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Unmet adolescent and young adult cancer survivors information and service needs: A population-based cancer registry study

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Abstract

Purpose—We described unmet information and service needs of adolescent and young adult (AYA) cancer survivors (15–39 years of age) and identified sociodemographic and health-related factors associated with these unmet needs.

Methods—We studied 523 AYAs recruited from 7 population-based cancer registries, diagnosed with acute lymphocytic leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma, germ cell cancer or sarcoma in 2007–08. Participants completed surveys a median of 11 months from diagnosis. Multivariable logistic regression analyses were used to estimate associations between unmet (information and service) needs and sociodemographic and health-related factors.

Results—More than half of AYAs had unmet information needs relating to their cancer returning and cancer treatments. AYAs needing services, but not receiving them, ranged from 29% for in-home nursing to 75% for a support group. The majority of AYAs who needed a pain management expert, physical/occupational therapist, mental health worker or financial advice on paying for health care did not receive services. In multivariable analyses, older participants, men, participants of non-White race/ethnicity, and participants who reported less than excellent general health, or

fair/poor quality of care were more likely to report unmet information needs. Factors associated with both unmet service and information needs included physical health or emotional problems interfering with social activities or having 3 physical treatment-related symptoms.

Conclusions—Recently diagnosed AYA cancer survivors have substantial unmet information needs varying by demographic and health-related factors.

Implications for Cancer Survivors—We identified subgroups of AYA cancer survivors with high unmet needs that can be targeted for interventions and referrals.

Keywords

adolescent; young adult; cancer survivor; information needs; service needs

Introduction

Stuck between pediatric and adult oncology, adolescent and young adult (AYA) cancer patients 15-39 years of age encompass a distinct, understudied, and underserved group in cancer care [1]. AYAs tend to present at a more advanced stage of disease than older age populations, at least in part due to social and developmental characteristics (sense of invincibility, lack of awareness of cancer risk), and lack of routine medical care or health insurance [2]. AYAs, particularly those under the age of 25, undergo many social, emotional, and developmental transitions, including increasing autonomy, responsibility, and independence [3-6]. A cancer diagnosis in AYAs has been found to affect sexuality and fertility, physical symptoms, psychosocial adjustment and quality of life, and family relationships [3].

Despite the great impact of cancer in this group, information and supportive care needs have been assessed in only a few prior studies [7-10]. In two Australian studies, one found AYAs identifying unmet health system and information needs in 12% to 21% of AYA patients (n=53) referred to an oncology service within 4 months of diagnosis [7]. The other study of 58 AYA patients 6-7 months after diagnosis found that 19%-47% of AYAs reported need for help with information and service needs [10]. Furthermore, in a United States study of 4-year AYA cancer survivors (n=879) recruited when actively pursuing health information, most information and service needs remained unmet for over 50% of survivors [9].

Prior studies in older adult and childhood cancer populations also have identified high levels of unmet needs across information and psychosocial domains [11-16]. The level of unmet needs has been found to vary by age [12, 11, 14, 17, 10], gender [11], race/ethnicity [14, 9], marital status [9], education [9], perceived quality of care [14], self-rated health status [9], extent to which health problems interfere with daily activities [9], comorbidities [14], type of cancer [14, 9], stage of cancer at diagnosis [12], occupational status [9], socioeconomic status [12, 17], and treatment/ treatment response [17, 11, 14, 18, 12, 9]. However, no prior studies in AYA's have used multivariable models to examine the associations of these sociodemographic and health-related factors on unmet needs. Additional studies of representative AYA cancer patients and off-treatment survivors are needed to fully characterize the needs related to information and services and the factors associated with the needs of this understudied population.

The Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study was designed to extend the limited research in this area and improve generalizability over existing studies by collecting medical and survey data from a large sample of newly diagnosed AYA cancer patients using population-based cancer registries in the United States [19]. The objective of the current manuscript is to describe the unmet information and

service needs of AYA cancer survivors and identify sociodemographic and health-related factors associated with unmet information and service needs. Understanding the information and service needs of AYA cancer patients within the first two years of their diagnosis can identify areas to target when developing age appropriate resources as well as inform practitioners of information and service referrals that may be indicated for this population.

Materials and Methods

Study Population and Recruitment

Patients were identified through population-based Surveillance, Epidemiology and End-Results (SEER) program cancer registries that cover the geographic areas of Detroit, Michigan; Seattle/Puget Sound, Washington; Los Angeles County, San Francisco/Oakland, Sacramento County, California, and the states of Iowa, and Louisiana. As detailed previously [19], 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 [1]: 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 diagnosed on autopsy or death certificate were ineligible. Among 1208 eligible patients, 43% (n=524) completed the AYA HOPE survey (one survey was lost). 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, a patient survey, and medical records. Potential participants were mailed a study packet and multiple follow-up attempts for non-respondents [19]. The survey was completed a median of 11 months (range: 4 to 22 months) from the date of diagnosis.

AYA HOPE Survey

The AYA HOPE survey asked questions about demographic characteristics; barriers to and quality of health care; treatment and symptoms; insurance status, information and service needs, the impact of cancer, and psychosocial and physical functioning. With the exception of two validated quality of life instruments, all items, including the information and service needs, were tested and revised during two rounds of one-on-one cognitive interviews (n=28). Most participants (76%) completed a paper version of the survey, with 22% completing it online and 2% completing it over the telephone.

