Original Article

Psychosocial Service Use and Unmet Need Among Recently Diagnosed Adolescent and Young Adult Cancer Patients

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BACKGROUND: Adolescents and young adults (AYAs) with cancer demonstrate biomedical risks and psychosocial issues distinct from those of children or older adults. In this study, the authors examined and compared the extent to which AYAs treated in pediatric or adult oncology settings reported use of, and unmet need for, psychosocial support services. **METHODS:** Within 4 months of initial cancer diagnosis, 215 AYAs ages 14 to 39 years (99 from pediatric care settings and 116 from adult care settings; 75% response rate) were assessed for reporting use of information resources, emotional support services, and practical support services. Statistical analyses derived odds ratios and 95% confidence intervals for service use and unmet needs after controlling for race, employment/school status, sex, relationship status, severity of cancer, treatment, and treatment-related side effects. **RESULTS:** AYAs ages 20 to 29 years were significantly less likely than teens and older patients ages 30 to 39 years to report using professional mental health services and were significantly more likely to report an unmet need with regard to cancer information, infertility information, and diet/nutrition information. Compared with teens who were treated in pediatric facilities, AYAs who were treated in adult facilities were more likely to report an unmet need for age-appropriate Internet sites, professional mental health services, camp/retreats programs, transportation assistance, and complementary and alternative health services. **CONCLUSIONS:** Substantial proportions of AYAs are not getting their psychosocial care needs met. Bolstering psychosocial support staff and patient referral to community-based social service agencies and reputable Internet resources may enhance care and improve quality of life for AYAs. *Cancer* 2013;119:201-14. © 2012 American Cancer Society.

KEYWORDS: psychosocial, young adult, supportive care, adolescent.

INTRODUCTION

When adolescents and young adults (AYAs) are diagnosed with cancer, issues like premature confrontation with mortality, changes in physical appearance, disruptions in school or work, increased dependence on parents, financial challenges, loss of reproductive capacity, and health-related concerns about the future are particularly distressing.[1-4] Disease and treatment confound AYAs' abilities to successfully achieve age-related developmental tasks, such as establishing autonomy and making independent decisions about employment, education, relationships, and starting a family.[3,5,6] All of these stressors may interfere with adherence to therapy[4,7,8] and ultimately impact emotional and social maturation.[5]

Emerging evidence suggests that the biomedical risks and psychosocial issues for AYAs are distinct from those of both pediatric and older adult populations and that AYA patients with cancer may be served inadequately or inappropriately by existing cancer services.[9-11] For example, disparities in survival outcomes for patients with acute lymphoblastic leukemia have been observed, favoring AYA patients who are treated on pediatric protocols as opposed to adult protocols for the same disease.[12-14] Possible explanations for these discrepant survival outcomes include the use of higher total doses of nonmyelosuppressive chemotherapy agents for a longer time in pediatric protocols, delays in diagnosis, and poor adherence to therapy.[15,16] These explanations suggest that, beyond individual patient characteristics or behaviors, characteristics of health care settings (eg, pediatric vs adult) may influence clinical and psychosocial outcomes for AYAs.

To date, we know little about AYAs' needs as they try to understand medical information, manage treatment-related side effects, maintain activity, and cope with the emotional challenges of cancer and its treatment. Thus, in the study presented here, we assessed AYA cancer patients' reports of using information, emotional, and practical support services within the first 4 months of diagnosis, and the extent to which their desire for these services were not met. We also compared AYAs' reports of services used and unmet needs across 3 age groups and across pediatric versus adult oncology settings.

MATERIALS AND METHODS

In a prospective, longitudinal survey of AYA patients with cancer, we assessed psychosocial support service use and unmet needs 4 times over 2 years after initial cancer diagnosis. The results presented here come from completed data collected from all participants at baseline only, all within the first 4 months of diagnosis. Participating institutions included 3 pediatric care institutions (Doernbecher Children's Hospital in Portland, Ore; Christus Santa Rosa Children's Hospital, San Antonio, Tex; and Children's Hospital, Los Angeles, Calif) and 2 university-affiliated adult care medical institutions (Oregon Health and Sciences University Hospital, Portland, Ore; and the University of Texas Health Science Center, San Antonio, Tex). Institutional review board approval for research with human subjects was obtained from each participating site and at the coordinating center. Physician approval also was obtained before each patient was approached.

Patients

Eligible patients were recruited from March 2008 through April 2010. Eligibility criteria included patients ages 14 to 39 years at the time of diagnosis (those aged 14 years were anticipated to turn age 15 years during treatment), first diagnosis of and treatment for any form of invasive cancer within the previous 4 months, and ability to read and understand English or Spanish. A 4-month eligibility window was determined based on the timing of referral patterns in which AYA patients are first diagnosed in the community but then transferred to tertiary care centers for further diagnostic staging and initiation of treatment. Also, we acknowledge the somewhat arbitrary nature of the proposed age range; however, there are no definitive biologic or psychological criteria for defining a "young adult." The age range proposed for this study is the same as that addressed in the National Cancer Institute's Progress Review Group on Adolescent and Young Adult Oncology.[17] Patients with a history of cancer diagnosed before age 15 years were excluded from this investigation, because the needs of long-term survivors diagnosed with cancer as a child who then experience a second malignancy may be different from the needs of newly diagnosed patients in their teens, 20s, or 30s.

Recruitment Procedures

Research staff at each participating institution monitored clinic registration rosters during the entire recruitment period to identify and approach 286 eligible patients. Fifty-eight patients did not participate, either because physicians denied access to patients who, in their estimation, were too sick to participate, or because patients refused to participate. Of 228 AYAs who were recruited and consented to participate in the study, 12 did not return a completed survey after providing consent, and 1 died before completing the survey. Thus, the overall participation rate was 75% (n = 215). Respondents received $25 for completing the baseline questionnaire. Surveys were available in both English and Spanish. Five respondents requested surveys in Spanish. Informed consent/assent was obtained from all participants and parents of patients aged <18 years.

Study Measures

For each study participant, research staff obtained data on cancer type, treatment setting (ie, pediatric or adult care facility), and treatment exposures (ie, chemotherapy, radiation, and/or surgery) from clinic medical records. Severity of disease was determined by using Surveillance, Epidemiology, and End Results codes to classify each diagnosis into 1 of 2 clusters based on 5-year survival rates. *Cluster 1* included diseases for which the 5-year survival rates are ≥90% (Hodgkin lymphoma, testicular tumors, thyroid cancer) and account for 39% of all incident cases of invasive cancers in AYAs ages 15 to 39 years in the United States.[18] *Cluster 2* was comprised of all other invasive malignancies (61% of remaining incident cases in the United States) with expected 5-year survival rates of 40% to 75%. Using self-report, a symptom checklist elicited respondent endorsement of 11 common treatment-related side effects (ie, shortness of breath, memory or concentration problems, stomach or chest pain, ringing in ears, pain in joints, weight loss, frequent fevers, sleep difficulty, tiredness or fatigue, mouth sores, frequent headaches), which were tabulated and considered in statistical analyses. Self-reported sociodemographic variables included sex, race, employment/school status, and marital/relationship status. Age was stratified across 3 age groupings (ages 14-19 years, 20-29 years, and 30-39 years) to capture developmental life stages, based on theoretical models of human development.[19,20] Two patients aged ≥18 years were treated in a pediatric setting, and 5 patients aged <18 years were treated in an adult care setting. These 7 patients were omitted from our analyses. Consequently, the sample for analysis included 97 patients ages 14 to 19 years who were treated in pediatric settings and 111 patients ages 20 to 39 years who were treated in adult care settings. Thus, we note that age and treatment setting are entirely confounded (100% correlation).

