

# Supporting Adolescents and Young Adults with Cancer: Oncology Provider Perceptions of Adolescent and Young Adult Unmet Needs

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Few studies have assessed oncology providers' perceptions of adolescent and young adult (AYA) cancer patients' unmet needs. In this statewide survey ( $N=91$ ), we found that most providers recognize the financial, insurance, and late effects needs of their AYA cancer patients. However, employment, education, behavioral health, sexuality, and social and family issues were endorsed by less than half of providers as areas where AYAs needed assistance. Few providers felt that their AYA cancer patients had unmet needs for these same concerns. Educational efforts are needed to improve providers' awareness of the impact of cancer for AYA cancer patients.

**Keywords:** oncology providers, health service needs, supportive service needs

## Introduction

OVER 70,000 ADOLESCENTS and young adults (AYAs) between the ages of 15 and 39 are diagnosed with cancer each year in the United States, but cancers in this age range represent <5% of cancers.<sup>1</sup> As a result, oncology care teams may have less experience in addressing the unique needs of this age group.<sup>2</sup> AYA cancer patients are more likely to receive care from a community oncology provider rather than an academic cancer center, potentially limiting their access to supportive care services.<sup>3</sup> This is of particular concern as cancers in the AYA age group arise during a time of social, emotional, and developmental transitions.<sup>4</sup> Therefore, many AYA cancer patients may have unaddressed care needs during treatment.

There is a growing body of literature demonstrating care gaps for AYAs with cancer. The AYA HOPE study, which is a large U.S. cohort of AYAs diagnosed with cancer between the ages of 15 and 39, found that over 50% of participants indicated at least one unmet need related to treatment, long-term side effects, and alternative therapies.<sup>5</sup> Other commonly reported unmet needs among AYAs who indicated care gaps included financial support for medical care (52%) and seeing a mental health professional (56%).<sup>5</sup> Despite the acknowledgment of unique supportive care issues for AYAs with cancer recognized by cancer organizations over the past decade,<sup>6–8</sup> there is still little known about oncology provider experiences and awareness of the unmet needs of the AYA population.

In this study, we report on results from a statewide oncology physician survey that was developed based on unmet needs identified in AYA HOPE. We surveyed providers regarding their awareness of their AYA cancer patients' unmet needs for financial support (e.g., insurance), treatment and clinical support (e.g., fertility care), and social and family support (e.g., mental health needs), as well as their knowledge of and referral practices to supportive care resources for their AYA cancer patients.

## Methods

### Participants

Eligible participants included pediatric, medical, surgical, and radiation oncologists providing medical services for cancer patients within the past year in Utah. We focused on oncologists as they oversee patient care from diagnosis through disease duration. Potential participants were identified from Huntsman Cancer Hospital (HCI) and Intermountain Healthcare, the two largest oncology providers in the state. We supplemented these with the Utah Department of Professional Licensing lists, the Society of Utah Medical Oncologists membership lists, and information from clinic websites. Through this process, we identified 240 potential participants. We excluded those who no longer practice in Utah, duplicates, and undeliverable email addresses, leaving

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a total of  $N=184$  for survey distribution. All study procedures were approved by the University of Utah Institutional Review Board.

#### Data collection

The survey included demographic characteristics of the providers as well as provider perceptions of AYA needs related to resources (e.g., employment), treatment/clinical support (e.g., fertility services), and social/family support (e.g., mental health counseling). The first wave of the survey was conducted electronically with two reminder emails. A second wave was conducted by mail to nonrespondents. Providers were given the option to return the survey in an enclosed stamped envelope, through interoffice mail for on-campus providers, or by fax, with a \$20 gift card (a common practice in U.S. studies). We received surveys from 106 providers (response rate=57.6%). We excluded 14 surveys from providers who reported they did not see patients in the AYA age range (15–39 years) and 1 incomplete survey for a final  $N=91$ .

