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ORIGINAL ARTICLE

Information and service needs for young adult cancer survivors

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Abstract

Background The intent of this study was to examine supportive care needs and preferences among young adult cancer survivors.

Method Eight hundred seventy-nine young adults aged 18–39 years at time of study and diagnosed with cancer between the ages of 15–35 completed an online survey. Questions assessed the extent to which subjects had utilized various information and supportive care services and/or expressed a desire to use those services either now or in the past.

Results Upwards of 60% of respondents expressed a desire or need for age-appropriate cancer information, information about diet, exercise, nutrition, complementary and alternative health services, infertility information, mental health counseling, and camp or retreat programs for young adults. In most cases, more than 50% of respondents indicated that their needs for information and services have been unmet. In addition, unmet needs were more likely reported by respondents who were younger at age of diagnosis, of poor physical health status, and less likely to be advanced in work, school, or a committed/marital relationship. Other significant differences in unmet need were observed across sociodemographic and health status variables.

Conclusion Findings suggest a need to enhance the provision of supportive care services to adolescent and young adult cancer survivors along a continuum of care, from diagnosis through treatment and on to off-treatment survivorship.

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Despite improvements in mortality and survival rates for children and older adults diagnosed with cancer, similar progress has been substantially lagging among adolescents and young adults (AYAs) [7]. Research suggests AYA cancer patients tend to present with more advanced and aggressive diagnoses and that AYA patients account for an estimated 2% of all invasive cancer diagnoses compared to 0.75% in childhood cancer patients [6]. Disparities in mortality and survival outcomes for AYAs may be attributable to low enrollment in clinical trials, poorer access to healthcare/higher rates of uninsured, and lack of treatment sites specifically geared toward an AYA population [11, 17, 20, 28].

Cancer during the adolescent and young adult years challenges these young people's ability to achieve crucial developmental milestones such as establishing autonomy and independence, intimate relationships, and financial independence [1, 4, 7, 13, 15]. A limited but emerging body of empirical research suggests that AYA cancer patients and survivors experience unique impacts of cancer with regards to self-esteem and identity development, psychological distress (among both patients and family members), family functioning, social relationships, fear of recurrence, employment/education, physical functioning (including fertility), and financial strain [4, 7, 8, 12, 14, 16, 18, 19, 26, 27, 30, 32]. In addition, some studies suggest that AYA cancer survivors, similar to survivors diagnosed at other stages of life, experience and report positive effects such as personal growth and perceived benefits, a reprioritizing of life and greater maturity when compared to same-age peers without a cancer history [5, 10].

Associated with these physical and psychosocial impacts are a set of informational practical, emotional, interpersonal, and existential needs [22, 30], many of which are being unmet by significant proportions of adolescent and young adult patients [29]. In general, however, relatively few empirical studies of cancer patients and off-treatment survivors have distinguished psychosocial outcomes and the health and supportive care needs of AYAs, particularly as they may differ from pediatric or older adult populations. Haase and Phillips [17] suggest that this gap in the research literature is due to a common trend of clumping adolescents and young adults with either pediatric or older adult populations.

Thus, the intent of the study reported here was to examine supportive care needs and preferences specific to adolescent and young adult cancer survivors. The study also examines the extent to which these needs or desires for services are being met throughout an entire continuum of care that is initiated at diagnosis and continues through treatment and on into off-treatment survival. The study has potential to guide the delivery of services in that findings suggest when along a continuum of care, young adults may need, desire, or benefit from particular services.

Materials and methods

Data collection procedures and participants

The data reported here come from an online survey of young adult cancer patients and survivors [29]. In coordination with the Lymphoma Research Foundation, the principal investigator telephoned or emailed staff from patient education and support service agencies from across the US and Canada, described the study and requested assistance in identifying and recruiting young adult cancer patients and survivors to the study. These organizations, including the Young Survival Coalition and Planet Cancer, are known for providing services specifically to young adults with cancer and agreed to post announcements about the survey in their own online and hard copy newsletters. The announcement directed eligible subjects to a website and link to the survey, whereupon a cover letter described the purpose of the study, indicated that results would be used to improve health care for young adults with cancer, and detailed human subjects rights and protections.