A service use questionnaire surveyed respondent's reported use of and unmet need for 1) *information or information resources*, 2) *emotional support services*, and 3)

Table 1. Needs Assessed

Information and informational resources
- Information about illness, treatment, risks for recurrence, or second cancers
- Internet sites that offer cancer education or support appropriate for adolescents and young adults
- Information about infertility or options for having children
- Information or counseling about exercise and physical fitness
- Information or counseling about diet and nutrition

Emotional support services
- Community centers, camps, retreats, or adventure programs that offer cancer education or support appropriate for adolescents and young adults
- Counseling by mental health professionals (such as psychiatrists, social workers, psychologists) to help with anxiety, depression, or emotional stress
- Counseling or guidance related to sexuality or intimacy
- Religious or spiritual support or counseling
- Family counseling

Practical support services
- Help with understanding health insurance, disability, or Social Security
- Child care
- Infertility treatment (including artificial insemination, in vitro fertilization, surrogacy)
- Transportation assistance (such as taxi vouchers, American Cancer Society van rides, paratransit)
- Complementary and alternative health care (ie, herbal treatment, acupuncture, biofeedback, meditation, visualization or guided imagery, etc)
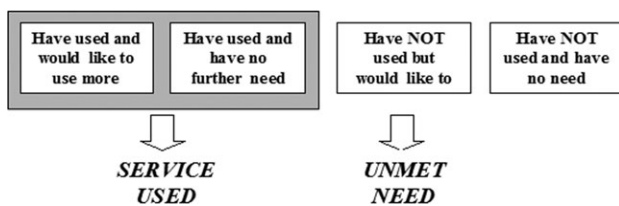

Figure 1. Four response options are illustrated distinguishing "service use" from an "unmet need."

practical support services (Table 1). We developed this instrument for use in the AYA population, and content was derived from prior qualitative research and theories of stress and coping as applied to AYA cancer survivors.[21] It has been used in prior investigations of adult cancer patients[22] and in AYA patients and survivors.[23-25] For each of 15 items, respondents are asked to indicate which services they have used and/or which they would like to use now or in the future. Response categories included "have used and would like to use more," "have used and have no further need," have NOT used but would like to," and "have NOT used and have no need" (see Fig. 1). A "service use" score was derived for each item by assigning a score of 1 if the respondent endorsed having used that service and a score of 0 if they had not used and/or had no need of that service. An "unmet need" score was calculated for each item by assigning a score of 1 if a respondent endorsed not having used the service but would have liked to use it and assigning a score of 0 if they al-

ready had used the service and/or had no need for the service.

Statistical Analysis

Descriptive statistics were used to summarize the proportions of patients indicating use, unmet need, or no need for each of the 15 service items. Cross-sectional analyses and chi-square tests were used to examine differences in service use and unmet needs as a function of developmental age groups (but also reflecting differences across treatment settings because of confounding of age at diagnosis and treatment setting). Multivariate logistic regression models were used to determine odds ratios (ORs) and 95% confidence intervals (95% CIs) for patients reporting whether 1) the service was used and 2) the need for the service was unmet after controlling for race, employment/school status, sex, relationship status, severity of cancer type, and the number of reported treatment-related symptoms. To examine differences across age groups, we constructed 2 dummy variables to compare the groups ages 20 to 29 years and ages 30 to 39 years, with all others. Data were analyzed using SPSS statistical software (version 17.0; (SPSS Inc., Chicago, Ill).

RESULTS

Demographic and disease characteristics of the respondents are summarized in Table 2. Descriptive data on nonrespondents were not collected. The average age (±standard deviation) of patients who were treated in pediatric and adult oncology settings was 15.7 ± 1.5 years

Table 2. Sample Descriptives, Frequencies, and Percentages

Variable	No. of Patients (%)		
	Pediatric Setting, n = 97	Adult Setting, n = 111	Total, n = 208
Age at diagnosis, y			
14-19	97 (100)	0 (0)	97 (46.6)
20-29	0 (0)	46 (41.4)	46 (22.1)
30-39	0 (0)	65 (58.6)	65 (31.3)
Sex			
Male	55 (56.7)	52 (46.8)	107 (51.4)
Female	42 (43.3)	59 (53.2)	101 (48.6)
Race			
White/Caucasian	29 (29.9)	61 (55)	90 (43.3)
Hispanic/Latino	55 (56.7)	34 (30.6)	89 (42.8)
African American	1 (1)	10 (9)	11 (5.3)
Asian American	11 (11.3)	2 (1.8)	13 (6.3)
American Indian	0 (0)	3 (2.7)	3 (1.4)
Education			
<High school	86 (88.6)	13 (11.7)	99 (47.6)
High school graduate/GED, some college	10 (10.3)	62 (55.8)	72 (34.6)
≥College graduate	0 (0)	35 (31.5)	35 (16.8)
Employment/school status			
Employed/in school	36 (37.1)	48 (43.2)	84 (40.4)
Not employed/in school[a]	58 (59.8)	59 (53.2)	117 (56.3)
Relationship status			
Married, live as married, committed relationship	7 (7.4)	72 (66.1)	79 (38)
Type of cancer			
Hodgkin disease	15 (15.5)	8 (7.2)	23 (11.1)
Non-Hodgkin lymphoma	6 (6.2)	10 (9)	16 (7.7)
Melanoma	0 (0)	1 (0.9)	1 (0.5)
Testicular	4 (4.1)	9 (8.1)	13 (6.3)
Thyroid carcinoma	0 (0)	1 (0.9)	1 (0.5)
Female genital	1 (1)	7 (6.3)	8 (3.8)
Soft tissue sarcoma	5 (5.2)	16 (14.4)	21 (10.1)
Brain	9 (9.3)	4 (3.6)	13 (6.3)
Leukemia	33 (34)	15 (13.5)	48 (23.1)
Other carcinomas	5 (5.2)	15 (13.5)	20 (9.6)
Breast	0 (0)	19 (17.1)	19 (9.1)
Bone tumors	19 (19.6)	5 (4.5)	24 (11.5)
All other	0 (0)	1 (0.9)	1 (0.5)
Cancer type			
Cluster 1: ≥90% 5-y survival	19 (19.6)	19 (17.1)	38 (18.3)
Cluster 2: 40%-75% 5-y survival	78 (80.4)	92 (82.9)	170 (81.7)
Type of treatments			
Chemotherapy received	92 (94.8)	76 (68.5)	168 (81.2)
Radiation received	15 (15.5)	22 (19.8)	37 (17.8)
Surgery	40 (41.2)	24 (21.6)	64 (30.9)

Abbreviations: GED, General Educational Development.

