Support Care Cancer (2008) 16:1353–1360
DOI 10.1007/s00520-008-0435-z

ORIGINAL ARTICLE

Information and service needs for young adult cancer patients

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Received: 2 October 2007 / Accepted: 6 March 2008 / Published online: 2 April 2008

Abstract

Background Young adulthood is a time of increased vulnerability to stress and presents young adult cancer patients and off-treatment survivors with major developmental challenges above and beyond those faced by their peers. The intent of this study was to examine supportive care needs and preferences among young adult cancer patients.

Methods Two hundred and seventeen young adults aged 18–40 years and diagnosed with cancer between the ages of 15–35 completed an online survey. Adapted from prior research on young adult survivors of childhood cancer, 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 While young adult patients demonstrate a high demand for information and assistance regarding diet and nutrition, exercise, fertility options, complementary and alternative services and assistance with health insurance, 40–50% of patients report that these needs are unmet. More than 50% of respondents who indicated a need or desire for camp programs and retreats, counseling or guidance related to sexuality, counseling for family members, infertility treatment and adoption services, transportation assistance, child care and alcohol or drug abuse counseling also indicated that these needs were unmet. Younger respondents (18–29 years olds) were significantly more likely to indicate unmet needs for the supportive care services assessed here.

Conclusion Findings serve as recommendations as to when and to whom to target delivery of supportive care services.

Keywords Young adult · Needs assessment · Cancer · Psychosocial · Support services

Introduction

Progress has been achieved in the treatment of cancer over the past 30 years as evidenced by improvements in mortality and survival rates in the United States. However, these improvements observed for the US population as a whole are not experienced as such by adolescent and young adult (AYA) patients. Cancer incidence among adolescents and young adults age 15–29 has risen faster, on an annual basis, than that of cancer diagnosed in younger children and older adults [2]. Furthermore, improvements in mortality rates and 5-year survival rates for adolescents and young adults have been below average when compared to the rest of the population [3, 9].

Recently, the National Cancer Institute (NCI), along with clinicians and advocacy organizations serving young adult patients and survivors, called for a better understanding of the health care and psychosocial needs of this age-specific population [12]. The first recommendation to come from the NCI's *Report of the Adolescent and Young Adult Oncology Progress Review Group* was to "identify the characteristics that distinguish the unique cancer burden in the AYA patient" (p. ii). The NCI report defines the AYA population as comprising individuals aged 15 through 39 years at cancer diagnosis "since this entire age range continues to experience a relative lack of improvement in survival and because a chief concern of AYAs with cancer is the lack of a 'home' in research and health care" (p.3).

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Young adulthood is a time of increased vulnerability to stress and presents cancer patients with major developmental challenges above and beyond those faced by other young people [11]. For example, negotiating interpersonal relationships (including intimacy and forming families), as well as educational and employment decisions and achievements, often requires a focus, perhaps for the first time, on the medical, social, cognitive, or psychologic effects of cancer treatment. Yet, empirical studies of cancer patients have not distinguished the health and supportive care needs of AYAs from those of pediatric or older adult populations. Most needs assessments in oncology focus on needs as they relate to a specific type of cancer [5, 6, 8, 19], type or location of treatment [20, 21] or time at which cancer was diagnosed [6, 21]. They most often involve homogenous samples of older adult patients or samples inclusive of patients across a wide range of ages. Few report on post-treatment needs [7] or the extent of unmet needs [17, 18]. Among these studies and others [4, 10, 20], most rely on newly developed or standardized instruments to assess needs related to information, education and communication, concrete services like transportation or assistance with activities of daily living, patient care, and psychological support. In some instances, health or supportive care needs are inferred from standardized measures of physical health status and psychosocial outcomes [7, 21]. None of these studies, however, assess needs as they relate to an age-specific population of AYA patients. Thus, the intent of the study reported here was to examine supportive care needs and preferences among young adult cancer patients, and the extent to which these needs or desires for services are being met. The study has potential to guide the delivery of services in that findings suggest when along a continuum of care young adults need or desire 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. In coordination with the Lymphoma Research Foundation (LRF), the principal investigator telephoned or emailed staff from patient education and support service agencies from across the United States and Canada, described the study and requested assistance in identifying and recruiting young adult cancer patients and survivors to the study (See Appendix for sources that referred participants to the survey). These organizations were known for providing services specifically to adolescent and 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 the Lymphoma Research Foundation 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 40 years at the time of study, and diagnosed with any form of cancer between the ages of 15 and 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 SPSS 15.0. All procedures were approved by the principal investigator's Institutional Review Board.