The study utilized a convenience sample of respondents who were between the ages of 18 and 39 years at the time of study and diagnosed with any form of cancer between the ages of 15–35. After reviewing the cover letter and consent form online, subjects advanced to the survey. Data were collected from March 15 through June 15, 2006 via *SurveyMonkey*, an online software program and interface that allows investigators to design their own surveys and collect responses electronically. Upon completion of the survey, all raw data were exported to the principal investigators' own secured server at the University of Southern California School of Social Work. Data were analyzed using Statistical Package for the Social Sciences 15.0. All procedures were approved by the principal investigator's Institutional Review Board.

Instruments

To explore the information and supportive care needs of young adult cancer survivors, survey questions were adapted from prior research on young adult survivors of childhood cancer [9, 31]. A list of 17 items were derived from a stress-coping framework suggesting that cancer survivors experience stress with regards to needs for information, practical support, emotional support, maintaining and establishing interpersonal relations, and addressing existential questions and issues such as uncertainty and mortality [30]. For each need item, respondents were asked to endorse one of the following response categories: (a) “Have not used and have no need,” (b) “Have not used but would like to,” (c) “Have used and would like to use more,” and (d) “Have used but have no further need.” These categories distinguished respondents who indicated a need for service (in the past or currently) from those who did not (see Fig. 1). They also distinguished respondents who indicated that they have accessed and used a particular service (“met need”) from those who expressed a desire or need but have not, for whatever reason, had that desire or need met (“unmet need”). Thus, the response categories (b) “Have not used but would like to,” (c) “Have used and would like to use more,” and (d) “Have used but have no further need” were combined to indicate “Total Need,” as these three response categories all suggest a desire or need for service at some point during a continuum of care. As a subset of Total Need, the response category (b) “Have not used but would like to” is used here

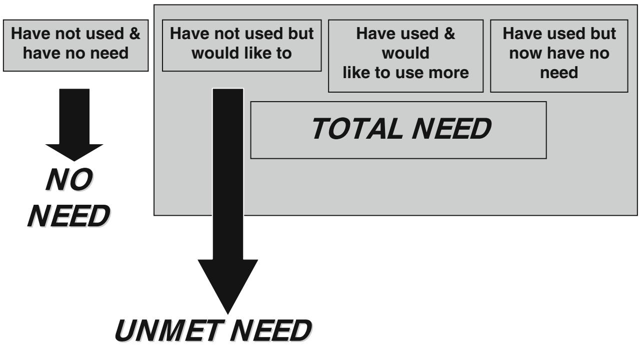

Fig. 1 Response categories distinguishing “Need” from “Unmet Need”

to suggest "Unmet Need," in that endorsement of this response category suggests that at some point along a continuum of care, a respondent would utilize a service but has not. In this instance, the desire or need for service has gone unmet. In contrast, the two response categories (c) "Have used and would like to use more" and (d) "Have used but have no further need," when combined, indicate a subset of "Total Need" called "Met Need."

Demographic information reported by survey participants included gender, educational attainment, occupational status, race, marital status, and age at study. Medical/health status variables included type of cancer, age at diagnosis, years since diagnosis, self-rated health status, recurrence of cancer, health problems attributed to cancer, and extent to which health problems interfere with daily activities.

Statistical analyses included a descriptive summary of participants reporting total need and of a subset reporting unmet need. Bivariate analyses examined differences in reporting total and unmet needs based on respondents' demographic and medical/health status. Type of cancer was categorized by (1) hematological malignancies (leukemia, lymphoma, and non-Hodgkin's lymphoma), (2) breast cancer, and (3) other carcinomas, germ cell tumors and soft tissue sarcomas. Patients diagnosed with brain tumors (*n*=24) and thyroid cancer (*n*=15) were excluded from statistical tests of association because these two cancers and their treatments are so unlike the cancers included in the other three categories. Respondents also indicated whether or not they had health problems and, if they had health problems, how much those health problems interfered with daily activities. The response categories for the variable indicating interference with daily activities were constructed such that those who reported no health problems were compared with those who indicated having health problems that interfered with their daily activities not at all or a little ("minimal interference") or else some or a lot ("substantial interference").

