral degree	29 (27.4)
Healthcare coverage (%)	
Private	98 (93.4)
Public	13 (12.3)

Variable	<i>N</i> (%) or <i>M</i> (SD), <i>N</i> =106
No health insurance	10 (9.4)
Other	12 (11.3)
<i>Health-related factors</i>	
Cancer (%)	
Hodgkin's lymphoma	24 (22.6)
Non-Hodgkin's lymphoma	9 (8.5)
Burkitt's lymphoma	4 (3.8)
Acute lymphoblastic leukemia	17 (16.0)
Acute myelogenous leukemia	3 (2.8)
Blastoma	6 (5.6)
Sarcoma	11 (10.4)
Thyroid	10 (9.4)
Other	22 (20.8)
Years since diagnosis (SD)	8.42 (5.73)
Treatment included (%)	
Chemotherapy	86 (81.1)
Surgery	82 (77.4)
Radiation	59 (55.7)
Other health problems (%) <sup>a</sup>	
Second cancer diagnosis	14 (13.8)
Diabetes	3 (2.8)
Hypertension	4 (3.8)
High cholesterol	8 (7.5)
Musculoskeletal problems	7 (6.6)
Reproductive problems	14 (13.2)

<sup>a</sup>Totals not equaling 106 due to missing data.

**Table 2**

Participant psychosocial factors, interaction with the healthcare system, and interest in resources for young adult cancer survivors

Variable	N (%) or M (SD), N=106
<i>Psychosocial factors</i>	
Significant depressive symptoms per PHQ-9 (%) <sup>a</sup>	21 (20.0)
Social support per MSPSS — total (SD)	23.01 (6.10)
Family	23.45 (6.10)
Friends	22.22 (6.30)
Significant other	23.01 (6.10)
How concerned are you about your health (SD) <sup>a,b</sup>	2.29 (1.32)
Do you ever feel uncertain about your health (SD) <sup>a,b</sup>	1.87 (1.24)
Do you worry that your cancer will come back (SD) <sup>a,b</sup>	1.65 (1.36)
How likely is it you'll develop a health problem related to cancer/treatment (SD) <sup>a,c</sup>	1.67 (1.09)
How painful do you remember cancer treatment being (SD) <sup>a,c</sup>	2.57 (1.19)
<i>Interaction with the healthcare system</i>	
Years since had clinic visit with oncologist (SD)	1.66 (2.43)
Years since had clinic visit with survivorship clinic (SD) <sup>a,d</sup>	0.96 (0.88)
Never attended (%)	54 (54.0)
Ever received a treatment summary (%)	
No	18 (17.0)
Yes	50 (47.2)
Don't know	38 (35.8)
Rating of healthcare provider during cancer treatment (SD) <sup>e</sup>	9.47 (1.06)
Have a primary care physician (%)	
No	33 (31.1)
Yes	73 (68.9)
In the last 2 years, number of times seen a provider of any type (SD) <sup>a,d</sup>	7.40 (12.27)
Never attended (%)	17 (17.0)
Type of setting where care received (%) <sup>a</sup>	
Primary care provider	53 (50.0)
Obstetrician/gynecologist	14 (13.2)
Cancer specialist's office	29 (27.4)
Cancer center	35 (33.0)
Hospital	37 (34.9)
Emergency room or urgent care center	28 (26.4)
Other	18 (17.0)
During your last doctor's visit, did a healthcare provider discuss: (%) <sup>a</sup>	
Symptoms related to cancer	67 (63.2)
Ensuring adherence to survivorship care recommendations	47 (44.3)