Instruments

Adapted from prior research on young adult survivors of childhood cancer [4, 22], the principal investigator administered a self-report questionnaire to explore the information and supportive care needs of young adult cancer patients and survivors. Respondents were presented with a list of 17 needs and 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,

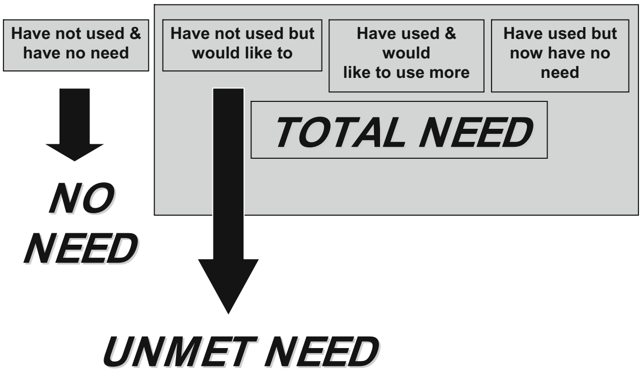

Fig. 1 Response categories distinguishing "Need" from "Unmet Need"

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 to suggest “Unmet Need,” in that endorsement of this item 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” were combined to 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 age at diagnosis, years since diagnosis, self-rated health status, recurrence of cancer, health problems attributed to cancer, and the extent to which health problems interfere with daily activities, and type of cancer.

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. Due to the disproportionately small number of male respondents (12.9%), gender was not included in subsequent analyses. 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 ($n=4$) and thyroid cancer ($n=3$) were excluded from further analyses because these two cancers and their treatments are so unlike the cancers included in the three categories. Respondents also indicated whether or not they had health problems and how much those health problems interfered with daily activities. The response categories for the variable indicating interference with daily activities were constructed such that the response value “none/a little interference” was assigned to those respondents indicating no health problems in combination with respondents who indicated health problems and either no interference or a little interference with daily activities. All others endorsed “some,” or “a lot.”

Categorizations of age (18–29, 30–40) and age at diagnosis (15–19, 20–24, 25–29, 30+) 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” [16]. For purposes of this study, ages 18–29 demarcates one “young adult” age category. A second 30- to 40-year-old age category is included in this study based on the NCI’s inclusion of this age range in their *Adolescent and Young Adult Oncology Progress Review Group Report* [12]. As for age at diagnosis categories, the American Cancer Society’s annual *Cancer Facts and Figures* [1] traditionally distinguishes pediatric cases as ranging in age from 0 to 14 years, and the NCI SEER database routinely utilizes 5-year increments in most analyses [14]. Due to sample size, three ages at diagnosis categories are presented here (15–24, 25–29, and 30–35). For all bivariate analyses, Chi-square parameters were evaluated and statistically significant differences reported where $p<0.05$.