Categorizations of age and age at diagnosis were derived from epidemiological research and developmental theory. Most investigations of young adults and cancer have focused primarily on young adult survivors of pediatric malignancies, and studies vary in their determination of eligibility criteria for defining a "young adult." Yet, adult developmental theories provide a rationale for suggesting age ranges to distinguish varied phases of adulthood. For example, research suggests that a transition from adolescence to adulthood occurs by age 20 and that age 30 serves as an upper boundary for defining a "young adult" [25]. For purposes of this study, ages 18–29 demarcate one "young

Table 1 Sample descriptives (*n*=879)

	Frequency (%)
Gender	
Male	230 (26.2)
Female	635 (72.2)
Education	
High school grad/GED equivalent, some college	299 (34.0)
College graduate/postgraduate education	570 (64.8)
Occupational status	
Employed[a]	785 (89.3)
Unemployed[b]	82 (9.3)
Racial/ethnic background	
White/Caucasian	741 (84.3)
Black/African American	22 (2.5)
Asian	33 (3.8)
Hispanic/Latin	32 (3.6)
Native American	3 (.3)
Marital/relationship status	
Married or committed relationship	519 (59.0)
Not currently married	350 (39.8)
Average household income[c] (standard deviation) range, $15,648–$159,538	$53,574 ($19,255)

Totals do not add up 100% due to missing data.

[a] Compensated employment, homemaker or student

[b] Temporary medical leave or disability or permanently unable to work

[c] Household income was determined via US Census zip code data. Data reported are the average incomes for the zip code in which each respondent resides and not the respondent's actual household income.

Table 2 Medical/health status characteristics (*n*=879)

	Frequency (%)
Type of cancer	
Hodgkin's disease	274 (31.1)
Non-Hodgkin's lymphoma	132 (15.0)
Leukemia	47 (5.3)
Breast cancer	147 (16.7)
Germ cell tumors	103 (11.7)
Soft tissue sarcomas/carcinoma[a]	136 (15.4)
Brain tumors	24 (2.7)
Thyroid	15 (1.7)
Self-rated health status	
Excellent	205 (23.3)
Very good	372 (42.3)
Good	234 (26.6)
Fair	55 (6.3)
Poor	12 (1.4)
Recurrence	
No	723 (82.3)
Yes	154 (17.5)
Cancer-related health problems interfere with daily activities	
No health problems reported	381 (43.3)
Minimal interference	254 (28.9)
Substantial interference	238 (27.1)

Not all percentages equal 100% due to missing data.

[a] Includes colorectal, endometrial/uterine, bone cancers (Ewing's, osteogenic sarcoma), kidney, liver, lung, ovarian, testicular, tongue/oral, multiple myeloma, neuroblastoma

adult" age category. A second 30–39-year-old age category is included here based on the National Cancer Institute's (NCI) inclusion of this age range in their *Adolescent and Young Adult Oncology Progress Review Group Report* [21]. As for age at diagnosis categories, the American Cancer Society's annual *Cancer Facts and Figures* [2] traditionally distinguishes pediatric cases as ranging in age from 0 to14 years, and the NCI Surveillance Epidemiology and End Results database routinely utilizes 5-year increments in most analyses [24]. Thus, four age-at-diagnosis categories are presented here (15–19, 20–24, 25–29, 30–35). For all bivariate analyses, chi-square parameters were evaluated and statistically significant differences reported where $p<.05$.

Results

A total of 879 survivors completed the entire survey, including all questions related to service needs and demographics. Survey respondents were, on average, 29.7 years old (standard deviation=8.08 years), diagnosed at an average age of 26.0 years (standard deviation= 5.80 years), and 4.7 years (standard deviation 4.01 years), on average, postdiagnosis. Additional details describing the sample characteristics are summarized in Tables 1 and 2.