[a] Includes temporary medical leave or disability, unemployed, permanently unable to work, Not all figures total 100% because of missing data.

and 31.0 ± 6.0 years, respectively. On average, respondents completed the survey 67 days after diagnosis (range, 3-123 days; standard deviation, 34.7 days; median, 66 days). The sample consisted of a heterogeneous mix of invasive cancer types, and 81.7% of patients were diagnosed with Cluster 2 cancers (lower survival rate). Compared with the distributions of cancer incidence for cancer patients in the US population,[18] patients who were diagnosed with cancers that had relatively low survival rates were over-represented. In addition, AYAs between ages 20

and 29 years participated disproportionately less than would be expected. The percentage of Latino respondents was disproportionately large but was representative of the catchment areas of the participating institutions. African Americans were under-represented.

Service Use and Unmet Need

Cross-tabulated comparisons of services used and unmet need by age group/treatment setting are summarized in Figure 2 (information services), Figure 3 (emotional support services), and Figure 4 (practical support services). The figures summarize and compare rates of service use and unmet need for adolescent patients ages 14 to 19 years who were treated in pediatric institutions and for adults ages 20 to 29 years and ages 30 to 39 years who were treated in adult care institutions.

Information

Most patients indicated use of information related to cancer and its treatment; however, the proportions of patients ages 20 to 29 years and ages 30 to 39 years indicating that a need for cancer-related information had been unmet were more than the proportions of teenage patients (Fig. 2a). A slightly smaller proportion of teenage patients reported use of age-appropriate, Internet-based resources, but larger proportions of young adults in their 20s and 30s indicated a greater unmet need (Fig. 2b). The proportion of patients ages 20 to 29 years who reported that their need for infertility information had been unmet was 1.5 times that of teens and 2 times greater than that of patients in their 30s (Fig. 2c).

In multivariate models (Table 3), adults in their 20s and 30s who were treated in adult care settings were significantly less likely than teens who were treated in pediatric centers to report use of information related to infertility and were significantly more likely to report an unmet need for age-appropriate Internet sites that offered education and support. AYAs ages 20 to 29 years were less likely than all others to report using diet/nutrition information and were more likely to report an unmet need for information about cancer, infertility, and diet/nutrition. Nonwhite respondents were less likely than white respondents to report the use of cancer information and infertility information and were more likely to report that their need for cancer information was unmet. Patients who were diagnosed with Cluster 1 high-survival-rate cancers (Hodgkin disease, testicular cancer, thyroid cancer) were more likely than all other cancer types to report using infertility information. Patients who had received chemotherapy were more likely to have used information related

to exercise and diet/nutrition and were less likely to report that these needs were unmet.

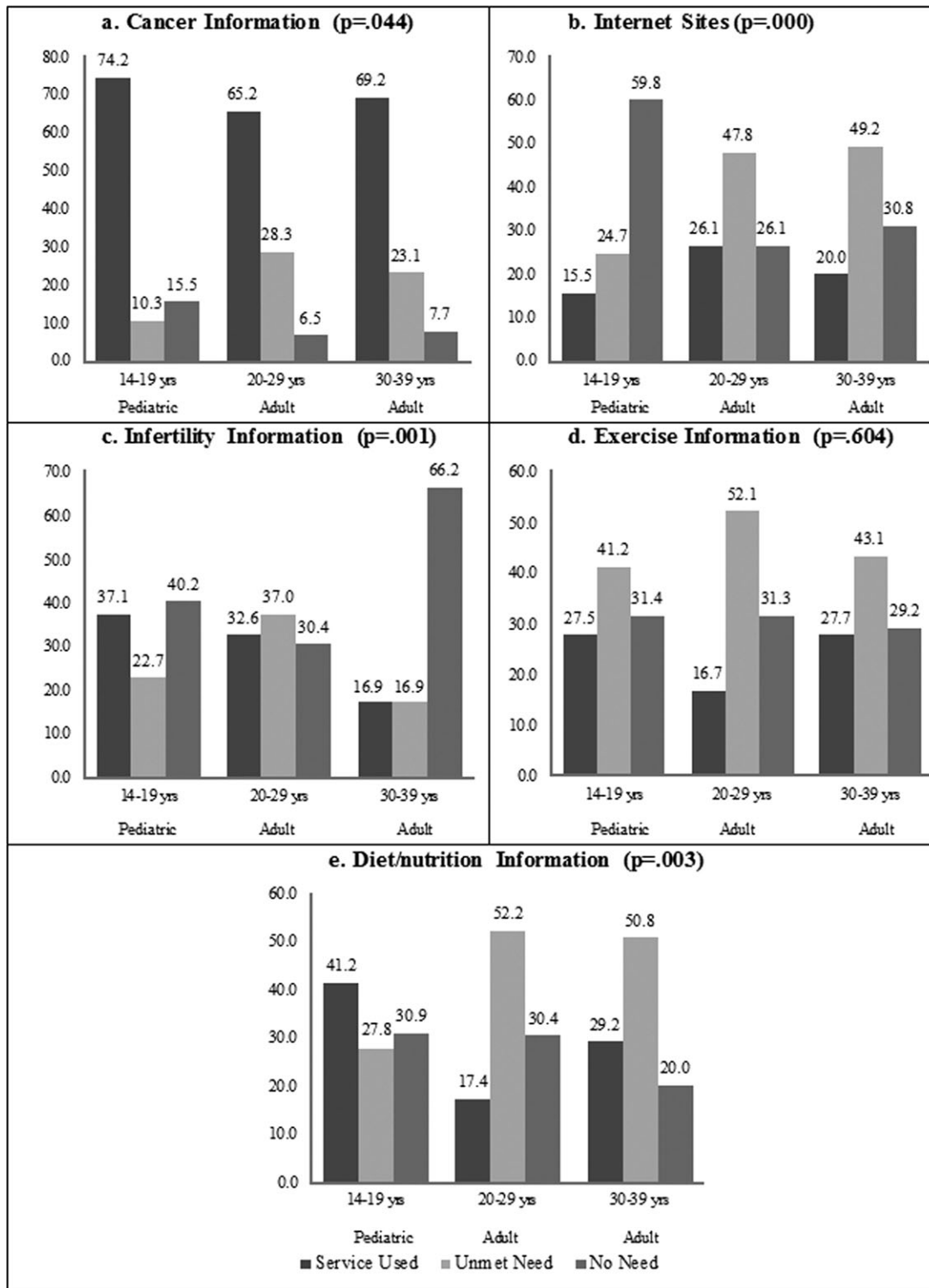### Emotional Support Services

The proportions of teens reporting use of camps and retreat programs, mental health counseling from a mental health professional, religious or spiritual counseling, and family counseling were greater than those for the 2 young adult groups (Fig. 3). In contrast, larger proportions of young adults ages 20 to 29 years and ages 30 to 39 years reported unmet needs for counseling from a mental health professional, counseling specific to sexuality and relational intimacy concerns, religious/spiritual counseling, and counseling for family members. Twenty-five percent of teens and approximately 40% to 45% of those in their 20s and 30s indicated an unmet need with regard to camps and retreat programs.