Information Needs—The information and service needs included in this study were adapted from questions in a prior study of adult cancer survivors [20]. Participants were asked if, at the time of the survey, they needed more information 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 (questions listed in Table 1). For each information domain, participants could indicate whether they 1) have enough information, 2) need some more information, 3) need much more information, or 4) does not apply. Endorsement of the “have enough information” category was categorized as a met need, whereas endorsement of the “need some more information” or “need much more information” categories were categorized as an unmet need. The percentage of participants with an unmet need was calculated by dividing the number of participants reporting an unmet need by the number reporting any level of need,

either met or unmet (total need). Participants who chose “does not apply” to or did not answer an information need were excluded from analyses of that need (Table 2).

Service Needs—Participants were asked to indicate whether they had received (before, during or after cancer treatment) the following services: participating in a support group; seeing a pain management expert; getting professional advice to help figure out payment for healthcare; seeing a physical or occupational therapist for rehabilitation; seeing a psychiatrist, psychologist, social worker or mental health worker; talking with a spiritual or religious counselor about cancer; or having a nurse come to home (Table 2). In addition, participants were asked whether they now (at the time of survey completion) need or have needed any of these services. The total service need refers to the percentage of participants who reported ever needing the service, while the unmet service need refers to the percentage of participants who did not receive the service, but reported needing the service. Participants who reported receiving a service, but left the needed service part question blank were assumed to have needed the service. Participants who did not answer these questions were excluded (Table 3).

Sociodemographic Variables—Participants reported their race/ethnicity, education level, marital status and whether they were responsible for raising any children under 18 on the patient survey. Because the number of American Indian /Alaska Natives (AI/AN) was small and their results were most similar to those for Blacks, these two race/ethnicities were collapsed for the multivariable analyses. Age at diagnosis, categorized into three groups (15-19, 20-29, 30-39), and gender were obtained from SEER registries. Marital status was categorized as married (married or living as married) and unmarried (never married, divorced, separated, missing).

Self-Reported Health—Participants were asked about whether they experienced the following symptoms in the past four weeks: nausea/vomiting, frequent/severe stomach pain, diarrhea/constipation, pain in joints/bones, weight loss, weight gain, frequent/severe fevers, hot flashes, tingling/weakness/clumsiness of the hands/feet, frequent/severe headaches, frequent/severe mouth sores that impact eating/drinking, problems with memory/attention/concentration. These symptoms were chosen because they were considered common symptoms for the cancers included in this study by an expert panel of clinicians. The number of symptoms were summed and categorized into four groups (0, 1-2, 3-4 and 5). Participants also reported on their general health (excellent, very good, good, fair, poor) and how much of the time their physical health or emotional problems interfered with their social activities (none, a little, some, most, or all of the time); these questions were from the general health and social functioning subdomains of the SF-12 [21, 22] and similar questions have been found to be associated with information and service needs [9]. Based on the distribution, general health and interferences with activities responses were collapsed into three categories, with the small number (2) of missing/invalid responses coded in the reference category.

Healthcare Factors—Participants were asked about their health insurance coverage (unknown/ missing responses were coded as no), the quality of care that they received since their cancer diagnosis (poor, fair, good, very good, excellent), and whether they were currently in treatment. For quality of care, responses were categorized into three groups, with missing responses considered in the reference category. Participants were also asked about their knowledge of clinical trials (yes, no, I don't know); missing responses were included with “I don't know”.

Medical information—Cancer histologies were determined from SEER data and verified via medical records. The medical record forms were specific to the cancer site and collected information on tumor characteristics and staging, details of surgery, radiation therapy and chemotherapy, and comorbid conditions. Radiation therapy and surgery were considered to have been given if valid treatment dates were recorded in the medical record. Surgery was only coded for sarcoma and germ cell patients. Chemotherapy was considered to have been given if a valid cancer agent was reported as having been administered in the medical records. Treatment was categorized as surgery only, chemotherapy, radiation, or radiation and chemotherapy. Patients who received surgery in addition to chemotherapy and/or radiation were included in the respective radiation and/or chemotherapy category. As described previously [23], the number of comorbidities that were considered to be chronic conditions and serious conditions noted in the medical record were summed for each participant.

Statistical Analysis

Unmet information and service needs (frequency, percent) were described for all participants and by cancer site. Multivariable logistic regression analyses estimated the associations between the study variables described above and specific unmet information needs (yes versus no), any unmet service need (any versus none) and high (≥ 6) unmet information needs (yes versus no). We examined variables associated with unmet needs in other studies [14, 11, 24, 18, 12, 17, 9], and we also investigated whether raising children would have an impact on overall level of need by affecting the physical and psychosocial burden that the illness placed on the patient. Results for the 8 most prevalent (> 40%) unmet information needs are presented. Because of the high proportion of individuals reporting unmet information needs, participants were dichotomized into a high or low unmet needs group, based on the median number of unmet information needs reported in this study population (high ≥ 6 versus low 0-5). The small number of unmet and total service needs in our sample precluded multivariable analyses of specific service needs; therefore, we examined associations between the study variables and any unmet service need, similar to other studies [11, 12]. In our analysis, cancer site, insurance status, knowledge of clinical trials, comorbid conditions, and mode of survey completion were not significantly associated ($p > 0.05$) with any unmet information or service needs and were removed from the multivariate models. Analyses were conducted using SAS version 9.2 software (SAS institute Inc., Cary, NC, USA).

Results

The 523 AYA cancer survivors included in these analyses were 28 years of age, on average, at diagnosis. The majority of participants were male, of non-Hispanic white race/ethnicity, and not currently in treatment (Table 3). Sixty-four percent of participants were diagnosed with early stage disease (stage I/II). Most (84%) participants had at least one physical symptom in the four weeks prior to completing the survey and 31% of participants reported that health or emotional problems interfered with social activities at least some of the time.