#### Unmet needs and supportive care measures

Providers were first asked on a 5-point Likert scale (1 = always to 5 = never) how often they perceived that their AYA cancer patients or survivors needed assistance with resources, treatment/clinical support, and social/family support. As a follow-up, they were asked how often these needs go unmet for their AYA patients for those same concerns. We grouped responses as always/often versus sometimes/rarely/never.

Participants were also asked to indicate which supportive services are available for their AYA cancer patients (e.g., social work, financial counseling), and how often in the past year they had referred their patients to each service, which we grouped as always/often versus sometimes/rarely/never/NA.

#### Data analysis

Analyses were conducted in Stata 14. Summary statistics of demographics and practice characteristics were generated for participants. We generated the proportion of participants responding to outcome measures of interest.

In Utah, 85% of cancer services are provided by either HCI, the only National Cancer Institute-designated cancer center in the multistate region, or Intermountain Healthcare, which is a system of 22 hospitals including Primary Children's Hospital (PCH), a children's hospital that serves the largest geographic catchment area in the country. Due to this arrangement, we anticipated that differences in access to research and supportive care resources between settings might affect provider awareness of AYA patient needs. Thus, we examined differences in the outcome measures by the primary practice location of the provider—either pediatric/adult academic cancer center ( $N=55$ ) or community oncology facility (i.e., not affiliated with an academic institution;  $N=36$ )—using chi-square tests with significance set at alpha  $p<0.05$ . Statistically significant results for the provider subanalysis are reported only in the article text.

#### Results

Table 1 displays provider characteristics. Most respondents (60.5%) were 10 or more years out of training and the most common provider types were medical oncology (41.8%) and

TABLE 1. UTAH ONCOLOGY PROVIDER CHARACTERISTICS ( $N=91$ )

	N	%
Gender <sup>a</sup>		
Male	66	74.2
Female	23	25.8
Years since clinical training completed		
<10	36	39.6
10–19	26	28.6
≥20	29	31.9
Race/ethnicity		
Non-Hispanic white	88	96.7
Other	3	3.3
Oncology specialty <sup>b</sup>		
Medical	38	41.8
Surgical	28	30.8
Radiation	18	19.8
Pediatric	11	12.1
Proportion of patients in AYA age range		
Mean (IQR)		21.2 (15–30)

<sup>a</sup>Missing  $n=2$  for gender.

<sup>b</sup>Specialty adds to more than 100% due to multiple specialties reported.

AYA, adolescent and young adult; IQR, interquartile range.

surgical oncology (30.8%). On average, providers reported that 21.2% (interquartile range=15%–30%) of their patients were ages 15–39 years at diagnosis.

#### Provider perceptions of unmet needs

**Resource support.** A majority of providers indicated that their AYA patients needed financial assistance (63.2%) and insurance, disability and social security assistance (69.7%) (Table 2). Employment (23.9%) and education (39.1%) needs were endorsed by fewer providers. When examined by practice location, academic cancer center providers reported their AYA patients needed employment support (37.7% vs. 2.9%,  $p<0.001$ ) and educational support (49.1% vs. 23.5%,  $p=0.02$ ) more often than community providers (data not shown).

Few providers reported that resource supports went unmet for their AYA cancer patients, ranging from approximately 17% for financial assistance and employment support to 9.8% for education support (Table 2). By practice location, 23.5% of academic cancer center providers compared to 6.1% of community providers indicated financial assistance as an unmet need ( $p=0.04$ ; data not shown).

**Treatment and clinical support.** Many oncology providers noted that AYA cancer patients needed support with late effects (70.1%) and information on fertility (65.2%), although treatment for infertility was less supported (50.0%). Diet/nutrition (49.4%), exercise (47.2%), physical therapy/rehabilitation (41.6%), and complementary/alternative medicine (CAM; 25.8%) were less commonly endorsed.