Results

A total of 217 patients completed the entire survey, including all questions related to service needs and demographics. Survey respondents were, on average, 31.3 years old (SD=5.4) and diagnosed at an average age of 28.5 years (SD=5.1). Approximately 85% of the sample was female. 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 (98.1%). Furthermore, large proportions of these young people reported a desire or need for information and guidance about exercise and physical fitness (86.1%), diet and nutrition (89.4%), and help with understanding health insurance, disability insurance and social security (80.8%). Ninety-five percent of respondents have used or want to use Internet sites that offer cancer education or support that is appropriate for young adult cancer patients. Upwards of two thirds of this study sample wanted mental health counseling (76.3%), complementary/alternative health services, including herbal treatment, acupuncture, biofeedback, meditation, visualization or guided imagery (80.5%), information about infertility and options for having children (65.7), and information about camp programs or retreats (78.5%). A smaller proportion of young adults indicated the need for infertility treatment (40.9%), adoption services (43.5%), counseling or guidance related to sexuality and intimacy (57.3%), family counseling (53.4%), and religious/spiritual support

Table 1 Sample descriptives (n=217)

	Freq (%)
Gender	
Male	28 (12.9)
Female	186 (85.7)
Education	
Less than high school graduate	6 (2.8)
High school grad/GED equivalent, some college	80 (36.9)
College Graduate/Post-graduate education	128 (59.0)
Occupational status	
Employed[a]	137 (63.1)
Unemployed[b]	78 (35.9)
Racial/ethnic background	
White/Caucasian	178 (82.0)
Black/African American	8 (3.7)
Asian	10 (4.6)
Hispanic/Latin	9 (4.1)
Native American	1 (0.5)
Marital/relationship status	
Married or committed relationship	137 (63.1)
Not currently married	77 (35.5)
Average Household Income (SD)[c]	$51,493
Range: $18,473–$132,373	($17,951)

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

[a] Includes compensated employment, homemaker or student

[b] Includes 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.

(49.8%). Needs for child care (17.5%), transportation assistance (27.8%), and alcohol or drug abuse counseling (3.8%) were relatively small.

Among respondents reporting needs were subsets of individuals who indicated that their needs had not been met. Of the total 205 respondents indicating need for information about cancer, 10% (n=21) suggested that this need had been unmet (Table 3). Among patients indicating needs for age-appropriate Internet sites, diet and nutrition information, exercise information, complementary and alternative services, assistance with health insurance, mental health counseling, infertility information, and religious/spiritual counseling, 25–50% suggested that these needs remain unmet. Needs for camp programs and retreats, counseling related to sexuality or intimacy, family counseling, adoption services, infertility treatment/services, transportation assistance, child care and alcohol/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 differences in reporting unmet needs

The following results compare proportions of patients whose responses indicated unmet need ("Have not used but would like to") to those whose responses indicated need but also that the need had been met ("Have used and no longer need," "Have used and would like to use more"). For the most part, the extent of reporting unmet needs did not differ across most sociodemographic and medical/health status variables. Statistically significant differences ($p<0.05$) are reported below.

For the 200 respondents indicating a need for age-appropriate Internet sites, 33% of patients with less than a college education, as compared to 19.5% of college-educated patients, reported this need as unmet ($X^2=5.07$, $p<0.05$). With regard to the need for family counseling, 58.3% of non-white respondents, compared to 30.1% of White respondents, indicated that this need was unmet ($X^2=7.56$, $p<0.01$). Among the 85 respondents indicating a need for infertility treatment/services, significantly more unmarried patients (34.7 to 19.5%) reported that this need was unmet ($X^2=5.76$, $p<0.05$). In addition, when compared to older patients (age 30–40 years), significantly larger proportions of younger patients (age 18–29 years) indicated that their needs for infertility information (37.9%), infertility treatment/services (40.0%), and adoption services (47.7%) were unmet (See Table 4).

Table 2 Medical/Health status characteristics (n=217)

	Freq (%)
Type of cancer	
Hodgkin's disease	32 (14.7)
Non-Hodgkin's Lymphoma	29 (13.4)
Leukemia	12 (5.5)
Breast Cancer	103 (47.5)
Other soft tissue sarcoma, carcinoma, germ cell tumor[a]	34 (15.7)
Excluded[b]	7 (3.2)
Health status	
Excellent	30 (13.8)
Very good	65 (30.0)
Good	75 (34.6)
Fair	42 (19.4)
Poor	5 (2.3)
Recurrence	
No	147 (67.7)
Yes	69 (31.9)
Cancer-related health problems interfere with daily activities	
No health problems reported	64 (29.6)
None	10 (4.6)
A little	34 (15.7)
Some	69 (31.8)
A lot	39 (18.0)