Unmet information needs

Fifty percent or more of participants reported unmet information needs relating to handling concerns about getting another type of cancer or the cancer returning, cancer treatments, possible long-term side-effects of treatment and complementary and alternative treatments (Table 1). Between 25 and 50% of AYAs had unmet information needs related to staying physically fit, meeting other AYA survivors, nutrition and diet, financial support, fertility and risk of other family members getting cancer. The percentage of unmet information needs did not differ by type of cancer (data not shown).

Total and unmet service needs

Nearly one-third of respondents indicated a need to see a mental health care professional. Of these, more than half indicated that their need had been unmet (Table 2). Need for other services ranged from 7.5% for in-home nursing care to 26% for professional assistance with health care payment. Among those indicating need, proportions of respondents indicated unmet service needs ranged from 29% for in-home nursing to 75% for a support group. In most instances, more than 50% of respondents indicating need for a service reported that their need had been unmet. Needs and unmet needs did not appear to differ significantly across cancer types (data not shown).

Sociodemographic and health-related differences in reporting unmet needs

In multivariable analyses of specific unmet needs (Table 4), we found that older participants (30-39 years versus 15-19 years) were more likely to report unmet needs related to treatments (new treatment, complementary and alternative treatment), possible long term side effects, financial support for care and concern about getting another type of cancer. In general, males were more likely than females to report unmet information needs. Participants who were Black, AI/AN or Hispanic race/ethnicity were more likely to report unmet needs related to recurrence (handling concern about cancer returning, how to check that cancer has returned), treatment, and financial support for medical care. Participants undergoing treatment had fewer unmet information needs related to their cancer returning, long term side effects of cancer or having their own children in the future. Compared to participants with excellent general health, participants with fair/poor health has more unmet needs related to possible long term side effects and getting another type of cancer. Participants with less than very good quality of care had more unmet needs related to financial support for medical care. Participants with symptoms in the past 4 weeks were more likely to have unmet information needs about how to check for signs that cancer has returned, treatments, having their own children in the future or concern about getting another type of cancer. Reporting any health or emotional problems interfered with activities was associated with most unmet needs. Participants treated with chemotherapy (versus surgery only) had greater unmet needs related to possible long term side effects of treatment.

Sociodemographic and health-related factors associated with a high number of unmet information needs (Table 5) were similar to analyses of specific unmet information needs. Participants of Black or AI/AN or Hispanic race/ethnicity (versus non-Hispanic whites) were more likely to report 6 unmet information needs, and men were more likely to report 6 unmet information needs compared to women. In addition, participants who reported fair/poor quality of health care, that their physical health or emotional problems interfered with their social activities, or 3 symptoms in the past 4 weeks were more likely to report 6 unmet information needs. Lastly, participants with stage II disease were less likely to have 6 unmet needs than those with stage I disease.

When we considered the associations of sociodemographic and health-related factors associated with any service need, participants who reported that their physical health or emotional problems interfered with their social activities at least a little/ some of the time, or had 3 symptoms, were more likely to report an unmet service need (Table 5). Our results also suggest that participants in treatment at the time of survey completion were less likely to have an unmet service need.

Discussion

In this population-based study of recently diagnosed AYA cancer survivors, we found that a substantial number of AYA cancer survivors have needs for information and/or services that

were not being met. More than half of the cancer survivors had unmet information needs relating to their cancer returning and cancer treatments. In multivariable analyses, older participants, men, participants of Black, AI/AN or Hispanic race/ethnicity, and participants who reported fair/poor general health, less than very good quality of care, that their physical health or emotional problems interfered with their social activities, or had physical symptoms were more likely to report unmet information needs. Additionally, 56% to 75% of AYA cancer survivors who needed a support group, a pain management expert, physical or occupational therapist, mental health worker or financial advice on paying for health care did not receive these services. Factors associated with unmet service needs included not currently being in treatment, reporting that their physical health or emotional problems interfered with their social activities, or having ≥ 3 physical symptoms. Our findings suggest that subgroups of AYA cancer patients with highest unmet information and service needs, particularly men, those of non-White race/ethnicity and with physical health and emotional problems, can be targeted for referrals or interventions and given particular attention in clinical care. Our findings also illustrate that the information and service needs of off-treatment survivors are greater than those currently in treatment, indicating the need of AYA cancer survivors to obtain information and service referrals after treatment ends.

Unmet information and service needs in AYA cancer survivors have only been assessed in a few studies [7-10]. The one United States study [8, 9], similar to the findings in our study, found that survivors of non-white race/ethnicity, with less than very good/ excellent health, or who reported that their health problems interfered with their daily activities were more likely to report unmet needs in stratified analyses [9]. Additionally, men in our study reported more unmet information needs, which may be related to the lower use of psychosocial support services in men than women [3]. As expected, having more physical and emotional symptoms was associated with unmet information and service needs, as these symptoms likely raise concerns about long term side effects of treatment or cancer recurrence. Conversely, patients currently in treatment had fewer unmet information and service needs, possibly because of the focus on their current treatment rather than on potential long term outcomes or because of their more frequent contact with health care professionals or other cancer patients.

In general, we did not find higher levels of unmet information or service needs in AYAs who were unmarried, had lower education levels or who were younger, as found previously [9]. Instead, we found 30-39 years-olds to have more unmet information needs than 15-19 year olds; this association of older age with some unmet needs in our study may be a reflection of the greater responsibility borne by older participants for their own health care.