After controlling for correlates in multivariate models (Table 4), AYAs in their 20s and 30s were significantly more likely to report unmet needs for professional mental health counseling and for camps or retreats programs that offer cancer education or support. AYAs ages 20 to 29 years were less likely than all others to report the use of mental health counseling, and those ages 30 to 39 years were more likely to indicate an unmet need for family counseling. The odds of reporting an unmet need for mental health counseling also increased as AYAs tended to report more treatment-related symptoms. Nonwhites were more likely to report the use of family counseling, but no significant race differences were observed in reporting an unmet need for counseling services. Females were less likely to use and more likely to report an unmet need for counseling related to sexuality and intimacy concerns. Males were more likely to use religious/spiritual counseling, and females were more likely to report an unmet need for religious/spiritual counseling.

Practical Support Services

Most teens reported no need for any of the practical support services listed in Figure 4. In contrast, a larger proportion of young adults ages 30 to 39 years reported using assistance with health insurance, disability, Social Security, child care, and complementary and alternative medical (CAM) services. Young adults ages 20 to 29 years comprised the largest proportions of respondents reporting an unmet need for infertility services and CAM services.

In multivariate models (Table 5), the use of practical support services did not vary significantly across age groups; however, AYAs in their 20s and 30s who were treated in adult settings were more likely than teens who

Figure 2. (a-e) Information resources and support services used and unmet needs are illustrated according to age group (n = 208). Numbers indicate percentages. Chi-square tests were used to determine statistically significant differences.

a. Camps and retreats (p=.024)

Pediatric 14-19 yrs: 14.4, 24.7, 60.8
Adult 20-29 yrs: 4.3, 39.1, 56.5
Adult 30-39 yrs: 6.2, 46.2, 47.7

b. Mental Health Counseling (p=.000)

Pediatric 14-19 yrs: 35.1, 13.4, 51.5
Adult 20-29 yrs: 8.7, 32.6, 58.7
Adult 30-39 yrs: 16.9, 38.5, 44.6

c. Sexuality/Intimacy Counseling (p=.250)

Pediatric 14-19 yrs: 5.9, 9.8, 84.3
Adult 20-29 yrs: 2.1, 14.6, 83.3
Adult 30-39 yrs: 4.6, 21.5, 73.8

d. Religious/spiritual Counseling (p=.001)

Pediatric 14-19 yrs: 20.6, 4.1, 75.3
Adult 20-29 yrs: 17.4, 6.5, 76.1
Adult 30-39 yrs: 24.6, 21.5, 53.8

e. Family Counseling (p=.000)

Pediatric 14-19 yrs: 18.6, 14.4, 67.0
Adult 20-29 yrs: 2.2, 19.6, 78.3
Adult 30-39 yrs: 16.9, 44.6, 38.5

■ Service Used ■ Unmet Need ■ No Need
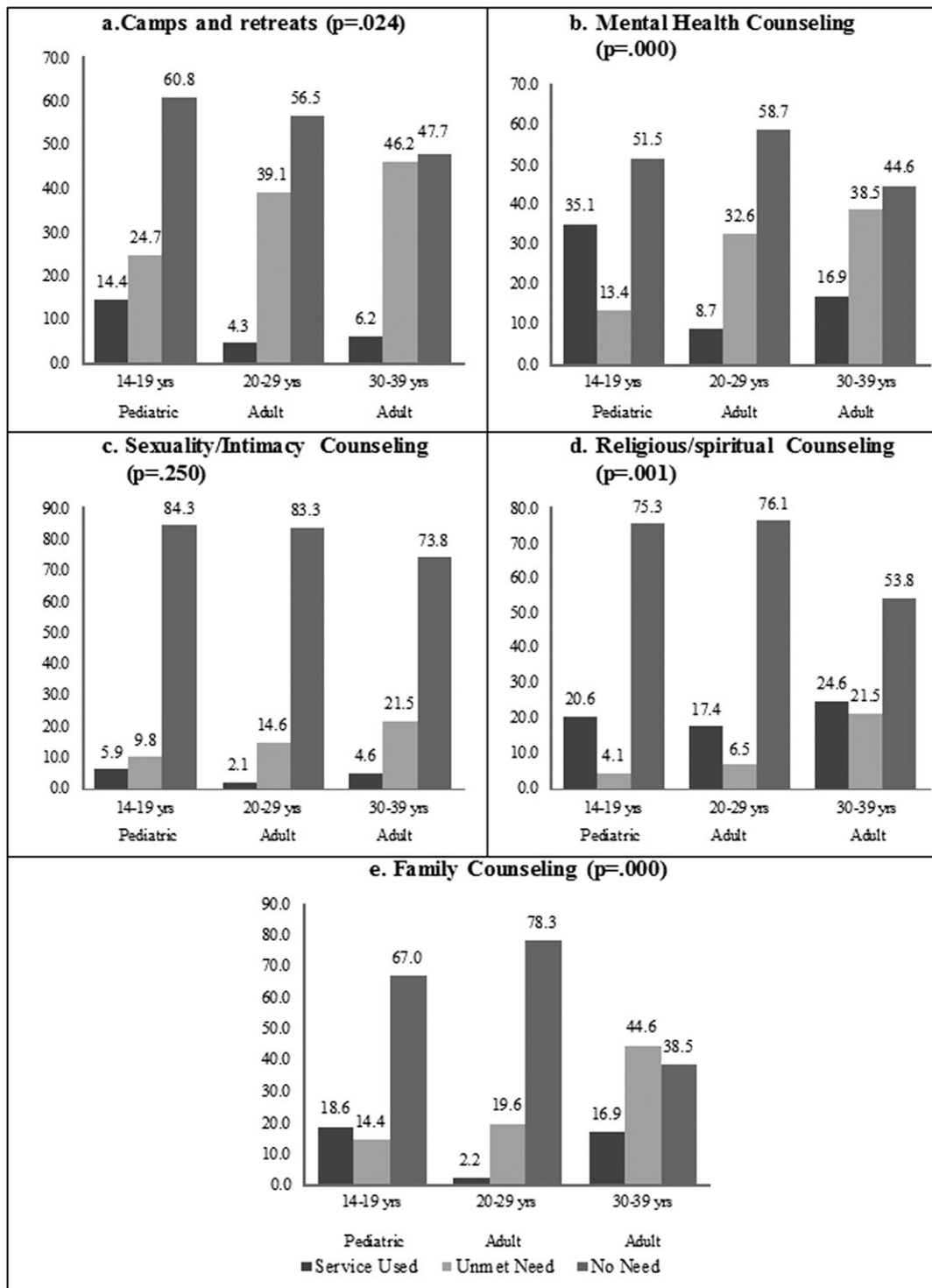
Figures are percentages; Chi-square tests used to determine statistically significant differences.