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

[b] Brain tumors, thyroid cancer

Table 3 Information and service needs (n=210), frequency (percent)

	Total need	Unmet need
Information about cancer	205 (98.1)	21 (10.2)
Internet sites	200 (95.2)	53 (26.5)
Diet and nutrition information	186 (89.4)	85 (45.7)
Exercise information	180 (86.1)	89 (49.4)
Complementary/alternative health care services	169 (80.5)	84 (49.7)
Assistance with health insurance, disability or social security	168 (80.8)	68 (40.5)
Camps, retreats	164 (78.5)	121 (73.8)
Mental health counseling	158 (76.3)	61 (38.6)
Infertility information	138 (65.7)	59 (42.8)
Counseling related to sexuality or intimacy	118 (57.3)	97 (82.2)
Family counseling	111 (53.4)	72 (64.8)
Religious/spiritual counseling	104 (49.8)	34 (32.7)
Adoption services	90 (43.5)	78 (86.7)
Infertility treatment/services	85 (40.9)	53 (62.4)
Transportation assistance	58 (27.8)	40 (68.9)
Child care	36 (17.5)	23 (63.9)
Alcohol or drug abuse counseling	8 (3.8)	6 (75.0)

"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."

Medical/health status differences in reporting unmet needs

As summarized in Tables 4 and 5, unmet needs were reported for several subgroups depending upon type of cancer, age at diagnosis, recurrence status, health status, and extent to which existing health problems interfere with daily activities. The proportions of patients reporting unmet needs for age-appropriate Internet sites, counseling related to sexuality or intimacy, and availability of infertility treatment/services differed by type of cancer (Table 4). In addition, patients diagnosed at younger ages (15–24 years) were less likely to report the need for sexuality counseling as being unmet, and more likely to report unmet need with regard to availability of infertility treatment/services. Unmet need for infertility information also appeared significantly different across age groupings, with 25- to 29-year-olds being most likely to indicate this need as going unmet.

Patients who had experienced a recurrence of their cancer were significantly less likely than those who had not to report unmet needs for mental health counseling, infertility information, and camp programs (Table 5). As patients reported the extent to which existing health problems interfered with their lives, there were significant within-group differences in reporting unmet needs for family counseling, counseling related to sexuality/intimacy, complementary/alternative health services, and transportation assistance. Patients reporting minimal interference were less likely to report these unmet needs. Among the 97 respondents indicating unmet need for counseling related to sexuality or intimacy, almost 60% of respondents reporting moderate interference of health problems in their lives indicated this need as unmet compared to 43% of patients indicating minimal interference and 37% of patients reporting maximal interference. Also, for the 78 respondents indicating need for adoption services, patients reporting excellent/very good health were significantly less likely to report that this need was unmet.

Discussion

This report provides insight into various supportive care needs for young adult cancer patients and suggests the

Table 4 Statistically significant proportional differences (%) in reporting unmet service needs by age at study, age at diagnosis, and type of cancer (Chi-square, p value)

	Current Age		Age at diagnosis			Type of Cancer		
	18–29 (n=66)	30–40 (n=140)	15–24 (n=45)	25–29 (n=51)	30–35 (n=109)	Hematologic (n=72)	Breast (n=103)	Other (n=34)
Internet sites	20 (30.3) ns	31 (22.1)	14 (31.1) ns	9 (17.6)	27 (24.8)	27 (37.0) 9.53**	17 (16.5)	9 (26.5)
Counseling related to sexuality or intimacy	26 (40.0) ns	70 (51.1)	14 (31.1) 6.64*	25 (50.0)	57 (53.8)	26 (36.6) 8.52*	58 (57.4)	13 (38.2)
Infertility information	25 (37.9) 4.54*	33 (23.6)	15 (33.3) 9.19**	21 (41.2)	21 (19.3)	20 (27.4) ns	26 (25.2)	13 (38.2)
Infertility treatment/services	26 (40.0) 11.45**	25 (18.0)	16 (35.6) 8.05*	16 (32.0)	18 (16.7)	14 (19.4) 7.81*	24 (23.5)	15 (44.1)
Adoption services	31 (47.7) 4.29*	45 (32.6)	21 (46.7) *N*s	21 (42.0)	33 (30.8)	22 (31.0) ns	42 (41.2)	14 (41.2)