Total and unmet needs

Almost all young adult respondents to this survey expressed a desire or need for information about their illness, treatment, and long-term effects (96.7%). Furthermore, large proportions of respondents reported a desire or need for information and guidance about exercise and physical fitness (79.0%), diet and nutrition (79.6%), and help with understanding health insurance, disability insurance, and social security (67.6%). Ninety-one percent of respondents have used or want to use Internet sites that offer cancer education or support that is appropriate for their age group. At some point between diagnosis and the time of study, more than half of this study sample wanted mental health counseling (67.3%), complementary/alternative health services, including herbal treatment, acupuncture, biofeedback, meditation, visualization, or guided imagery (64.2%), information about infertility and options for having children (68.7%), and programs (e.g., camps, retreats, workshops) that offer cancer education and support appropriate for young adults (62.2%). A smaller proportion of young adults indicated need for infertility treatment (38.2%), adoption services (36.1%), counseling or guidance related to sexuality and intimacy (40.2%), family counseling (35.0%), and religious/spiritual support (40.3%). Needs for child care (15.1%), transportation assistance (18.1%), and alcohol or drug abuse counseling (4.2%) were relatively small.

Among respondents reporting needs were subsets of individuals who indicated that their needs had not been met. Of the total 850 respondents indicating need for information about cancer, 9.1% (n=77) suggested that this need had been unmet (Table 3). Between one fourth and one half of survivors indicating needs for age-appropriate Internet websites about cancer, diet and nutrition information,

Table 3 Information and service needs (n=), frequency (percent)

	Total need	Unmet need
Information about cancer	850 (96.7)	77 (9.1)
Internet sites	801 (91.1)	263 (32.8)
Diet and nutrition information	700 (79.6)	356 (50.9)
Exercise Information	694 (79.0)	368 (53.0)
Assistance with health insurance, disability or social security	594 (67.6)	240 (40.4)
Mental health counseling	592 (67.3)	208 (35.1)
Family counseling	308 (35.0)	191 (62.0)
Counseling related to sexuality or intimacy	353 (40.2)	260 (73.7)
Religious/spiritual counseling	354 (40.3)	121 (34.1)
Alcohol or drug abuse counseling	37 (4.2)	21 (56.8)
Infertility information	604 (68.7)	257 (42.5)
Infertility treatment/services	336 (38.2)	209 (62.2)
Adoption services	317 (36.1)	262 (82.6)
Complementary/alternative health care services	564 (64.2)	273 (48.4)
Camps, retreats	547 (62.2)	407 (74.4)
Transportation assistance	159 (18.1)	95 (59.7)
Child care	133 (15.1)	77 (57.9)

"Total Need" is the number and proportion of patients who endorsed one of the following response categories: "Have not used but would like to," "Have used and would like to use more," or "Have used but have no further need." "Unmet Need" is a subset of total need, identifying the number and proportion of patients who endorsed "Have not used but would like to."

exercise information, complementary/alternative health care services, assistance with health insurance, mental health counseling, infertility information, and religious and spiritual counseling suggested that these needs remain unmet. Needs for camps and retreat programs, sexuality and intimacy counseling, family counseling, adoption services, infertility treatments, transportation assistance, child care, and alcohol or drug abuse counseling appeared unmet for more than 50% of those who indicated need. See Table 3 for a summary of respondents' total and unmet needs.

Sociodemographic and medical/health status differences in reporting unmet needs

The following results compare proportions of survivors whose responses indicated unmet need ("Have not used but would like to") to everyone else regardless of whether or not they indicated need for a particular service. In most instances where significant differences in unmet need were observed across sociodemographic groups, survivors who were (1) unmarried or not in a significant long-term

Table 4 Proportional differences (frequency, percent) in unmet service needs by sociodemographic status (chi-square)