Figure 3. (a-e) Emotional support services used and unmet needs are illustrated according to age group (n = 208). Numbers indicate percentages. Chi-square tests were used to determine statistically significant differences.
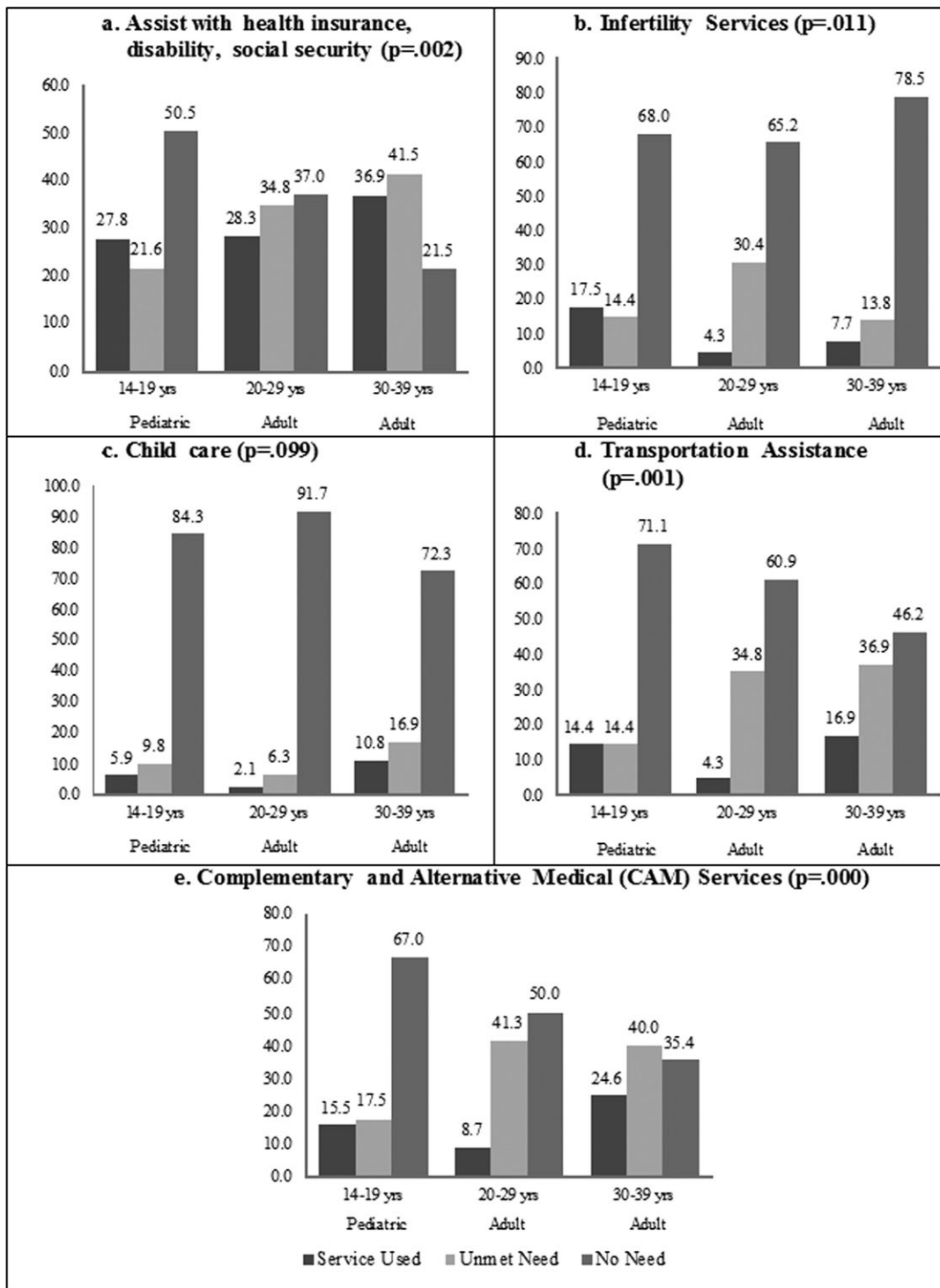
Figures are percentages; Chi-square tests used to determine statistically significant differences.

Figure 4. (a-e) Practical support services used and unmet needs are illustrated according to age group (n = 208). Numbers indicate percentages. Chi-square tests were used to determine statistically significant differences.

were treated in pediatric settings to report an unmet need for transportation assistance and CAM services. AYAs ages 30 to 39 also were more likely to report an unmet need for assistance with health insurance, disability, and

Social Security benefits. Patients who were diagnosed with Cluster 1 (high survival) cancers were less likely to report an unmet need for transportation services. In contrast, the likelihood of reporting an unmet need for

Table 3. Select Predictor Variables for Information Resources and Services: Odds Ratios and 95% Confidence Intervals