*p<0.05; **p<0.01

Table 5 Statistically significant proportional differences (%) in reporting unmet service needs by recurrence status, extent of interference with daily activities, and self-reported health status (Chi-square)

	Recurrence		Interference			Health status		
	Yes ($n=66$)	No ($n=143$)	Minimal ($n=107$)	Moderate ($n=64$)	Maximal ($n=38$)	Excellent/Very good ($n=94$)	Good ($n=71$)	Fair/Poor ($n=44$)
Mental health counseling	12 (18.2) 6.09*	49 (35.0)	28 (26.4) ns	18 (29.0)	15 (39.5)	28 (30.1) ns	20 (28.6)	13 (29.5)
Family counseling	19 (29.2) ns	53 (37.3)	27 (25.7) 8.01*	27 (42.2)	18 (47.4)	25 (26.9) 5.93***	26 (36.6)	21 (47.7)
Counseling related to sexuality or intimacy	28 (43.1) ns	69 (49.3)	45 (42.9) 6.30*	37 (59.7)	14 (36.8)	40 (43.5) ns	36 (51.4)	21 (47.7)
Infertility information	10 (15.2) 8.41**	49 (34.3)	30 (28.0) ns	16 (25.0)	13 (34.2)	24 (25.5) ns	20 (27.8)	15 (34.1)
Adoption services	28 (43.1) ns	50 (35.5)	32 (30.5) 5.05***	28 (44.4)	18 (47.4)	22 (23.7) 15.04**	32 (45.7)	24 (54.5)
Complementary/alternative health care services	22 (33.3) ns	62 (43.4)	34 (31.8) 6.79*	30 (46.9)	20 (52.6)	31 (33.0) ns	32 (44.4)	21 (47.7)
Camps, retreats	29 (44.6) 6.62*	91 (63.6)	59 (55.1) ns	39 (61.9)	23 (60.5)	56 (59.6) ns	39 (54.2)	26 (60.5)
Transportation assistance	12 (18.5) ns	27 (18.9)	13 (12.3) 6.76*	17 (26.6)	10 (26.3)	15 (16.0) ns	16 (22.2)	9 (20.9)

*$p<0.05$; **$p<.01$; ***$p<0.10$

extent to which these needs may remain unmet. It is clear that young adult patients want information about their cancer, and that many are already locating and using this information. However, the extent to which existing information is age-appropriate or produced at a level of literacy that makes it accessible to persons of varied education levels may be at issue, particularly as respondents with less education were more likely to indicate that their need for age-appropriate Internet resources was unmet. There also appears to be a high demand for information and assistance with regard to diet and nutrition, exercise, infertility, complementary and alternative health services and assistance with health insurance, disability, and social security. Findings indicate that these needs are going unmet for approximately 40–50% of the patients needing or desirous of this support. To a large extent, these young adult patients also are expressing needs for psychological counseling for self and family, peer support, and religious/spiritual counsel. Again, data suggest that these needs are going unmet for 35–80% of those patients indicating need or desire for these services (See Table 3). Furthermore, there was evidence of racial disparity in this study, with racial minority patients being significantly more likely to report that their need for family counseling was unmet.