Variable	<i>N</i> (%) or <i>M</i> (SD), <i>N</i> =106
Interest in reproduction	45 (42.5)
Social support	42 (39.6)
Mental health issues	52 (49.1)
In the next 2 years, what are the chances that you will: (SD) <sup>a,f</sup>	
Go to the doctor to check on problems associated with cancer/treatment	2.92 (1.28)
Go to a doctor for a routine checkup	3.32 (1.04)
Barriers to going to cancer survivorship clinic (%) <sup>a</sup>	
Moved	13 (12.4)
Attending college, so time is an issue	36 (34.3)
Attending college in a new city or state, so distance is an issue	10 (9.5)
Insurance does not cover cost	11 (10.5)
Forgetting to schedule an appointment	16 (15.2)
Negative emotional reaction to going to clinic/hospital	8 (7.6)
Parents not around to prompt going to the doctor	5 (4.8)
<i>Interest in resources</i>	
How interested would you be in: (SD) <sup>a,g</sup>	
Attending a group meeting or class with other young adult cancer survivors	1.96 (1.28)
A telephone-based group meeting with other young adult cancer survivors	1.21 (1.02)
Online network with other young adult cancer survivors	2.08 (1.28)
Having a face-to-face meeting with a counselor	1.57 (1.26)
Email interaction or instant messaging with a counselor	1.39 (1.24)

<sup>a</sup>Totals not equaling 106 due to missing data.

<sup>b</sup>0=almost never to 4=almost always

<sup>c</sup>0=not at all to 4=extremely

<sup>d</sup>Among those who had attended survivorship clinic or saw a healthcare provider, respectively.

<sup>e</sup>0=worst care possible to 10=best care possible

<sup>f</sup>0=very unlikely to 4=very likely

<sup>g</sup>0=not at all interested to 4=very interested

**Table 3**

Themes and sample responses regarding experiences with cancer and care, experiences with follow-up care, barriers to engagement in care, and resources for promoting engagement in follow-up care among young adult cancer survivors

Theme	Sample quote
<i>Experiences with cancer and care</i>	
Being informed	
Being well informed	They told me if I ever needed to talk to anybody, they gave me all the names and numbers. They were really helpful. My head doctor, my surgeon, he explained it thoroughly because I'd never been through surgery before, so that was probably the scariest experience.
Not being informed of diagnosis or treatment	It was really frustrating actually because I had to stay at the hospital and I didn't know why. Like I knew there was something wrong; I just had no idea what it was because nobody would tell me, because I'm sure they didn't know either... Right before they diagnosed me, it was really frustrating because I didn't know what was wrong with me, everyone kept telling me there was something wrong, but I didn't know what it was.  I think I would've been probably a little bit more comfortable knowing that these are the steps that they were going to be taking, and that the end result would be good, that I would get over it. Just to know that they had a plan, because in my mind, of course, I knew deep down that they know what they're doing, but for me not to know specifically what was going on, what were the next steps, what were we looking at in the future, for me not knowing, I was kind of scared. I didn't know what was going to happen in the future, so I definitely believe that if I would've known something, it would've comforted me a little bit more...
Parents as gatekeepers to information	Just since I was so young, the doctors would basically tell my mom everything of what was going on, and then I would have to hear it from my mom, and I wouldn't be told anything. If there was something serious, like okay I have to have radiation, they would come and say that to me, but they would never go into detail with me. I guess they were under the impression that I wouldn't understand. I kind of felt that I was out of the circle, and I kind of felt confused, like I didn't know what was going on, like everything was kind of out of control.
Physical impact	
Feeling sick	The treatment was very harsh, to say the least. I lost all my hair and I lost a lot of weight, and I was completely bedridden for at least 2 months. I lost the ability to walk because of atrophy in my legs. It was really difficult on my body.
Reproductive issues	They gave me quite a lot of information, not just the normal side effects of the drugs that I was given but also the long-term side effects of the different treatments, of the different components of the treatments, the long-term effects of all the different drugs. I felt like that went pretty well and also we discussed the potential loss of fertility and the banking of my sperm and all that. That was all discussed. That was all put right out there in the open for consideration; nothing was withheld at all that I feel.  One thing that isn't really discussed at all is the sexual health of cancer survivors, especially when it comes in terms for a guy to lose fertility and whether or not you're still fertile after you've had chemotherapy or radiation. There's not really, at least from my experience (I wasn't at entirely the right age to deal with that) I don't have a lot of resources in front of me to discuss that and talk about whether or not the effects of maybe not being fertile and dealing with having children in that case.
Physical appearance	It was like [the] chemicals in your body [that cause] that kind of destroy you because you wake up one day with no hair or your face is all black and your nose is all black and your tongue is black.
Social impact	
Impact on family	Everybody, my grandparents, my mom, my dad, my boyfriend, brothers, sisters, cousins, everybody, to make sure that I'm doing what I'm supposed to, because if not they are on my case.  At 13, kids don't understand the gravity of things, but having to see my family process what was going on, seeing their response, and once I was able to go back to school, having to present myself to other people and wanting them to understand what had happened but not draw attention to it that is a really hard thing, definitely to relate to for kids.  Then just trying to manage going to the hospital and managing my family life because I have two younger sisters. My parents had to go back and forth with me in the hospital and then my sisters trying to go through high school at the same time, and my dad trying to go to work.  My parents were very protective; I'm an only child. It was a lot of me still wanting to do things that a normal 16 years old would do and my parents thinking that it would be best if I didn't, because they didn't want me exposed to illnesses or anything that could hamper my treatment.
Difficulty keeping up with friends	I remember hanging out with friends and having them come over and they were always going over to friends' houses, and I just couldn't keep up with them energy-wise as much because I was pretty