Information and service needs likely change throughout the survivorship continuum. Compared to AYA cancer survivors who were surveyed an average of 4.7 years from their diagnosis [9], we found that a lower percentage of AYA cancer survivors reported unmet information needs related to diet/nutrition (40.1% versus 50.9% [9]) and exercise (31.5% versus 53.0% [9]), and a higher percentage reported unmet mental health counseling needs (55.5% versus 35.1% [9]); however, the percentage of AYAs reporting unmet infertility information and unmet religious/spiritual counseling were similar in the two studies. Our findings may have differed from this study because our participants were surveyed more recently after diagnosis, the cancer sites of participants differed from those included in our study and the relevance of specific information and service needs may differ by type of cancer, different measurement/analytic approaches or the method of recruitment. The prior survey was conducted online in a study population that was recruited while actively pursuing health information on the internet or from e-mail announcements through patient service or advocacy organizations [8, 9]. Only 22% of our participants completed the survey

online, likely because they had the option to return a hard-copy version of the survey included in the study recruitment mailing.

Our findings of greater unmet information needs in non-White participants and those reporting less than excellent quality of care agree with findings of a study of 1,040 adult cancer survivors (mean age = 61.9 years) surveyed 2-5 years after diagnosis [14]. The reasons behind the greater unmet information needs in Blacks, AI/AN and Hispanics in our study likely are complex and may be related to previously documented racial/ethnic disparities in treatment and outcomes [25-29]. While a greater proportion of Blacks or AI/AN (22%) and Hispanics (22%) than Whites (14%) and Asian/Pacific Islanders (16%) reported less than very good quality of care in our study, racial/ethnic differences remained after adjustment for self-reported quality of care, treatment, and other health-related factors. Factors we were unable to control for, such as individual-level income, differential access to health care, institutional discrimination, comfort with or trust in the health care system, and cultural factors, may also have contributed to the observed disparities.

Differences in awareness about and availability of various sources of information may also be contributing to the observed racial/ethnic disparities. The internet is increasingly being used as a source of health-related information. However, internet use patterns differ by race/ethnicity [30]. We found a significant difference in survey completion method by race/ethnicity, with a higher percentage of Blacks (87%), AI/AN (100%), and Hispanics (81%) completing the paper survey than Whites (77%) and Asians/Pacific Islanders (65%), suggesting less interest in, comfort with, or access to online information in these racial/ethnic groups.

By recruiting a large number of participants from cancer registries across the United States that enumerate all newly diagnosed cancers, our findings are likely more representative of the AYA cancer population than previous studies that used convenience samples. However, the generalizability of our findings may be limited by the requirement that participants read and write English as well as our overall response rate of 43%. 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 [19]. In addition, by excluding participants who chose “does not apply” to information needs, we may have overestimated unmet information needs. However, sensitivity analysis including these participants did not result in significant changes for the factors associated with unmet need or in the rank order of the questions that had greatest unmet need. While the variables examined in this study were chosen primarily because of their association with unmet needs in other studies, it is possible that some of the associations found in this study resulted from multiple comparisons. Despite these limitations, our study extends the limited research in this area by identifying sociodemographic and health-related factors associated with unmet information and service needs in a population-based sample of AYAs.

Our findings suggest that the majority of AYAs who needed services did not receive them and recently diagnosed AYA cancer survivors have substantial unmet information needs, with high unmet needs varying by demographic and health-related factors. Even after considering other factors, Blacks, AI/AN and Hispanics were more likely than non-Hispanic whites to report unmet information needs. Future studies need to identify why racial/ethnic disparities exist so that culturally appropriate materials and services can be better accessed. We also found that physical health, emotional problems and not currently being in treatment were associated with both unmet information and service needs; therefore, it is possible that close medical follow-up and management of late effects as well as providing information and service referrals may reduce these needs in AYA cancer survivors. In this first

population-based, multi-center study to use cancer registries to enroll AYA cancer survivors from across the United States, we identified subgroups of AYA cancer patients with high unmet needs that can be targeted for interventions and referrals as well as topics to focus on when developing age-appropriate informational resources.

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Table 1

Total^a and unmet^b information needs from adolescents and young adult cancer patients, frequency (percent).

Type of information	Total need ^a	Unmet need ^b	Does not apply ^c	Missing
Handling concern about getting another type of cancer	500 (95.6)	309 (61.8)	19 (3.7)	4
How to check signs that cancer has returned	508 (97.1)	279 (54.9)	9 (1.7)	6
Handling concern about the cancer returning	510 (97.5)	281 (55.1)	11 (2.1)	2
New treatments for your cancer	469 (89.7)	264 (56.3)	50 (9.6)	4
Complementary and alternative treatments (i.e., acupuncture or herbal remedies)	434 (83.0)	261 (60.1)	83 (16.1)	6
Possible long-term side effects of cancer treatment	505 (96.6)	259 (51.3)	17 (3.3)	1
Financial support for medical care	470 (89.9)	245 (52.1)	48 (9.3)	5
Having your own children in the future (i.e., fertility/reproduction issues)	414 (79.2)	218 (52.7)	106 (20.4)	2
A family member's risk of getting cancer	486 (92.9)	208 (42.8)	34 (6.5)	3
Nutrition and diet	501 (95.8)	201 (40.1)	19 (3.7)	3
Meeting other adolescents or young adult cancer patients/survivors	462 (88.3)	199 (43.1)	58 (11.2)	3
Staying physically fit or getting exercise	499 (95.4)	157 (31.5)	21 (4.0)	2
How to talk about your cancer experience with family and friends	477 (91.2)	118 (24.7)	42 (8.1)	3
6 unmet information needs	<i>d</i>	276 (53.1)	<i>d</i>	

^aTotal need is the number of participants who reported the amount of information needed as none, some or much more. The denominator for the total need percentage is the total number of participants in the study (n=523).

^bUnmet need refers to the number of participants who reported the amount of information needed as some or much more. The denominator for the unmet need percentage is the number of participants who reported the amount of information needed as none, some or much more (total need). 1-6 participants, depending on the information question, did not answer the information question and were excluded.