While the expressed need for concrete services (transportation assistance, child care, alcohol or drug abuse counseling) was relatively small, these needs were reported to be unmet by most patients indicating need for these services. It is notable that in this sample of moderate to upper income respondents the need for concrete services (transportation, child care) did not differ according to educational attainment or occupational status, thereby suggesting that need for these services may not be limited to patients and families of low socioeconomic status. Finally, while only a small percentage of respondents indicated need for alcohol or drug abuse counseling, clinicians ought not overlook the possibility that for some cancer patients substance abuse may be a salient issue just as it is for many young adults who have never had cancer.

Findings here also suggest that younger respondents (18- to 29-years-olds) and those diagnosed at younger ages may be more amenable to, or desirous of, the supportive care services related to family planning information and services. It may be that older young adults in their 30s are beyond these needs or else find them met within the context of their own families. Thus, investments of time and resources for program and service delivery may be of greatest benefit to older teens and young adults in their 20s who may be on the verge of anticipating use of these services if they have not done so already.

Although certain unmet needs appeared to differ across three cancer type categories, it is possible that these differences were confounded by age and gender, as well as by the type and severity of treatment received by patients of these vastly different types of cancer. Indeed, there were statistically significant age differences across the three cancer type categories (mean ages for hematologic cancer patients, breast cancer patients, and soft tissue/solid tumor patients were 29.3, 33.8, and 28.3 years, respectively; $F=24.82$, $p<0.001$). Also, the significantly larger proportion of breast cancer patients indicating unmet need for counseling related to sexuality may in fact suggest that women are more desirous or in need of this type of counseling.

Finally, data suggest that health status and physical functioning may be associated with the extent to which patients experience their needs as being met. Patients indicating minimal effect of health problems on daily activities were less likely than others reporting more significant impacts of cancer on their lives to report unmet needs. It is reasonable to suggest that patients with more health problems have greater needs, thereby also increasing the likelihood that more of these individuals also experience these needs as unmet.

This study reflects the perspectives of young adult cancer patients with select characteristics and may not represent the universe of adolescent and young adult cancer patients in the United States. 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 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 [13]. Yet, generalizability is limited in that the sample was disproportionately female, Caucasian and well-educated, and no objective health status or cancer treatment information was available. A dearth of male respondents prohibited adequate gender comparisons, and the selection of a needs measure with nominal response categories and without established psychometric properties limited the analyses reported here to descriptive bivariate associations that can only suggest possible contributors to unmet needs in this population. Also, the proportions of breast cancer patients (48%), leukemia and lymphoma patients (34%) and patients diagnosed with a variety of soft tissue cancers and solid tumors (16%) contrasted with proportions found in the general population (22%, 7% and 71%, respectively) [15]. Future investigations should better examine the potential simultaneous effects of health status, type of cancer and type of treatment, as well as gender, race/ethnicity and socioeconomic status, as these factors may distinguish young adult patient needs.

This descriptive study represents one of the first published reports to document empirically the unique experiences and needs of young adults with cancer. 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 proportions of young adults reporting unmet needs with regards to camp and retreat programs, addressing issues of sexuality and intimacy, 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. Future investigations that assess the extent to which satisfying services needs is associated with psychosocial adjustment or quality of life outcomes will further advance our understanding of this age-specific population.

Acknowledgments Thank you to the Lymphoma Research Foundation (LRF) for their financial support, and to LRF staff members Ms Jennifer Mills, MSW and Ms Tammy Weitzmann, MSW for their contributions of time and effort to this work. Furthermore, the success of this project is also due to the efforts of Ms Jodi Sax, Dr Karen Albritton, MD, Dr Stuart Kaplan, MD, and the staff members of numerous cancer support organizations that directed respondents to the online survey. Finally, I would like to express appreciation to the 1,500 young adults who completed the online survey, and recognize the many “young adults” over the age of 39 who did not qualify for this study but wrote to us and expressed the need for research into how cancer has affected their lives as well.