	Marital status		Occupational status		Education		Race		Gender	
	Yes (*n*=519)	No (*n*=350)	Yes (*n*=785)	No (*n*=82)	<College grad (*n*=299)	College grad (*n*=570)	White (*n*=741)	Nonwhite (*n*=90)	Female (*n*=635)	Male (*n*=230)
Information about cancer	35 (6.8) 4.52**	38 (10.9)	62 (7.9) 2.90*	11 (13.4)	32 (10.7) 2.82*	42 (7.4)	57 (7.7) ns	11 (12.4)	49 (7.7) ns	25 (10.9)
Internet sites	144 (27.7) 3.31*	117 (35.5)	230 (29.3) ns	31 (37.8)	112 (37.6) 12.59****	148 (26.0)	217 (29.3) 2.75*	34 (37.8)	186 (29.3) ns	74 (32.3)
Diet and nutrition information	231 (44.7) 7.68***	123 (35.2)	318 (40.7) ns	36 (43.9)	143 (47.8) 9.12***	211 (37.2)	291 (39.4) 4.99**	46 (51.7)	265 (41.9) ns	89 (38.7)
Exercise Information	230 (44.5) ns	136 (39.0)	323 (41.3) 3.77*	43 (52.4)	147 (49.5) 9.69***	219 (38.5)	298 (40.3) 7.13***	49 (55.1)	267 (42.2) ns	100 (43.7)
Mental health counseling	127 (24.6) ns	79 (22.6)	180 (23.0) 3.36*	26 (32.1)	87 (29.3) 7.56***	119 (20.9)	168 (22.7) 3.38*	28 (31.5)	146 (23.1) ns	29 (25.8)
Family counseling	111 (21.5) ns	78 (22.4)	161 (20.6) 8.39***	28 (34.6)	70 (23.6) ns	119 (21.0)	143 (19.4) 23.79****	37 (42.0)	145 (23.0) ns	43 (18.7)
Counseling related to sexuality or intimacy	149 (28.8) ns	110 (31.7)	223 (28.6) 8.82***	36 (44.4)	96 (32.2) ns	163 (28.8)	209 (28.4) 9.81***	40 (44.4)	209 (33.1) 11.00***	49 (21.4)
Religious/spiritual counseling	62 (12.0) 3.74*	58 (16.6)	107 (13.7) ns	13 (15.9)	53 (17.8) 6.02**	67 (11.8)	103 (13.9) ns	15 (16.9)	94 (14.8) ns	26 (11.4)
Alcohol or drug abuse counseling	6 (1.2) 7.51***	14 (4.0)	18 (2.3) ns	2 (2.4)	12 (4.0) 6.00**	8 (1.4)	18 (2.4) ns	1 (1.1)	11 (1.7) 3.51*	9 (3.9)
Infertility information	130 (25.1) 10.84***	124 (35.5)	229 (29.3) ns	25 (30.5)	94 (31.5) ns	160 (28.2)	207 (28.0) 5.53**	36 (40.0)	197 (31.1) 2.98*	57 (25.0)
Infertility treatment/services	107 (20.9) 7.31***	100 (28.9)	187 (24.1) ns	19 (23.8)	76 (25.7) ns	130 (23.1)	174 (23.7) ns	26 (29.5)	146 (23.3) ns	61 (26.6)
Adoption services	157 (30.6) ns	103 (29.9)	234 (30.2) ns	25 (30.9)	83 (28.1) ns	177 (31.4)	220 (30.1) ns	30 (33.7)	206 (33.0) 6.96***	54 (23.6)
Complementary/ alternative health care services	162 (31.3) ns	110 (31.6)	249 (31.8) ns	23 (28.0)	108 (36.4) 5.15**	164 (28.8)	224 (30.4) 5.23**	38 (42.2)	198 (31.3) ns	72 (31.3)
Camps, retreats	225 (43.9) 4.67**	179 (51.4)	363 (46.7) ns	41 (51.3)	148 (50.2) ns	256 (45.3)	343 (46.7) ns	47 (52.8)	316 (50.2) 9.08***	87 (38.5)
Transportation assistance	44 (8.5) 7.34***	50 (14.3)	73 (9.3) 20.33****	21 (25.6)	43 (14.5) 6.18**	51 (8.9)	68 (9.2) 19.85****	22 (24.7)	58 (9.1) 6.59**	35 (15.3)
Child care	55 (10.8) 5. 51**	21 (6.1)	67 (8.7) ns	9 (11.5)	33 (11.4) 3.30*	43 (7.7)	71 (9.8) ns	5 (5.8)	53 (8.5) ns	23 (10.2)

**p*<.10; ***p*<.05; ****p*<.01; *****p*<.001
ns Not significant

relationship, (2) not employed, (3) not college graduates, (4) nonwhite, and (5) female were significantly more likely to report unmet needs (Table 4).