Predictor Variable [OR, Reference Category]	Cancer Information	Age-Appropriate Internet Sites	OR (95% CI) Infertility Information	Exercise Information	Diet/Nutrition Information
For using information services					
Sex [1.00, male]	0.60 (0.30-1.19)	1.28 (0.60-2.75)	1.16 (0.57-2.38)	1.46 (0.71-2.99)	0.98 (0.50-1.92)
Race [1.00, nonwhite]	0.33 (0.15-0.74)[a]	1.25 (0.54-2.88)	0.31 (0.14-.67)[a]	1.43 (0.65-3.15)	0.66 (0.32-1.35)
Employment/school status [1.00, yes]	1.24 (0.61-2.51)	1.38 (0.64-2.98)	1.30 (0.64-2.64)	1.61 (0.78-3.31)	0.86 (0.44-1.70)
Relationship status [1.00, yes]	0.91 (0.39-2.13)	1.61 (0.65-4.00)	1.00 (0.40-2.51)	0.64 (0.24-1.70)	1.68 (0.68-4.25)
Symptoms	0.92 (0.81-1.05)	0.99 (0.85-1.15)	1.00 (0.87-1.16)	0.99 (0.86-1.14)	0.97 (0.85-1.11)
Cancer [1.00, high survival]	1.79 (0.71-4.51)	1.98 (0.82-4.75)	2.87 (1.26-6.51)[a]	0.96 (0.38-2.42)	1.08 (0.46-2.54)
Chemotherapy [1.00, yes]	2.02 (0.83-4.92)	2.51 (0.81-7.76)	0.97 (0.34-2.74)	11.83 (2.49-56.28)[a]	4.29 (1.30-14.15)[a]
Radiation [1.00, yes]	2.09 (0.81-5.39)	0.70 (0.24-2.03)	0.98 (0.38-2.53)	1.40 (0.58-3.40)	2.27 (0.98-5.26)
Ages 20-29 y[b]	0.44 (0.15-1.27)	1.91 (0.64-5.71)	0.34 (0.12-.95)[a]	0.88 (0.28-2.76)	0.19 (0.06-.59)[a]
Ages 30-39 y[c]	0.76 (0.27-2.11)	1.45 (0.48-4.44)	0.28 (0.09-.85)[a]	2.57 (0.87-7.58)	0.49 (0.17-1.39)
For reporting unmet need for information services					
Sex [1.00, male]	1.55 (0.66-3.62)	0.69 (0.36-1.32)	1.18 (0.57-2.45)	0.51 (0.27-.96)[a]	0.78 (0.41-1.47)
Race [1.00, nonwhite]	6.06 (2.03-18.11)[a]	1.26 (0.62-2.56)	1.84 (0.80-4.22)	0.87 (0.44-1.70)	1.07 (0.54-2.13)
Employment/school status [1.00, yes]	0.54 (0.22-1.31)	0.71 (0.37-1.38)	0.42 (0.19-.92)[a]	0.79 (0.42-1.49)	1.07 (0.56-2.05)
Relationship status [1.00, yes]	1.01 (0.39-2.64)	0.60 (0.27-1.34)	1.09 (0.44-2.71)	1.23 (0.56-2.69)	0.85 (0.38-1.86)
Symptoms	1.04 (0.89-1.21)	1.09 (0.96-1.23)	1.05 (0.91-1.21)	1.06 (0.94-1.20)	1.08 (0.95-1.22)
Cancer [1.00, high survival]	0.83 (0.28-2.46)	0.91 (0.39-2.13)	0.58 (0.22-1.55)	0.73 (0.33-1.60)	0.85 (0.37-1.93)
Chemotherapy [1.00, yes]	0.65 (0.23-1.80)	0.74 (0.31-1.73)	2.05 (0.68-6.21)	0.21 (0.09-.51)[a]	0.27 (0.12-.64)[a]
Radiation [1.00, yes]	0.53 (0.18-1.60)	1.09 (0.48-2.48)	0.73 (0.27-1.94)	1.27 (0.57-2.84)	0.78 (0.34-1.80)
Ages 20-29 y[b]	8.24 (2.18-31.13)[a]	4.42 (1.68-11.67)[a]	4.04 (1.41-11.59)[a]	1.08 (0.43-2.70)	2.73(1.08-6.91)[a]
Ages 30-39 y[c]	3.33 (0.96-11.53)	3.89 (1.50-10.10)[a]	0.93 (0.30-2.84)	0.47 (0.18-1.21)	2.02 (0.80-5.12)

Abbreviations: CI, confidence interval; OR, odds ratio.
[a] This variable is statistically significant at $P \leq .05$.
[b] This is a dummy variable comparing patients ages 20 to 29 years with all others.
[c] This is a dummy variable comparing patients ages 30 to 39 years with all others.

Table 4. Select Predictor Variables for Emotional Support Services: Odds Ratios and 95% Confidence Intervals

Predictor Variable [OR, Reference Category]	OR (95% CI)				
	Camps, Retreats	Mental Health Counseling	Sexuality, Intimacy Counseling	Religious, Spiritual Counseling	Family Counseling
For using emotional support services					
Sex [1.00, male]	0.77 (0.25-2.34)	0.97 (0.46-2.04)	0.20 (0.04-0.98)[a]	3.26 (1.45-7.32)[a]	0.77 (0.32-1.86)
Race [1.00, nonwhite]	1.18 (0.36-3.86)	2.28 (1.00-5.22)	1.66 (0.32-8.63)	0.66 (0.29-1.49)	4.16 (1.41-12.26)[a]
Employment/school status [1.00, yes]	1.27 (0.42-3.89)	0.82 (0.38-1.77)	0.61 (0.14-2.62)	1.07 (0.50-2.30)	1.27 (0.52-3.10)
Relationship status [1.00, yes]	1.52 (0.42-3.90)	2.25 (0.77-6.60)	2.16 (0.33-14.06)	1.12 (0.42-2.95)	2.13 (0.64-7.06)
Symptoms	0.99 (0.80-1.23)	1.06 (0.92-1.22)	0.63 (0.46-0.86)[a]	0.92 (0.79-1.07)	0.93 (0.79-1.10)
Cancer [1.00, high survival]	2.77 (0.84-9.14)	1.18 (0.46-3.02)	1.65 (0.25-10.86)	1.07 (0.41-2.76)	1.50 (0.50-4.51)
Chemotherapy [1.00, yes]	3.26 (0.37-31.64)	2.08 (0.61-7.10)	1.41 (0.18-11.40)	1.87 (0.64-5.44)	6.76 (1.26-36.14)[a]
Radiation [1.00, yes]	3.09 (0.96-9.91)	0.92 (0.36-2.36)	1.31 (0.21-8.08)	0.28 (0.08-1.03)	1.82 (0.67-4.98)
Ages 20-29 y[b]	0.00 (0.00-∞)	0.17 (0.04-0.74)[a]	0.22 (0.02-2.98)	0.60 (0.18-1.97)	0.17 (0.02-1.55)
Ages 30-39 y[c]	0.35 (0.06-2.03)	0.31 (0.09-1.01)	0.26 (0.03-2.37)	1.93 (0.62-6.00)	0.87 (0.24-3.14)
For reporting unmet need for emotional support services					
Sex [1.00, male]	0.61 (0.31-1.20)	0.54 (0.26-1.12)	0.34 (0.14-0.85)[a]	0.26 (0.08-.86)[a]	0.63 (0.30-1.30)
Race [1.00, nonwhite]	1.57 (0.76-3.28)	0.96 (0.44-2.10)	1.28 (0.51-3.21)	1.84 (0.57-6.07)	01.42 (0.64-3.14)
Employment/school status [1.00, yes]	0.50 (0.25-1.00)[a]	1.36 (0.66-2.82)	0.89 (0.38-2.11)	0.82 (0.27-2.46)	0.89 (0.42-1.86)
Relationship status [1.00, yes]	0.49 (0.22-1.12)	0.57 (0.24-1.32)	1.57 (0.58-4.26)	1.52 (0.48-5.14)	1.61 (0.69-3.78)
Symptoms	1.09 (0.96-1.24)	1.17 (1.01-1.35)[a]	1.11 (0.94-1.30)	1.18 (0.97-1.43)	1.10 (0.96-1.27)
Cancer [1.00, high survival]	1.21 (0.50-2.90)	1.01 (0.40-2.56)	0.76 (0.23-2.49)	0.75 (0.15-3.85)	0.52 (0.18-1.51)
Chemotherapy [1.00, yes]	0.95 (0.39-2.31)	0.90 (0.35-2.30)	0.66 (0.21-2.03)	0.31 (0.09-1.10)	0.96 (0.37-2.49)
Radiation [1.00, yes]	0.56 (0.23-1.37)	1.02 (0.41-2.53)	0.68 (0.22-2.11)	1.47 (0.46-4.77)	0.66 (0.25-1.70)
Ages 20-29 y[b]	4.03 (1.48-10.99)[a]	4.93 (1.71-14.15)[a]	1.77 (0.51-6.22)	1.94 (0.32-11.80)	1.98 (0.64-6.12)
Ages 30-39 y[c]	4.88 (1.80-13.22)[a]	5.04 (1.80-14.17)[a]	1.26 (0.37-4.30)	2.88 (0.61-13.61)	3.76 (1.33-10.59)[a]