Theme	Sample quote
	exhausted and fatigued all the time and just not feeling fantastic. I didn't feel nauseated or physically sick, but I was definitely very tired and worn out most of the time.
Social isolation	When I was 13, kids didn't understand, kind of like [Name] is sick; I don't want her around me like that. That's how I felt. They just felt sorry for me. But I did the rest of my cancer treatment and went through all that, and then me and [Name] met and we're still married.  Some of my friends handled it well and then some of them, like I couldn't really talk to them about it at all. Then other people who had been my friends, they couldn't handle it at all and they really didn't talk to me, so that was kind of weird.
Social stigma	It was the whole stigma of you having a bald head, therefore you have cancer and you're dying and you're dangerous and you're sick and you're going to get me sick, because people are completely ignorant of such diseases.
Social support from medical professionals	They came to my school and talked to my classmates at that time to let them know what was going on with me and losing my hair and all of that. They talked to me... They were great.
Psychological impact	
Shock due to age/prior health	For me, I was shocked because I never really knew of the possibility of cancer at a young age. I'd always been very healthy growing up and active. I was never really sick. I had perfect attendance from kindergarten through the first year of high school when I got diagnosed. I was never sick, so it was a huge change. I was very independent, and all my independence just went out the door when I had to rely on my parents to take care of me. I still wasn't an adult, so I couldn't choose how I wanted to be treated in terms of medicine and stuff like that. I think it was also just scary because it had gotten so bad and I didn't even know.
Difficulty processing diagnosis	They were focused on my physical health first, I guess and then they would always ask how I was doing emotionally. For a really long time, I was just kind of, like I said, I don't think I was really processing things. I was saying I was fine, but things were bothering me. I don't know if that was a defense mechanism or what, but I think I eventually broke down.
Depression and anxiety	I was a wreck. I was very depressed. I had a lot of anxiety issues. I would get really nervous.
Guilt	Maybe one of the harder parts was just knowing that...I mean I knew it wasn't my fault, but I could see what it was doing to my family and my mom and dad, and my brother, and all my friends. I felt so bad because I felt like I had done this to them and made them feel so bad; this was bringing all sorts of strife and sadness.
Sense of loss of time	Really the biggest challenge was I was 13, just a teenager. I kind of lost all my teenage years which was really rough, being sick all the time, losing my hair at 13 being a teenager. I didn't get to play sports. I missed a lot of school. I missed out on a lot from being sick from the chemo and the radiation and having to be at the hospital a lot... They made my hospital life—it was like having a hospital life and a home life—the hospital life was pretty good, but then when I left the hospital and went to school, not having any hair, being sick all the time, it was really hard.  I think the hardest part for me was feeling like I was in a time warp. I feel like those days I spent in the hospital where I'm going through treatment, my time in my room was frozen, and outside of my room, time was just moving faster. And Twitter and Facebook don't help when you see your friends in school, accomplishing their goals and dreams, and you just feel like, you know, right now there's a pause being put on your life for the moment.
Sense of loss due to reproductive issues	I lost both of my ovaries, and so thinking about the future in terms of kids kind of makes me sad, and sometimes a little angry, but that would be the only major emotional impact.
Concern about recurrence	The main thing that I'm worried about now is it coming back, something happening to me, and not being able to be there for my husband and my kids, or being too sick...
Impact of medication on emotion	Just the strength of the effect of the steroid on me and completely smearing my emotions all over the place; mood swings going up, down, around, and all over the place and being pretty scattered. That was stressful and scary not really being that much in control of my emotions...
Pride	I feel pretty proud of it. I mean, I know a lot of other people have gone through a lot more serious cancers than I did, but it's still, you know... it's something that I did. It's something that's a part of me, and I'm pretty proud of it.
Gratitude	I feel it made me a stronger person and made me appreciate all the work that everybody does and that everybody is kind of looking out for you, especially the hospitals and doctors.
Providers addressing mental health	I guess if they saw something they'd talk to me about it and I think I saw a health therapist for children once or twice. I was having really bad anger issues and that was about it. Everything else was just the physical health issues. They took amazing care of me.  Everyone that we were in contact with was super helpful. Everyone had a positive attitude, an encouraging attitude. I luckily never got to the point where I was down or had to talk to someone, felt like I needed someone to talk to professionally, but I know that they had that available. Part of the reason that I didn't need that was because everyone was so positive.