^cThe denominator for the does not apply percentage is the total number of participants who answered the question.

^dNot calculated.

Table 2

Total^a and unmet^b services needed before, during or after cancer treatment for adolescents and young adults recently diagnosed with cancer, frequency (percent), overall and by cancer site.

Type of service	Total need ^a	Unmet need ^b	Missing ^c
Participate in a support group	96 (19.2)	72 (75.0)	22
See a pain management expert	68 (13.5)	43 (63.2)	20
Get professional advice to help figure out payment for healthcare	131 (26.1)	80 (62.0)	21
See a physical or occupational therapist for rehabilitation	80 (16.0)	46 (58.2)	23
See a psychiatrist, psychologist, social worker or mental health worker	139 (27.5)	76 (55.5)	18
Talk with a spiritual or religious counselor about your cancer	92 (18.3)	33 (35.9)	19
Have a nurse come to your home	38 (7.5)	11 (29.0)	16
Any service need	<i>d</i>	179(34.9)	

^aTotal need is the number of participants who reported needing the service. Participants who reported receiving the service but did not answer the need question were assumed to have needed the service. The denominator for the total need percentage is the number of participants who answered the service questions.

^bUnmet need refers to the number of participants who did not receive the service, but reported needing the service. The denominator for the unmet need percentage is the number of participants who reported needing the service. Participants who reported receiving the service but did not answer the need question were assumed to have needed the service.

^c6-13 participants, depending on the service type, did not answer a specific service question and were excluded from those services; an additional 10 participants did not answer any of the service need questions and were excluded.

^dNot calculated.

Table 3

Characteristics of Adolescent and Young Adult study participants (n=523).

	Frequency (%)
Gender	
Male	331 (63.3%)
Female	192 (36.7%)
Age at diagnosis (years)	
15-19	66 (12.6%)
20-24	92 (17.6%)
25-29	134 (25.6%)
30-34	116 (22.2%)
35-39	115 (22.0%)
Race/ethnicity	
Non-Hispanic White	310 (59.3%)
Non-Hispanic Black	45 (8.6%)
Hispanic	108 (20.7%)
Non-Hispanic Asian/Pacific Islander	51 (9.8%)
American Indian/Alaska Native	9 (1.7%)
Type of cancer	
Acute Lymphoblastic Leukemia	21 (4.0%)
Germ Cell Cancer	204 (39.0%)
Hodgkin Lymphoma	142 (27.2%)
Non-Hodgkin Lymphoma	131 (25.0%)
Sarcoma	25 (4.8%)
Stage at diagnosis	
I	206 (39.4%)
II	127 (24.3%)
III	73 (14.0%)
IV	67 (12.8%)
Unknown/missing	28 (5.4%)
Unstaged (acute lymphoblastic leukemia) ^a	23 (4.2%)
Treatment type	
Surgery only	60 (11.5%)
Radiation	52 (9.9%)
Chemotherapy	249 (47.6%)
Radiation and Chemotherapy	121 (23.1%)
Missing/unknown/no treatment	41 (7.8%)
Currently in treatment	
Yes	91 (17.4%)
No	419 (80.1%)
Unknown	13 (2.5%)
Education	

	Frequency (%)
High School or less	149 (28.5%)
Some college or associate degree	191 (36.5%)
College graduate or post-graduate	182 (34.8%)
Missing	1 (0.2%)
Marital Status	
Single (never married)	273 (52.2%)
Married or living as married	219 (41.9%)
Divorced	21 (4.0%)
Separated	9 (1.7%)
Missing	1 (0.2%)
Responsible for raising children	
Yes	207 (39.6%)
No	316 (60.4%)
Currently covered by health insurance (self-reported)	
Yes	479 (91.6%)
No	37 (7.1%)
Missing	7 (1.3%)
Had health insurance at time of initial cancer diagnosis and treatment (self-reported)	
Yes	439 (84.0%)
No	75 (14.3%)
I don't know	5 (1%)
Missing	4 (0.8%)
Knowledge of clinical trials	
Yes	86 (16.4%)
No	105 (20.1%)
I don't know	324 (62.0%)
Invalid/multiple response	1 (0.2%)
Missing	4 (0.8%)
Self-reported general health	
Poor	16 (3.1 %)
Fair	76 (14.5%)
Good	197 (37.7%)
Very Good	157 (30.0%)
Excellent	73 (14.0%)
Missing	2 (0.4%)
Overall quality of care	
Poor	3 (0.6%)
Fair	14 (2.7%)
Good	69 (13.2%)
Very Good	143 (27.3%)
Excellent	281 (53.7%)
Missing/multiple response	13 (2.5%)

	Frequency (%)
Health or emotional problems interfere with social activities	
None of the time	234 (44.7%)
A little of the time	125 (23.9%)
Some of the time	102 (19.5%)
Most or all of the time	62 (11.9%)
Invalid/multiple response	1 (0.2%)
Total number of symptoms ^b reported in past 4 weeks	
0	84 (16.1%)
1-2	178 (34.0%)
3-4	121 (23.1%)
5 or more	140 (26.8%)
Total number of comorbidities	
0	342 (65.4%)
1	86 (16.4%)
2	36 (6.9%)
3	25 (4.8%)
Unknown	34 (6.5%)
Total number of unmet information needs	
0	78 (14.9%)
1-2	62 (11.9%)
3-5	106 (20.3%)
6-8	129 (24.7%)
9-11	95 (18.2%)
12-14	52 (10.0%)
Missing	1 (0.02%)
Total number of unmet service needs	
0	325 (62.1%)
1	79 (15.1%)
2-3	76 (14.5%)
4	24 (4.6%)
Missing	19 (3.6%)

^a Acute lymphoblastic leukemia unstaged.