Abbreviations: CI, confidence interval; OR, odds ratio.
[a] This variable is statistically significant at $P \leq .05$.
[b] This is a dummy variable comparing patients ages 20 to 29 years with all others.
[c] This is a dummy variable comparing patients ages 30 to 39 years with all others.

Table 5. Select Predictor Variables for Practical Support Services: Odds Ratios and 95% Confidence Intervals

Predictor Variable [OR, Reference Category]	OR (95% CI)				
	Health Insurance Assistance	Child Care	Infertility Services	Transportation Assistance	Complementary Alternative Health Services
For use of practical support services					
Sex [1.00, male]	1.32 (0.68-2.57)	0.44 (0.12-1.60)	0.86 (0.31-2.37)	0.96 (0.38-2.42)	0.79 (0.35-1.76)
Race [1.00, nonwhite]	1.36 (0.65-2.83)	0.88 (0.25-3.14)	0.66 (0.23-1.84)	4.40 (1.31-14.81)[a]	0.59 (0.25-1.40)
Employment/school status [1.00, yes]	0.74 (0.37-1.46)	3.82 (1.08-13.57)[a]	0.74 (0.27-2.07)	0.92 (0.36-2.34)	0.74 (0.33-1.68)
Relationship status [1.00, yes]	1.23 (0.53-2.89)	0.53 (0.12-2.37)	0.43 (0.09-1.98)	1.33 (0.40-4.42)	1.19 (0.42-3.36)
Symptoms	1.00 (0.88-1.14)	0.90 (0.72-1.12)	0.94 (0.78-1.14)	0.87 (0.74-1.02)	0.93 (0.80-1.09)
Cancer [1.00, high survival]	0.92 (0.39-2.15)	0.38 (0.04-3.35)	2.92 (0.99-8.65)	1.02 (0.30-3.47)	1.14 (0.41-3.19)
Chemotherapy [1.00, yes]	7.64 (2.30-25.38)	1.09 (0.23-5.10)	<0.01 (0.00-∞)	1.66 (0.46-5.96)	1.63 (0.51-5.25)
Radiation [1.00, yes]	1.22 (0.52-2.84)	1.59 (0.38-6.72)	0.74 (0.19-2.88)	1.40 (0.49-3.99)	1.96 (0.77-4.97)
Ages 20-29 y[b]	1.36 (0.50-3.70)	0.43 (0.04-4.48)	0.13 (0.02-1.11)	0.24 (0.03-2.31)	0.45 (0.12-1.72)
Ages 30-39 y[c]	2.30 (0.85-6.24)	1.82 (0.37-9.10)	0.81 (0.17-3.97)	1.22 (0.33-4.57)	1.36 (0.42-4.42)
For reporting unmet need for practical support services					
Sex [1.00, male]	0.81 (0.40-1.64)	0.88 (0.34-2.31)	0.86 (0.40-1.96)	1.51 (0.72-3.18)	1.45 (0.72-2.94)
Race [1.00, nonwhite]	2.24 (1.03-4.86)[a]	1.36 (0.48-3.87)	0.92 (0.39-2.18)	1.28 (0.57-2.90)	1.61 (0.74-3.48)
Employment/school status [1.00, yes]	0.50 (0.24-1.05)	0.28 (0.09-.86)[a]	0.74 (0.33-1.66)	0.75 (0.36-1.59)	0.86 (0.42-1.74)
Relationship status [1.00, yes]	0.89 (0.38-2.06)	2.01 (0.61-6.61)	1.70 (0.66-4.40)	0.78 (0.32-1.93)	0.57 (0.24-1.33)
Symptoms	1.01 (0.88-1.15)	0.96 (0.81-1.14)	1.01 (0.87-1.18)	1.19 (1.03-1.37)[a]	1.20 (1.05-1.38)[a]
Cancer [1.00, high survival]	1.08 (0.44-2.67)	1.33 (0.39-4.54)	0.96 (0.36-2.56)	0.08 (0.02-0.39)[a]	0.61 (0.24-1.57)
Chemotherapy [1.00, yes]	0.34 (0.14-.83)[a]	0.64 (0.19-2.21)	1.06 (0.35-3.19)	0.49 (0.19-1.28)	1.07 (0.43-2.69)
Radiation [1.00, yes]	0.40 (0.15-1.08)	0.40 (0.10-1.60)	0.61 (0.19-1.94)	0.66 (0.25-1.74)	0.89 (0.37-2.17)
Ages 20-29 y[b]	2.54 (0.89-7.27)	0.52 (0.10-2.73)	1.91 (0.64-5.71)	6.23 (2.00-19.39)[a]	5.05 (1.76-14.48)[a]
Ages 30-39 y[c]	3.09 (1.11-8.57)[a]	1.36 (0.33-5.56)	0.68 (0.20-2.28)	3.87 (1.28-11.77)[a]	5.63 (1.98-15.98)[a]

Abbreviations: CI, confidence interval; OR, odds ratio.
[a] This variable is statistically significant at $P \leq .05$.
[b] This is a dummy variable comparing patients ages 20 to 29 years with all others.
[c] This is a dummy variable comparing patients ages 30 to 39 years with all others.

transportation assistance increased significantly as patients reported more treatment-related symptoms. An unmet need for CAM services also was associated with reporting more symptoms. Compared with whites, nonwhites were more likely to use transportation assistance and were more likely to report an unmet need for assistance with health insurance, disability, and Social Security.

DISCUSSION

For recently diagnosed AYA cancer patients, the use of and need for information and supportive care services is substantial and appears to vary, depending on the age/developmental stage and associated cognitive capabilities of the patient when cancer is diagnosed. Findings suggest that use and desire for services also vary, depending on sociodemographic characteristics and clinical conditions, but rarely according to the type or severity of cancer. Of particular note is the observation that an unmet need for professional mental health services increased as AYAs reported more treatment-related symptoms. This finding suggests a critical deficiency around the availability or accessibility of psychosocial support when cumulative,

treatment-related symptoms may be contributing to high levels of distress.