Theme	Sample quote
	They had a psychologist that I talked to and she was great. I really liked her. We dealt with some issues that I had been dealing with before. She talked to me and she was like 'here's my number if you want to call me' and I did. I was really struggling with some stuff but yeah, I think they were great. There were times where I was really emotional because everything was just getting to be too much and I feel like they overreacted, but I can't really blame them.
Academic impact	
Academic delay due to missing school	I didn't finish school because I was way behind from me being sick. I didn't get to have a regular life so it was a lot harder, especially as a teenager. I was behind on school and ended up quitting.
	Having to deal with missing a lot of school right in the last quarter of my freshman year of high school, which conveniently lined up with all of the finals [periods] and everything like that. Fortunately, all of my teachers were incredibly helpful, and all, but one, were pretty much bending over backward to make sure I wasn't impacted by what was going on.
Academic implications of medications	That was the least pleasant part because it made a lot of stuff in school very hard. After the end of the school year, it wasn't that bad. I wasn't trying to learn algebra [at] all while I was having such trouble, while I was under the influence of a steroid that was basically preventing me from thinking straight.
<i>Experiences with follow-up care</i>	
Receiving a SCP	Going back again to the <i>Survivor Healthcare Plan</i> , it lays it out like this is what might happen, so you need to follow it in this way. Like for me, I might have a risk of getting an incurable leukemia, but it's less than one percent risk, and then potential lung issues outside of asthma, potential kidney problems, and reproductive issues.
	[They gave me] a notebook of all the treatments and the drugs. They gave me a breakdown of all the potential later effects of those drugs and the things that would need to be monitored on a yearly or every 2-year basis in maintaining my health.
Presentation of information	
Little information	They didn't tell anything. They just told me how my counts would look when I would go to the doctor.
Overwhelming amounts or presentation of information	You know how you go to the pharmacy and you get a prescription and they explain to you on the side effects and stuff, that's basically what I got. While they're giving it to me or when I'm about to get it, they'll say, 'well, this is for this and this helps you do that, but it also can cause this, this and that,' and you're going, 'okay, whatever,' but now it's not 'whatever.' It's like, 'dagnabbit!' That's what it feels like now. It's like I thought it was going to be like another 20 years from now! Because now, I have to get like mammograms and stuff like that.
Lack of information about day-to-day health implications	They gave me specific numbers and statistics in terms of very severe things that could happen... I think it would've been more helpful to include just more common issues like your skin might be more sensitive in the areas you received radiation. I didn't really have any information about that kind of stuff... I would want some sort of chart that says yes, if you've been exposed to this drug for this amount of time, you're at a greater risk for not necessarily leukemia, or something severe like that, but also irritable bowel syndrome, or things like that, things that aren't going to kill you, but are going to affect you every day.
Personalization of information	It was really interesting and I think really useful, because before they had the set up relating to my specific type of chemotherapy. If there were any specific affects that it would have, then they would go and have the test done to see about those reactions, and then we would have the appointment, discuss them, and talk about potential directions.
Setting expectations	She said that it's especially important even just to know what the effects are because some effects might not come until your 30s or 40s, and to catch those effects early is especially important so you don't have to go through a lengthy process of trying to treat that. Having that knowledge base and giving that knowledge base to future physicians so that they don't just brush it off as something weird, but you can say this is attributed to my cancer and to my chemotherapy.
	That y'all basically take everything that we've done, everything that we've been through, all the medicines that we've received and y'all tell us what could happen to us, like what could come up in the future because of these medications and everything and ways to prevent stuff from popping up from our past.
Importance of survivorship care	I think they said that [survivorship care] is one of the best ways to maintain a healthy lifestyle, and it is able to follow up and monitor those later effects that could be a result of the treatments that you've gone through.
Confidence in survivorship clinic's expertise/specialization	I think it's just the fact that knowing they had my records from the time of diagnosis until the present time, that they are specialists in this field, and that whether it's something that's common that happens as a result or whether it's something a little more different or atypical, that they're more prepared to handle it, versus a primary care physician or someone that doesn't see on a regular basis cancer survivors.