As summarized in Table 5, when statistically significant proportional differences in reporting unmet need were observed, younger survivors and survivors diagnosed at earlier ages reported more unmet need. Breast cancer survivors appeared less likely to report unmet need for cancer information and infertility information, whereas survivors of hematological and other malignancies appeared significantly more likely to report unmet need for cancer information and infertility information.

Survivors who indicated that they had no health problems appeared to be less likely to report unmet needs (Table 6). In most instances, unmet needs were significantly greater among respondents for whom health problems interfere with their lives. Survivors who had experienced a recurrence of their cancer were significantly more likely than those who had not to report unmet needs for assistance with health insurance and transportation (Table 6). With regards to self-reported health status, results indicated that survivors reporting excellent to very good health were less likely to report unmet needs.

Discussion

This report provides insight into various supportive care needs for young adult cancer survivors and suggests that many information and supportive care needs remain unmet, even for survivors who are years beyond their diagnosis and treatment. For instance, it is clear that AYA survivors want information about their cancer and that many are already locating and using this information. In contrast, findings suggest that AYAs are finding it more difficult to find age-appropriate resources. Thirty percent of respondents indicated that their need for age-appropriate Internet sites was unmet, and three fourths of respondents indicating need or desire for peer support programs suggested that they had yet to benefit from them.

To a large extent, AYAs' needs and desires for psychological support and counseling and guidance around

Table 5 Proportional differences (frequency, percent) in unmet service needs by age at study, age at diagnosis, and type of cancer (chi-square)

	Current age		Age at diagnosis				Type of cancer		
	18–29 (*n*=344)	30–40 (*n*=490)	15–19 (*n*=149)	20–24 (*n*=197)	25–29 (*n*=226)	30–35 (*n*=289)	Breast (*n*=147)	Hematologic (*n*=453)	Other (*n*=278)
Information about cancer	40 (11.6) 8.61***	31 (6.0)	22 (14.8) 10.4**	14 (7.1)	17 (7.6)	18 (6.2)	3(2.0) 11.27***	41 (9.1)	28 (11.8)
Internet sites	113 (32.9) ns	147 (28.4)	52 (35.1) ns	66 (33.5)	66 (29.2)	75 (26.0)	27 (18.4) 21.26****	163 (36.1)	58 (24.4)
Assistance with health insurance, disability or social security	114 (33.2) 9.62***	122 (23.6)	46 (31.1) ns	67 (34.0)	56 (24.9)	67 (23.2)	32 (21.8) ns	120 (26.7)	72 (30.3)
Mental health counseling	95 (27.7) 4.32**	111 (21.5)	38 (25.7) ns	52 (26.5)	46 (20.4)	70 (24.2)	29 (19.7) ns	102 (22.7)	68 (28.6)
Alcohol or drug abuse counseling	13 (3.8) 5.39**	7 (1.4)	6 (4.0) ns	5 (2.6)	4 (1.8)	5 (1.7)	4 (2.7) ns	11 (2.4)	4 (1.7)
Infertility information	143 (41.6) 41.42****	109 (21.2)	64 (43.0) 33.00****	74 (37.6)	55 (24.4)	59 (20.6)	25 (17.0) 14.12***	148 (32.9)	76 (32.1)
Infertility treatment/services	107 (31.6) 16.88****	99 (19.3)	56 (38.1) 25.11****	48 (24.6)	55 (24.7)	47 (16.4)	29 (19.7) ns	111 (25.0)	64 (27.0)
Adoption services	109 (32.2) ns	149 (29.0)	60 (40.3) 11.35***	53 (27.6)	72 (32.4)	73 (25.4)	53 (36.1) ns	132 (29.7)	69 (29.2)
Complementary/alternative health care services	122 (35.6) 4.27**	149 (28.9)	48 (32.2) ns	65 (33.2)	61 (27.1)	97 (33.7)	42 (28.8) ns	155 (34.4)	66 (27.8)
Camps, retreats	178 (52.2) 5.60**	225 (43.9)	72 (49.3) ns	95 (48.7)	101 (44.9)	134 (46.9)	64 (44.4) 5.01*	228 (51.0)	101 (42.6)
Transportation assistance	44 (12.8) ns	49 (9.5)	18 (12.2) ns	25 (12.8)	26 (11.5)	24 (8.3)	7 (4.8) 8.03**	58 (12.9)	23 (9.7)
Child Care	19 (5.6) 7.81***	57 (11.3)	12 (8.3) ns	12 (6.2)	23 (10.4)	29 (10.3)	14 (9.7) ns	44 (9.9)	17 (7.3)