Within the first 4 months of diagnosis, most AYAs have used information about cancer and its treatment. In contrast, nearly half of the AYAs in the current study indicated an unmet need for information and counseling specific to exercise and diet/nutrition, thereby suggesting a gap in the provision of these services. Interventions that facilitate AYA involvement in physical activity to the extent possible may minimize treatment-related side effects but also promote social involvement with same-age peers, thereby reducing isolation and improving quality of life.[26-28] The finding that AYAs who had received chemotherapy were more likely to use exercise, diet, and nutrition information suggests that chemotherapy likely disrupts AYAs' routine fitness and/or dietary regimens, thus making them more desiring of and amenable to recommendations related to how they can incorporate exercise and healthful eating into their lives to the extent possible.

The relatively low use of age-appropriate, Internet-based resources among teenagers in the current study (15.5%) suggests that, although teens may be heavy users

of computers and social media in general, perhaps only a minority of these recently diagnosed patients use the Internet for cancer-related information and support. Indeed, cancer information can exacerbate anxiety and distress, particularly for young people.[29] In contrast, nearly half of AYAs ages 20 to 39 years who were treated in adult care institutions wanted but did not use age-appropriate Internet resources for information and support, despite existing and emergent social media and resources designed specifically by and for AYAs (eg, Planet Cancer, mAssKickers, StupidCancer.com). Perhaps a large majority of AYA patients is not informed about the existence of these online resources or else believe that the information they find on the Internet is not relevant or age-appropriate. Furthermore, teens who were treated in pediatric settings were more likely than young adults who were treated in adult-oriented settings to report having used information and services related to infertility. AYAs in their 20s were significantly more likely than all others in this study to report an unmet need for infertility information and support, despite the existence of American Society of Clinical Oncology guidelines for fertility preservation.[30] Regardless of the treatment setting, the provision of information about options for fertility preservation during early stages of diagnosis and before the initiation of treatment in this young population is critical.

With regard to emotional support services, approximately half of this entire AYA sample indicated a need for mental health counseling, and young adults who were treated in adult care facilities fared worse than those who were treated in pediatric settings in terms of getting their mental health care needs met. Similarly, young adults in their 20s and 30s were more likely than teens to indicate that their need for camps and retreat programs was unmet. Clinicians and community-based agencies running peer-support programs for teens are now recognizing a growing need for extending peer support to a substantial subset of young adult patients and survivors who age out of their teen programs.[3] Because larger proportions of teens indicated that they had no need for camps or retreat programs, the differences in use and unmet needs more likely reflect the lack of availability of these programs and services to AYAs who were treated in adult-oriented care settings.

With regard to practical support services, nonwhite respondents indicated significantly greater unmet needs for help with health insurance, disability, and Social Security benefits and greater use of transportation assistance. The need for transportation assistance also appeared to be greater among AYAs who reported more treatment-related side effects, presumably because they had more

medical appointments. Facilitating transportation for sicker patients and those experiencing socioeconomic pressures may contribute to improved adherence to therapy and, subsequently, greater likelihood of survival. The differences observed across races serve as further evidence that service use and unmet needs of AYAs vary, depending on individual patient characteristics *and* health care system factors. For example, nonwhite respondents' underuse of information services may be attributable to sociocultural factors or economic pressures. For some patients and families, culturally based traditions and values, reliance on languages other than English, or the need to work multiple jobs preclude them from being able to read, understand, or trust information that comes from outside their community. Institutional barriers like a dearth of language-appropriate or culturally relevant materials or a limited availability of translators also may contribute to reports of greater unmet needs.

This study's strengths include a moderately sized and ethnically diverse, multi-institutional sample of AYAs recruited to a prospective, longitudinal study relatively close to the time of their initial cancer diagnosis, along with a high participation rate (75%) and equal sex distribution. The study is somewhat limited by use of a nonstandardized measure of service use, a 4-month window of recruitment, which may contribute to variation in terms of some respondents having had more time to identify and use services, and the inclusion of a broad age range of patients. Certainly, the life experiences and psychosocial needs for a patient aged 15 years are different from those of a patient aged 35 years; however, the sample size permitted us to make comparisons and to identify variations in service use and needs across 3 meaningful age groups within the sample. The findings are also limited in that objective information about patients' health status and cancer-specific clinical conditions are lacking. The over-representation of teenage patients in this sample likely reflects the greater number of teenage patients available for study across the 3 pediatric facilities (including 1 site based in Los Angeles) compared with the 2 relatively smaller adult facilities, which draw patients from less populated geographic regions. However, active lifestyles, an aversion to research participation, and/or geographic mobility among young individuals in their 20s also may explain the relatively smaller rate of participation in this and perhaps future studies. The over-representation of patients with relatively low survival rates may reflect normative referral patterns across the United States, in which patients with more severe or life-threatening cancer types are referred to tertiary treatment centers, and those whose

cancers have relatively higher survival rates more typically remain in community-based settings for care. Population-based samples, in contrast to clinic-derived samples, may offer better representation of the AYA population and may improve measurement precision when estimating probabilities or likelihood of reporting service use, unmet needs, or other outcomes of interest.

The observed differences in service use and unmet needs across age groupings may be a function of differences in AYAs' preferences, behaviors, or cognitive capabilities related to their developmental life stage. However, these observed differences also could be influenced by treatment settings, specifically in how psychosocial services are organized, implemented, and delivered in pediatric care settings in contrast to adult care settings. The current findings suggest that AYAs who are treated in pediatric care settings were advantaged to the extent that they used services more often and were less likely to report an unmet need compared with AYAs in their 20s and 30s. Investigations that include young adults who are treated in pediatric settings and older teens who are treated in adult care settings are needed to distinguish the independent effects of age-related developmental and cognitive conditions and organizational characteristics of treatment settings (eg, the availability of psychosocial services) on AYA service use and satisfaction of psychosocial care needs.

In summary, the findings reported here serve as evidence suggesting that substantial proportions of AYAs are not getting their psychosocial needs met. Time pressures, excessive caseloads, and limited access to psychosocial support services for patients, particularly in adult care settings, may be precluding trained psychosocial health care professionals (eg, social workers, psychologists) from adequately assessing and offering developmentally appropriate psychosocial care services.[31] Furthermore, lacking a well developed evidence base, program planners and clinicians are limited in their ability to develop, test, and implement adequate and age-appropriate services to meet the unique psychosocial challenges experienced by AYAs. An emerging literature summarizes psychosocial care interventions and components that may lead to enhanced health and quality-of-life outcomes for AYAs.[32-34] Referring AYAs to community-based agencies or age-appropriate, Internet-based support programs run by and for AYAs also may enhance care and improve quality of life for this population.

FUNDING SOURCES

CONFLICT OF INTEREST DISCLOSURES

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