^b Symptoms included nausea/vomiting, frequent/severe stomach pain, diarrhea/constipation, pain in joints/bones, weight loss, weight gain, frequent/severe fevers, hot flashes, tingling/weakness/clumsiness of the hands/feet, frequent/severe headaches, frequent/severe mouth sores that impact eating/drinking, problems with memory/attention/concentration.

Table 4

Multivariate adjusted^a odds ratios (OR) and 95% confidence intervals (95% CI) for unmet information needs among adolescents and young adult cancer survivors by sociodemographic and health-related characteristics.

	Handling concern about cancer returning OR (95% CI)	How to check signs that cancer has returned OR (95% CI)	New treatments for your cancer OR (95% CI)	Complementary and alternative treatments OR (95% CI)	Possible long term side effects OR (95% CI)	Financial support for medical care OR (95% CI)	Having own children in future OR (95% CI)	Concern about getting another type of cancer OR (95% CI)
Age group (years)								
15-19 years	0.67 (0.31 - 1.46)	0.66 (0.29 - 1.50)	0.33 (0.14 - 0.75)	0.18 (0.07 - 0.45)	0.45 (0.21 - 0.98)	0.31 (0.13 - 0.75)	0.68 (0.29 - 1.60)	0.42 (0.19 - 0.92)
20-29 years	0.91 (0.57 - 1.45)	0.93 (0.58 - 1.49)	0.80 (0.50 - 1.28)	0.45 (0.27 - 0.75)	0.84 (0.54 - 1.31)	0.67 (0.41 - 1.09)	0.93 (0.56 - 1.56)	0.69 (0.43 - 1.11)
30-39 years	reference	reference	reference	reference	reference	reference	reference	reference
Gender								
Female	reference	reference	reference	reference	reference	reference	reference	reference
Male	1.67 (1.05 - 2.65)	1.49 (0.93 - 2.38)	1.68 (1.05 - 2.69)	1.83 (1.11 - 2.99)	1.57 (1.01 - 2.46)	1.52 (0.93 - 2.48)	0.89 (0.54 - 1.47)	1.56 (0.98 - 2.50)
Race/ethnicity								
Non-Hispanic White	reference	reference	reference	reference	reference	reference	reference	reference
Asian /Pacific Islander	1.18 (0.59 - 2.36)	1.05 (0.53 - 2.09)	1.07 (0.54 - 2.13)	0.78 (0.38 - 1.61)	0.68 (0.34 - 1.33)	1.12 (0.54 - 2.31)	0.41 (0.19 - 0.86)	1.39 (0.69 - 2.81)
Black and AI/AN	2.19 (1.07 - 4.49)	2.36 (1.13 - 4.96)	2.37 (1.11 - 5.03)	2.50 (1.05 - 5.93)	1.38 (0.70 - 2.72)	4.78 (2.11 - 10.84)	1.77 (0.79 - 3.97)	1.62 (0.77 - 3.42)
Hispanic	1.51 (0.90 - 2.53)	2.47 (1.43 - 4.26)	1.84 (1.07 - 3.16)	1.79 (1.00 - 3.20)	0.66 (0.40 - 1.08)	1.79 (1.03 - 3.11)	1.48 (0.84 - 2.62)	1.10 (0.64 - 1.87)
Education								
College graduate or post-graduate	reference	reference	reference	reference	reference	reference	reference	reference
High school or less	1.44 (0.80 - 2.61)	1.17 (0.63 - 2.15)	1.48 (0.79 - 2.77)	0.83 (0.43 - 1.62)	1.21 (0.68 - 2.14)	1.00 (0.54 - 1.87)	0.80 (0.40 - 1.60)	1.53 (0.83 - 2.81)
Some college or associate degree	1.58 (0.97 - 2.56)	0.75 (0.45 - 1.23)	1.06 (0.65 - 1.72)	0.98 (0.58 - 1.67)	1.46 (0.91 - 2.34)	1.34 (0.80 - 2.23)	1.31 (0.76 - 2.27)	1.41 (0.86 - 2.30)
Currently in Treatment								
No or unknown	reference	reference	reference	reference	reference	reference	reference	reference
Yes	0.53 (0.30 - 0.94)	0.81 (0.44 - 1.48)	0.96 (0.53 - 1.74)	1.02 (0.54 - 1.94)	0.53 (0.30 - 0.92)	1.01 (0.55 - 1.86)	0.46 (0.23 - 0.90)	0.97 (0.53 - 1.76)
Marital Status ^b								