*$p<.10$; **$p<.05$; ***$p<.01$, ****$p<.001$

ns Not significant

Table 6 Proportional differences (frequency, percent) in unmet service needs by self-reported health status, recurrence status, and extent of interference with daily activities (chi-square)

	Recurrence		Interference			Health status		
	Yes (*n*=154)	No (*n*=723)	No health problems (*n*=381)	Minimal interference (*n*=254)	Substantial interference (*n*=238)	Excellent/ very good (*n*=577)	Good (*n*=234)	Fair/ poor (*n*=67)
Information about cancer	12 (7.8) ns	65 (9.0)	24 (6.3) 9.56***	21 (8.3)	32 (13.6)	40 (7.0) 8.00**	27 (11.6)	10 (15.2)
Internet sites	55 (35.7) 2.81*	208 (28.9)	97 (25.6) 7.16**	83 (32.7)	83 (35.0)	160 (27.8) 6.15**	76 (32.5)	27 (41.5)
Diet and nutrition information	54 (35.1) ns	302 (42.1)	141 (37.3) 4.82*	106 (41.7)	109 (46.2)	213 (37.2) 10.58***	116 (49.6)	27 (40.9)
Exercise Information	64 (41.6) ns	304 (42.3)	138 (36.6) 9.68***	115 (45.3)	115 (48.5)	214 (37.3) 16.33****	120 (51.3)	34 (52.3)
Assistance with health insurance, disability or social security	53 (34.4) 4.50**	187 (26.0)	90 (23.7) 5.76*	74 (29.2)	76 (32.2)	155 (27.0) ns	65 (27.9)	20 (30.3)
Family counseling	36 (23.7) ns	155 (21.6)	75 (19.7) 7.12**	50 (19.8)	66 (28.2)	107 (18.7) 12.45***	61 (26.2)	23 (34.8)
Counseling related to sexuality or intimacy	49 (32.0) ns	211 (29.4)	92 (24.4) 31.14****	64 (25.2)	104 (44.3)	143 (25.0) 21.50****	97 (41.5)	20 (30.8)
Religious/spiritual counseling	23 (15.0) ns	98 (13.6)	45 (11.9) 12.78***	27 (10.6)	49 (20.8)	66 (11.5) 8.17**	44 (18.9)	11 (16.9)
Infertility treatment/ services	36 (23.4) ns	173 (24.3)	73 (19.4) 13.81***	60 (23.8)	76 (32.6)	131 (22.9) ns	65 (28.3)	13 (20.3)
Adoption services	48 (31.4) ns	214 (30.1)	91 (24.3) 12.85***	84 (33.5)	87 (37.2)	171 (30.0) ns	73 (31.5)	18 (28.6)
Camps, retreats	66 (43.4) ns	341 (47.8)	152 (40.4) 13.65***	125 (49.4)	129 (55.4)	240 (42.0) 16.891****	129 (56.1)	38 (58.5)
Transportation assistance	27 (17.6) 9.14***	67 (9.3)	35 (9.2) 19.77****	16 (6.3)	43 (18.2)	44 (7.6) 21.25****	36 (15.5)	15 (23.1)
Child Care	15 (10.0) ns	62 (8.8)	25 (6.7) 5.97**	22 (8.8)	29 (12.6)	40 (7.1) 7.14**	28 (12.2)	9 (13.8)