Appendix. Alphabetical listing of referring organizations

Organizations
American Cancer Society
Camp Māk-a-Dream
Cancer Care Resources (Portland, OR)
Cancer Survivors Unite
Fertile Hope
First Descents
Gilda’s Club (Detroit Metro, NYC)
Global Campaign for Cancer Survivorship
HopeLab
Lance Armstrong Foundation
Leukemia & Lymphoma Society (Portland, OR)
Lymphoma Research Foundation
Minnie Pearl Foundation
NY Lifelab
Planet Cancer
Realtime Cancer
Steps for Living
Testicular Cancer Resource Center/TC-Net
Ulman Family Fund for Young Adults
Vital Options
Working Against Cancer
Young Survival Coalition

References

1. American Cancer Society (2006) Cancer facts and figures 2006. American Cancer Society, Atlanta
2. Bleyer A, Albritton K (2003) Special considerations for the young adult and adolescent. In: Kufe DW, Pollock RE, Weichselbaum R (eds) Cancer medicine. BC Decker, Hamilton, Ontario, Canada, pp 2414–2422
3. Bleyer A, Viny A et al (2006) Cancer epidemiology in older adolescents and young adults 15 to 29 years: SEER incidence and survival, 1975–2000. National Cancer Institute, Bethesda
4. Bonevski B, Sanson-Fisher R et al (2000) Evaluation of an instrument to assess the needs of patients with cancer. Cancer 88: 217–225
5. Duke JM, Treloar CJ et al (2005) Evaluation of a revised instrument to assess the needs of men diagnosed with prostate cancer. Support Care Cancer 13(11):895–903
6. Galloway S, Graydon J et al (1997) Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. J Adv Nurs 25(6):1175
7. Ganz PA, Schag CA et al (1992) The CARES: a generic measure of health-related quality of life for cancer patients. Qual Life Res 1:19–29
8. Gustafson DH, Taylor JO et al (1993) Assessing the needs of breast cancer patients and their families. Management in Health Care 2(1):6–17
9. Hampton T (2005) Cancer treatment's trade-off. J Am Med Assoc 294:167–168
10. Harris KA (1998) The informational needs of patients with cancer and their families. Cancer Pract 6(1):39
11. Hobbie WL, Stuber M et al (2000) Symptoms of posttraumatic stress in young adult survivors of childhood cancer. J Clin Oncol 18(24):4060–4066
12. National Cancer Institute (2006) Closing the gap: Research and care imperatives for adolescents and young adults with cancer. Report of the adolescent and young adult oncology progress peview group. US Department of Health and Human Services, National Institutes of Health, National Cancer Institute; and the LiveStrong Young Adult Alliance, Bethesda
13. Rideout V (2001) Generation Rx.com: How young people use the internet for health information. Menlo Park, CA., Henry J. Kaiser Family Foundation
14. Ries LAG, Harkins D et al (2006) SEER Cancer Statistics Review, 1975–2003
15. Ries LAG, Melbert D et al (2007). Estimated Number of Cancer Survivors in the US on January 1, 2004 by Site. SEER Cancer Statistics Review, 1975–2004
16. Rowland JH (1990) Developmental stage and adaptation: Adult model. In: Holland JC, Rowland JH (eds) Handbook of psychooncology, Chapter 3. Oxford University Press, New York, NY
17. Sanson-Fisher R, Girgis A et al (2000) The unmet needs of cancer patients. Cancer 88(1):226–237
18. Siegel K, Mesagno FP et al (1992) Reducing the prevalence of unmet needs for concrete services of patients with cancer. Evaluation of a computerized telephone outreach system. Cancer 69(7):1873–1883
19. Steginga SK, Occhipinti S et al (2001) The supportive care needs of men with prostate cancer. Psycho-Oncology 10(1):66–75
20. Tamburini M, Gangeri L et al (2000) Assessment of hospitalised cancer patients' needs by the Needs Evaluation Questionnaire. Ann Oncol 11(1):31–37
21. Whelan BM, Mohide EA et al (2000) The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. Cancer 80(8):1518–1524
22. Zebrack BJ, Chesler MA (2000) Managed care: the new context for social work in health care—Implications for survivors of childhood cancer and their families. Soc Work Health Care 31(2):89–104