	Handling concern about cancer returning OR (95% CI)	How to check signs that cancer has returned OR (95% CI)	New treatments for your cancer OR (95% CI)	Complementary and alternative treatments OR (95% CI)	Possible long term side effects OR (95% CI)	Financial support for medical care OR (95% CI)	Having own children in future OR (95% CI)	Concern about getting another type of cancer OR (95% CI)
Married	reference	reference	reference	reference	reference	reference	reference	reference
Not married	0.92 (0.56 - 1.51)	1.14 (0.69 - 1.90)	1.24 (0.75 - 2.08)	1.89 (1.08 - 3.31)	0.93 (0.57 - 1.50)	1.52 (0.89 - 2.59)	0.98 (0.55 - 1.72)	1.25 (0.75 - 2.07)
Raising children								
No	reference	reference	reference	reference	reference	reference	reference	reference
Yes	1.12 (0.68 - 1.86)	1.42 (0.84 - 2.40)	1.25 (0.74 - 2.12)	0.90 (0.51 - 1.57)	0.88 (0.54 - 1.44)	1.43 (0.84 - 2.46)	0.54 (0.30 - 0.97)	1.02 (0.61 - 1.71)
General Health								
Excellent	reference	reference	reference	reference	reference	reference	reference	reference
Very good/ good	1.13 (0.63 - 2.02)	1.28 (0.70 - 2.33)	1.16 (0.64 - 2.10)	0.98 (0.53 - 1.80)	1.68 (0.94 - 3.00)	1.39 (0.75 - 2.61)	1.06 (0.58 - 1.96)	1.40 (0.79 - 2.49)
Fair or poor	1.75 (0.78 - 3.94)	1.89 (0.81 - 4.39)	1.37 (0.60 - 3.11)	1.12 (0.47 - 2.68)	2.35 (1.07 - 5.17)	2.06 (0.87 - 4.88)	2.13 (0.87 - 5.20)	2.73 (1.16 - 6.43)
Quality of care								
Very good, excellent, missing/ invalid	reference	reference	reference	reference	reference	reference	reference	reference
Good	1.61 (0.85 - 3.06)	1.59 (0.83 - 3.03)	1.39 (0.74 - 2.60)	0.99 (0.52 - 1.90)	1.18 (0.66 - 2.13)	1.95 (1.01 - 3.74)	1.47 (0.75 - 2.87)	1.39 (0.73 - 2.67)
Fair or poor	2.49 (0.65 - 9.61)	2.24 (0.57 - 8.78)	4.06 (0.83 - 19.78)	2.11 (0.54 - 8.24)	3.05 (0.78 - 11.86)	9.27 (1.10 - 78.52)	1.95 (0.48 - 8.01)	1.50 (0.39 - 5.85)
Health or emotional problems interfere with activities								
None of the time	reference	reference	reference	reference	reference	reference	reference	reference
A little or some of the time	2.89 (1.82 - 4.58)	2.47 (1.55 - 3.93)	1.29 (0.81 - 2.07)	1.53 (0.93 - 2.52)	1.51 (0.96 - 2.36)	1.46 (0.89 - 2.39)	1.99 (1.18 - 3.35)	2.04 (1.28 - 3.23)
Most or all of the time	2.66 (1.20 - 5.86)	2.47 (1.07 - 5.70)	2.65 (1.14 - 6.18)	2.19 (0.86 - 5.58)	2.19 (1.01 - 4.72)	3.85 (1.53 - 9.68)	1.76 (0.73 - 4.27)	2.97 (1.23 - 7.17)
Treatment								
Surgery only	reference	reference	reference	reference	reference	reference	reference	reference
Radiation and chemotherapy	1.25 (0.57 - 2.75)	1.42 (0.63 - 3.21)	1.11 (0.49 - 2.48)	1.03 (0.42 - 2.51)	1.97 (0.89 - 4.36)	1.44 (0.62 - 3.31)	1.82 (0.73 - 4.52)	1.23 (0.55 - 2.76)
Chemotherapy	1.55 (0.77 - 3.14)	0.99 (0.48 - 2.06)	0.90 (0.43 - 1.85)	0.59 (0.26 - 1.31)	2.41 (1.17 - 4.93)	1.13 (0.54 - 2.36)	1.70 (0.75 - 3.83)	1.03 (0.50 - 2.10)
Radiation	0.94 (0.40 - 2.19)	0.91 (0.38 - 2.19)	0.57 (0.24 - 1.36)	0.62 (0.24 - 1.59)	1.00 (0.42 - 2.37)	0.78 (0.32 - 1.90)	1.34 (0.51 - 3.49)	0.97 (0.40 - 2.31)

	Handling concern about cancer returning OR (95% CI)	How to check signs that cancer has returned OR (95% CI)	New treatments for your cancer OR (95% CI)	Complementary and alternative treatments OR (95% CI)	Possible long term side effects OR (95% CI)	Financial support for medical care OR (95% CI)	Having own children in future OR (95% CI)	Concern about getting another type of cancer OR (95% CI)
Missing/unknown/no treatment	2.04 (0.78 - 5.35)	1.70 (0.63 - 4.56)	1.21 (0.45 - 3.24)	2.02 (0.63 - 6.43)	2.22 (0.86 - 5.73)	0.79 (0.29 - 2.15)	1.26 (0.44 - 3.62)	1.15 (0.44 - 3.01)
Total symptoms ^c								
0	reference	reference	reference	reference	reference	reference	reference	reference
1-2	1.16 (0.63 - 2.13)	2.15 (1.14 - 4.06)	1.31 (0.71 - 2.40)	1.61 (0.85 - 3.06)	1.25 (0.69 - 2.29)	1.38 (0.72 - 2.62)	2.55 (1.30 - 5.03)	1.96 (1.08 - 3.56)
3-4	1.60 (0.82 - 3.12)	3.30 (1.65 - 6.61)	2.10 (1.06 - 4.17)	2.53 (1.23 - 5.19)	1.65 (0.85 - 3.19)	1.59 (0.78 - 3.24)	3.39 (1.59 - 7.22)	2.31 (1.17 - 4.53)
5+	1.70 (0.81 - 3.54)	3.55 (1.65 - 7.63)	1.79 (0.84 - 3.80)	1.66 (0.76 - 3.66)	1.90 (0.92 - 3.90)	1.55 (0.71 - 3.39)	2.85 (1.24 - 6.53)	2.04 (0.98 - 4.26)
AJCC stage at diagnosis								
I	reference	reference	reference	reference	reference	reference	reference	reference
II	0.71 (0.41 - 1.23)	0.68 (0.39 - 1.20)	0.66 (0.37 - 1.17)	0.73 (0.40 - 1.32)	0.83 (0.48 - 1.42)	0.61 (0.34 - 1.10)	0.57 (0.30 - 1.08)	0.80 (0.45 - 1.39)
III/IV	0.99 (0.57 - 1.72)	0.79 (0.45 - 1.38)	0.85 (0.47 - 1.51)	0.92 (0.49 - 1.70)	0.69 (0.41 - 1.19)	0.92 (0.51 - 1.65)	0.69 (0.37 - 1.30)	1.05 (0.60 - 1.86)
Unstaged	1.51 (0.55 - 4.19)	1.53 (0.52 - 4.56)	1.35 (0.47 - 3.87)	2.33 (0.77 - 7.00)	2.06 (0.76 - 5.59)	1.00 (0.35 - 2.85)	0.75 (0.25 - 2.25)	1.36 (0.48 - 3.89)
Unknown	1.54 (0.54 - 4.43)	2.13 (0.64 - 7.02)	0.61 (0.22 - 1.70)	2.86 (0.79 - 10.41)	1.98 (0.70 - 5.62)	1.87 (0.57 - 6.14)	1.78 (0.57 - 5.53)	1.32 (0.44 - 3.98)