Theme	Sample quote
<i>Barriers to engaging in follow-up care</i>	
Limited/no insurance coverage	<p>I haven't been in it since I was 16. I haven't been able to go back in to get checked out. I tried to Medicaid, even though I let them know that I have a history of cancer, and I still can't get any help to go back to the doctor...If I get sick, I'd have to go to the emergency room. I haven't been back for a checkup since I was 16 for my cancer and I'm 24 now.</p> <p>If you get a treatment and it has a side effect, you'd think that they would cover the medicine to deal with that side effect, but some things they don't, or some things they don't cover enough to be able to get it yourself if they don't cover it all.</p> <p>I have been turned down from health insurance three different times, and so now I have that black mark on my health insurance record, and I don't... I haven't been with my company long enough to qualify for health insurance, which should be coming up in the next month or so; but paying for healthcare has definitely been the biggest challenge since then.</p>
Time	I have school and work 24/7 pretty much, so I just don't really have that much time. They work with me and my scheduling and stuff, and they know if I have to cancel and stuff and they're pretty good about that, but I just have so much on my plate.
Transportation	Sometimes my dad would have to take a day off work to drive me all the way to the doctor, which would take about an hour, so there have been some days where I couldn't go because I couldn't find a ride because my dad had missed too many days of work already.
<i>Life changes</i>	
Starting a family	It's really hard right now because I just don't have myself to worry about; I've got three kids. I know I should be watching out for my health, too, but I mostly just watch out for theirs.
Going to college	I'm at school so we have to schedule it so that I can go home and so that I don't have to miss classes and still be able to have the time to attend the appointments.
Location/moving	Well, I'm kind of in the middle of finding [a doctor], because I moved to Los Angeles not too long ago, so a lot of things are happening. I've got a job, and I'm apartment hunting, and all this stuff. Finding a doctor, honestly, is a little lower priority than some of those things.
Change in social support	My parents, my mom, especially, would take me to the doctors'. It was super easy. They dealt with most of the doctors and whatever and the appointments, and I was just along for the ride. I guess as I got a little bit older, it got a little bit more difficult.
Avoidance	<p>A big thing for me is having to go back to the hospital. It's just full of bad memories... Having to go back and take all the tests and the blood work and all that. I'd like to think of it as in the past, but I know it's always going to be there. So that's probably the biggest thing, having to go back.</p> <p>I want to be able to do what every other normal kid does.... Me having to quit being stubborn and suck it up and go to the doctor and hear things that I don't really want to hear. That's the only obstacle in going to my appointments.</p>
Transitioning from pediatrics to adult care	<p>It was just different, having a doctor for 6 or 7 years and then having to go to someone who has no idea what's been going on. That's completely different.</p> <p>Then I think being a teenager, and being diagnosed, and having to go through that, and then becoming a legal adult at 18, and then having to make your own decisions, going from your parent's decisions to your decisions, and then also on top of that, having to transition from pediatrics to adult medicine. All of those life changes make things really difficult to have to deal with, because now you're not only transitioning from being a child to being an adult, you're having to make your own decisions in healthcare, you're potentially moving away from home, going to school, dealing with all the things that everyone else has to deal with, but you also have to make all your own health decisions, and you have to keep up with your health.</p>
<i>Potential resources for promoting follow-up care</i>	
Printed materials/brochures	They could have sent me a letter to let me know about these other places that I could get help at, like to keep the checkup, and maybe they could offer some kind of help. I mean I don't know, there may be help out there but I just don't know of any. They could have sent us letters suggesting somewhere for us to go.
Technology-based resources	
Email	I guess the more technologically dependent we've become, maybe email reminders would be the best thing from my personal standpoint. Mail is still a good thing, but with the potential of moving it does seem easier, since most people keep their same email address, that that would be one of the best ways for reminders.