Few providers reported their AYA patients had unmet needs related to treatment/clinical support, with the most common unmet need being CAM healthcare (18.3%) and the

TABLE 2. UTAH ONCOLOGY PROVIDERS' PERCEPTIONS OF UNMET NEEDS FOR ADOLESCENT AND YOUNG ADULT ONCOLOGY PATIENTS (N=91)

	AYAs need assistance with support <sup>a</sup>		Support goes unmet for AYAs <sup>a</sup>	
	N	%	N	%
<b>Resource support</b>				
Financial assistance information	55	63.2	14	16.7
Insurance, disability, or social security assistance	62	69.7	12	14.8
Employment support	21	23.9	14	16.9
Education support	34	39.1	8	9.8
<b>Treatment and clinical support</b>				
Late effects information	63	70.1	11	13.1
Genetic counseling information	42	47.2	6	7.1
Fertility information	58	65.2	4	4.8
Infertility treatment (e.g., <i>in vitro</i> , artificial insemination)	44	50.0	9	11.0
Diet and nutrition information	44	49.4	10	12.1
Exercise and physical fitness	42	47.2	10	11.9
Physical therapy/functional rehabilitation	37	41.6	10	12.5
Complementary/alternative medicine	23	25.8	15	18.3
<b>Social and family support</b>				
Sexuality or intimacy counseling	35	39.3	23	28.4
Appearance/body image support	36	40.9	16	19.3
Mental health counseling for anxiety, depression, or stress	41	46.1	13	15.5
Family or relationship counseling	28	31.5	12	14.6
Religious or spiritual support	16	18.2	8	10.1
Peer connections	30	34.5	15	19.0

<sup>a</sup>Always to often.

least common fertility information (4.8%). There were no differences by practice location.

**Social and family support.** Social and family supports, including sexuality or intimacy (39.3%), appearance/body image (40.9%), and mental health counseling (46.1%) were endorsed by less than half of providers as areas AYA patients needed assistance, and for sexuality and intimacy, 28.4% of providers reported that AYAs' needs went unmet. There were no differences by practice location.

**Supportive care services**

Social work (95.6%) was the most common supportive care service available for AYA cancer patients (Table 3). Referral to social work was more common for academic

center providers than community providers (72.7% vs. 47.2%,  $p=0.01$ ; not shown). Other common services available for AYAs include financial counseling (79.1%), spiritual care (67.0%), and behavioral health (59.0%), although financial counseling was the only other service besides social work where at least half of providers indicated often-always referring their AYA patients to the service. There were no other practice location differences.

**Discussion**

Over a decade ago, the AYA Oncology Progress Review Group report delineated the unique resource, treatment, and social needs of AYA cancer patients.<sup>9</sup> Since the release of this report, there has been a growing body of research demonstrating continued care gaps for AYA cancer patients. Yet,

TABLE 3. UTAH ONCOLOGY PROVIDERS' AWARENESS OF SUPPORTIVE CARE SERVICES FOR ADOLESCENT AND YOUNG ADULT CANCER PATIENTS (N=91)

	Awareness of service		Always/often referred to service	
	N	%	N	%
Social work	87	95.6	57	62.6
Financial counseling	72	79.1	46	51.1
Spiritual care or chaplain services	61	67.0	6	6.7
Behavioral health provider <sup>a</sup>	36	59.0	7	11.5
In-person support or information group	33	36.3	13	14.4
Online support or information group	36	39.6	18	20.2
Peer-to-peer support group	21	23.1	8	9.2

<sup>a</sup>Question was only asked in online survey (N=61 respondents).

there have been few studies on oncology providers' experiences with AYA cancer patients, which is essential information for improving care for this population. In this statewide survey, we found that many providers recognize the financial, insurance, and late effects needs of their AYA cancer patients. However, several areas of concern that have been noted by AYA cancer patients across multiple studies, including employment, education, behavioral health, sexuality, and social and family issues,<sup>5,10-12</sup> were endorsed by less than half of providers as areas where AYAs needed assistance. Few providers felt that their AYA cancer patients had unmet needs for these same concerns.