^a Adjusted for all the variables in the table.

^b Married includes married or living as married; unmarried includes single, divorced, or separated

^c Symptoms included nausea/vomiting, frequent/severe stomach pain, diarrhea/constipation, pain in joints/bones, weight loss, weight gain, frequent/severe fevers, hot flashes, tingling/weakness/clumsiness of the hands/feet, frequent/severe headaches, frequent/severe mouth sores that impact eating/drinking, problems with memory/attention/concentration.

Table 5

Multivariate adjusted^a odds ratios (OR) and 95% confidence intervals (95% CI) for high unmet information needs or any service need among adolescents and young adult cancer survivors by sociodemographic and health-related characteristics.

<i>Characteristics</i>	Six or More Unmet information needs OR (95% CI)	Any unmet service needs OR (95% CI)
Age group (years)		
15-19 years	0.49 (0.22 - 1.09)	0.71 (0.30 - 1.67)
20-29 years	0.90 (0.56 - 1.43)	1.08 (0.67 - 1.72)
30-39 years	reference	reference
Gender		
Female	reference	reference
Male	1.66 (1.04 - 2.64)	1.35 (0.84 - 2.16)
Race/ethnicity		
Non-Hispanic White	reference	reference
Asian /Pacific Islander	1.31 (0.65 - 2.62)	0.97 (0.47 - 2.00)
Black and AI/AN	2.58 (1.24 - 5.36)	1.43 (0.72 - 2.86)
Hispanic	1.81 (1.07 - 3.06)	1.17 (0.68 - 2.01)
Education		
College graduate or postgraduate	reference	reference
High school or less	1.37 (0.75 - 2.50)	0.63 (0.34 - 1.18)
Some college or associate degree	1.34 (0.83 - 2.18)	1.30 (0.79 - 2.14)
Currently in Treatment		
No or unknown	reference	reference
Yes	1.09 (0.61 - 1.96)	0.56 (0.31 - 1.00)
Marital Status ^b		
Married	reference	reference
Not married	1.14 (0.69 - 1.89)	0.94 (0.57 - 1.55)
Raising children		
No	reference	reference
Yes	1.27 (0.76 - 2.12)	1.03 (0.62 - 1.73)
General Health		
Excellent	reference	reference
Very good/ good	1.51 (0.83 - 2.75)	0.79 (0.42 - 1.50)
Fair or poor	1.65 (0.73 - 3.71)	0.97 (0.42 - 2.26)
Quality of care		
Very good, excellent, missing/invalid	reference	reference
Good	1.80 (0.95 - 3.42)	1.53 (0.83 - 2.81)
Fair or poor	5.06 (1.04 - 24.59)	1.63 (0.55 - 4.85)
Health or emotional problems interfere with activities		
None of the time	reference	reference
A little or some of the time	2.64 (1.66 - 4.19)	2.04 (1.26 - 3.31)

<i>Characteristics</i>	Six or More Unmet information needs OR (95% CI)	Any unmet service needs OR (95% CI)
Most or all of the time	2.96 (1.32 - 6.62)	3.80 (1.72 - 8.39)
Treatment		
Surgery only	reference	reference
Radiation and chemotherapy	1.59 (0.70 - 3.58)	1.19 (0.51 - 2.78)
Chemotherapy	0.96 (0.47 - 1.98)	1.42 (0.66 - 3.04)
Radiation	0.93 (0.39 - 2.22)	0.61 (0.22 - 1.68)
Missing/unknown/no treatment	1.53 (0.59 - 4.00)	0.94 (0.34 - 2.63)
Total symptoms ^c		
0	reference	reference
1-2	1.77 (0.95 - 3.32)	1.10 (0.54 - 2.25)
3-4	2.68 (1.35 - 5.31)	3.41 (1.63 - 7.13)
5+	2.55 (1.21 - 5.40)	2.17 (0.98 - 4.80)
AJCC stage at diagnosis		
I	reference	reference
II	0.50 (0.28 - 0.87)	1.33 (0.74 - 2.37)
III/IV	0.75 (0.43 - 1.30)	1.74 (0.99 - 3.04)
Unstaged	1.08 (0.39 - 3.00)	0.83 (0.27 - 2.57)
Unknown	1.37 (0.46 - 4.10)	0.70 (0.21 - 2.29)

^a Adjusted for all the variables in the table.

^b Married includes married or living as married; unmarried includes single, divorced, or separated

^c Symptoms included nausea/vomiting, frequent/severe stomach pain, diarrhea/constipation, pain in joints/bones, weight loss, weight gain, frequent/severe fevers, hot flashes, tingling/weakness/clumsiness of the hands/feet, frequent/severe headaches, frequent/severe mouth sores that impact eating/drinking, problems with memory/attention/concentration.