*$p<.10$; **$p<.05$; ***$p<.01$; ****$p<.001$
ns Not significant

self-care (i.e., diet and nutrition, exercise and fitness), health care, and family care remain unmet. In addition, these data suggest that the transition from adolescence into adulthood is a critical time of need, as younger respondents (18–29 years olds) and those diagnosed at younger ages were most likely to signify greater unmet need when compared to older respondents and those diagnosed in their later 20s and 30s. These findings are consistent with an emergent literature on “emerging adulthood” [3]. Nearing the end of or having completed high school, young people turn their attention to “what's next,” particularly employment, further formal education, and perhaps establishing an independent living situation and intimate relationships with peers. Respondents who were not employed, less formally educated, and not yet in an established marital or long-term committed relationship were more likely to report unmet needs. Thus, investments of time and resources for program and service delivery during this period of transition and emerging adulthood may contribute to satisfaction of AYA’s needs and perhaps the enhancement of their psychosocial functioning and quality of life.

Unmet needs also appeared to have a strong association with physical health status. Respondents who either perceived their health to be less than optimal or reported that health problems interfered with their lives also were more likely to indicate unmet needs and desires for information and services. Medical follow-up and management of late effects may reduce survivors' actual needs for services and possibly the proportion of those indicating that their needs are unmet.

Implications for provision of psychosocial care

The findings reported here may be useful in guiding practitioners and program developers as to where and to whom to target their efforts in terms of referral or development of supportive care programs, services, and resources. For instance, the proportion of young adults reporting unmet needs with regards to camp and retreat programs, addressing issues of sexuality, intimacy and infertility, and family counseling suggest that these may be underdeveloped areas of service delivery. Psychosocial assessments and planning with this population should thus include these issues of concern. Also, with Internet usage so prevalent among teenagers and young adults, development of age-appropriate web-based resources has great potential. Finally, while only a small percentage of respondents indicated need for alcohol or drug abuse counseling, clinicians ought not to overlook the observation that for some AYA survivors, substance use and potential abuse is a salient issue, just as it is for many young adults who have never had cancer.

Findings reported here reflect the perspective of cancer survivors with select characteristics and may not represent the universe of adolescent and young adult cancer survivors in the US. The study is limited in that only young adults actively pursuing health information on the Internet or registered to receive mailed announcements through patient service and advocacy organizations became informed of the study and elected to complete it. The number of people who may have seen announcements about the survey but elected not to complete it is unknown. Use of a web-based interface may have precluded individuals without Internet access to hear about or access the survey, although a recent Kaiser Family Foundation study found that 90% of teens and young adults (age 15–24) have gone online, 75% of young people have Internet access at home, and 75% have searched the Internet for health information [23]. Yet, generalizability is limited in that the sample was disproportionately female, Caucasian, and well educated. Finally, the presentation of only bivariate analytic results restricts the conclusions that may be derived from this report. For example, absent of a summary or composite score derived from an established needs assessment or index with established validity and reliability, the analyses reported here did not examine the extent to which certain statistically significant associations may in fact be confounded by other significant variables that were not tested simultaneously in multivariate statistical models. For instance, significant differences in unmet needs across type of cancer, marital status, occupational status, or level of education may in fact be accounted for by age at study or age at diagnosis. Future investigations should better examine the potential effects of health status, type of cancer, and type of treatment, as well as race/ethnicity, class, and socioeconomic status, as these factors may distinguish young adult survivor needs.

This descriptive study represents one of the first published reports to document empirically the unique experiences and needs of cancer survivors diagnosed in later adolescence and young adulthood. Future investigations that assess the extent to which satisfying service needs is associated with psychosocial adjustment or quality of life outcomes will further advance our understanding of outcomes and needs for this age-specific population.

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