Theme	Sample quote
Automated scheduling	<p>I'm working at exactly the same time the doctor is, so it's kind of hard for me to take time out to call them and talk with them and discuss with them if I'm having any sort of issue. I have to take time off from work to go see them, so if I had a good way to communicate with them outside of work hours, whether it be email or something similar, that would also be handy.</p>
Blog/message board	<p>An email from the doctor or something similar since I use the calendar on the computer and my phone, even just being able to set up the electric calendar invitation from the doctor when I set up an appointment with them; put it right on my calendar and Outlook on my computer or on my phone so that I would see that.</p> <p>I think a message board for a hospital or an oncology clinic could be very beneficial, in that if somebody has a question they could actually post a question about it, and if I have an answer I could provide, I could answer as well.</p>
Internet forum/network	<p>Maybe like a forum, an internet forum, because you could meet a bunch of people through that, and then if you wanted to talk to them over the phone, or whatever, then you would have all those different channels that a forum has. It's got group discussion, but then it's also got private messaging, so if you want to privately message someone through text, you could do that and you could give them your phone number through that if you did want to talk to somebody on there.</p>
Support groups	<p>On the website that I'm with...there are people pretty much coming on there every day saying that they just got diagnosed, that they're scared, and having all the feelings that I remember having back when I was 15, and just to be able to encourage them and tell them it will come out good, and it's not a bad type of cancer.</p> <p>Just support groups, which I know are available through hospitals. I know that support groups are available to people so I think those are helpful.</p>
Counselors	<p>It would be interesting if there was a therapist that I could talk to or see, or that a cancer survivor could see that deals specifically with cancer survivors and even cancer survivors my age, young adults. That would be a good resource to have because even someone who themselves is a cancer survivor because it has such a unique effect upon your life and a major effect at that.</p> <p>I think it would be cool if I saw a psychologist or somebody every once in a while. It would be nice to talk about all that stuff, especially because I do have a problem with keeping things bottled up and not processing upsetting things in life. That would be really helpful.</p>