We found that community providers, in particular, lack awareness of employment and education concerns of AYA patients, which suggests a need for educational efforts in this area. Over 34% of AYAs working or in school full-time before their diagnosis report that their cancer had a negative impact on their employment and education.<sup>13</sup> Relatedly, AYAs with cancer in Utah note challenges balancing work and school when accessing cancer-related follow-up care.<sup>14</sup> AYAs clearly need better support to manage work or school during cancer treatment, yet our findings suggest that oncology providers may not recognize or address these concerns with their patients.

An earlier assessment of AYAs with cancer in Utah found that many needed support to develop healthy eating habits and to be physically active. However, for some patients, the information they received from their providers on strategies to engage in these lifestyle behaviors was not helpful.<sup>15</sup> In the AYA HOPE study, approximately 16% of participants reported unmet needs related to physical therapy.<sup>5</sup> However, surprisingly, few providers we surveyed reported that AYA patients needed assistance with or had unmet needs related to healthy behaviors and physical therapy.

Seventy percent of male and 34% of female AYAs report discussing fertility preservation with a healthcare provider before their cancer treatment.<sup>16</sup> Only 50% of providers in our study felt that AYAs need infertility treatment assistance and <5% felt this was an unmet need for these patients. A similar disconnect exists where half of AYAs report negative effects on their sexuality function in the first year after diagnosis,<sup>17</sup> approximately 60% report negative effects on body image,<sup>18</sup> and 20% report poor mental health.<sup>19</sup> Yet, less than half of providers we surveyed reported sexuality, appearance/body image, and mental health counseling as areas of need for their AYA cancer patients.

Complementary and alternative health services are the other commonly cited unmet need by AYA patients,<sup>5</sup> but few providers in our study felt this was a concern. Many cancer patients report using CAM therapies during their cancer treatment,<sup>20</sup> suggesting that oncology providers may need to better communicate with their AYA patients about services they have interest in or are using, as this could impact their treatment.

In our survey, 73% of academic cancer center and 47% of other providers reported always or often referring their AYA cancer patients to social work, meaning many AYAs may not have access to a social worker. Social work services provide important face-to-face support and reassurance with a trained professional who can help identify community and national resources, which could help to address some of the unmet needs faced by AYAs, and reduce the burden on oncologists.

Our assessment has certain limitations. Our response rate is high for a physician survey.<sup>21</sup> Still, there may be differences in perceptions and practices of nonrespondents. As this effort was part of a needs assessment to inform the development of an AYA navigator program, our questions focused on understanding providers' experiences of AYAs' unmet needs, rather than actual care delivery. As such, our findings may not fully represent the spectrum of care for AYAs in our state. Finally, while there were few differences between academic cancer center and community providers, we did find a higher awareness of certain needs, such as employment and education, for academic providers. Academic providers likely have greater access to educational resources on the unique needs of AYAs and this is important to confirm in future research.

AYAs with cancer require multidisciplinary healthcare that addresses their unique developmental concerns related to employment, education, fertility, psychosocial health, and health behaviors.<sup>6</sup> From our findings, we have several recommendations for future work. First, efforts should be directed to raising oncology providers' awareness of employment, education, infertility, sexuality, and psychosocial issues, which are key concerns for AYA cancer patients. Second, research is needed to understand why providers endorse that AYA patients need assistance, but are less likely to say these needs go unmet. For example, oncologists may perceive these concerns as already addressed by other providers (e.g., social workers). Potential avenues for addressing this disconnect include disseminating education via state community oncology organizations, as many oncologists are members of their local chapters, as well via continuing medical education strategies. Finally, further studies are needed to determine whether our findings are consistent among providers in other states and countries.

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### Author Disclosure Statement

No competing financial interests exist.

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