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Who Treats Adolescents and Young Adults with Cancer? A Report from the AYA HOPE Study

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Purpose: Physicians play a critical role in delivering effective treatment and enabling successful transition to survivorship among adolescent and young adult (AYA) cancer patients. However, with no AYA cancer medical specialty, information on where and by whom AYAs with cancer are treated is limited.

Methods: Using the National Cancer Institute's population-based AYA HOPE Study, 464 AYAs aged 15–39 at diagnosis treated by 903 physicians were identified. Differences in physician and hospital characteristics were examined by age at diagnosis and cancer type (germ cell cancer, non-Hodgkin lymphoma, Hodgkin lymphoma, acute lymphocytic leukemia [ALL], and sarcoma) using chi-square tests.

Results: Treating physicians were predominately 51–64 years old, male, United States-trained in non-pediatric specialties, and in group practices within large metropolitan areas. Older patients were less often treated by pediatric physicians ($p < 0.01$) and more likely to be treated by United States-trained physicians without research/teaching responsibilities and in hospitals without residency programs ($p < 0.05$). The majority of the few pediatricians ($n = 44$) treated ALL patients. Physicians with research/teaching responsibilities and those based in medical schools were more likely to treat patients with ALL and sarcoma compared with other cancer types ($p < 0.01$). Of HL patients, 73% were treated at a cancer center compared with 56% of patients with germ cell cancer ($p < 0.01$), while ALL (85%) and sarcoma (87%) patients were more likely to be treated in hospitals with residency programs ($p < 0.01$).

Conclusions: Most AYAs with cancer were treated by non-pediatric physicians in community settings, although physician characteristics varied significantly by patient cancer type and age at diagnosis.

Keywords: treatment, physicians, place of care, AYA HOPE Study

IMPROVING CARE AND OUTCOMES for adolescents and young adults (AYAs) diagnosed with cancer between 15 and 39 years of age remains a priority in the United States, as this population has experienced limited survival gains relative to pediatric and older adult cancer populations over the past two decades.^{1–4} Addressing and improving health outcomes in the approximately 70,000 AYA cancer patients diagnosed annually is challenging and has been hampered by organizational and resource-related factors, including knowledge

about the most effective treatment settings (e.g., pediatric vs. adult oncology settings^{5,6}) and limited recommendations for ongoing medical care (i.e., needed post-treatment services) for this population.^{7–11} In order to improve outcomes in AYA cancer patients, physicians are increasingly asked to take on critical roles of ensuring treatment continuity, care coordination, and effective transition to survivorship among recently diagnosed AYA patients, despite uncertainty about whether pediatric or adult protocols are most appropriate for

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this population.^{7,12,13} However, because there is no AYA cancer medical specialty (unlike pediatric oncology), there is limited information as to who specifically treats AYAs with cancer, potentially creating situations in which patients may slip through the crack between pediatric and adult oncology. This knowledge is essential to support the development of effective interventions and programs for providing evidence-based quality care to this population.^{1,14}

Research on the characteristics of physicians who treat AYAs with cancer has focused on adolescents 15–19 years of age. Previous studies demonstrated significant variation in the types of providers treating AYAs with cancer, with referral of AYAs to pediatric oncology centers diminishing greatly with increasing age, type of cancer diagnosis, and distance to pediatric oncology centers.^{15,16} Furthermore, reduced access to pediatric centers may influence the overall availability of supportive care resources for AYAs, particularly for those diagnosed with malignancies more common in children.¹⁶ While institutional factors can influence treatment practices and access to supportive care (e.g., support groups and financial and care coordination services),¹⁷ physicians are essential for providing the most appropriate therapy and counseling, and referring patients to recommended services, allaying treatment concerns, and providing psychosocial support for transitions back to work or school after treatment.^{1,14} Understanding who treats AYAs with cancer is a crucial first step for the development of best institutional practices and treatment delivery models, as well as improving positive transitions to post-treatment care for AYAs throughout the United States.¹⁴

Based on research recommendations from the AYA Oncology Progress Review Group¹ and recent follow-up workshops from the Institute of Medicine¹⁴ and National Cancer Institute (NCI)¹⁸ regarding the need to characterize providers of AYA cancer care, the NCI's Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study^{19,20} were used to examine the characteristics of physicians and hospitals who treated AYAs recently diagnosed with cancer. Specifically, differences in treating physician characteristics by patient age at diagnosis and cancer type were examined. It was hypothesized that physician specialty, sex, and type of medical practice would vary by cancer type and age at diagnosis.

Methods

Data and participants

The AYA HOPE Study is an observational cohort study fielded in 2008 to examine demographic and cancer-related factors associated with self-reported outcomes such as insurance status, quality of life, and perceived impact of cancer on AYA cancer patients in the United States.¹⁹ Recruitment methods, characteristics of non-respondents, generalizability, study and survey design, and validation have been described in detail elsewhere.¹⁹ Briefly, after obtaining Institutional Review Board approval from the cancer registries involved, the State of California, and the NCI, AYA patients were recruited from seven of the NCI's population-based Surveillance, Epidemiology, and End Results (SEER) registries.²¹ Patients were eligible to be contacted if they were: (1) diagnosed between July 1, 2007, and October 31, 2008; (2) aged 15–39 years at diagnosis; (3) diagnosed with primary

germ cell cancer, non-Hodgkin lymphoma (NHL), Hodgkin lymphoma (HL), acute lymphocytic leukemia (ALL), Ewing sarcoma, osteosarcoma, or rhabdomyosarcoma (as they were common but understudied cancers in the AYA population)¹; and (4) able to read and write in English. An initial survey, healthcare utilization form, and medical records release were mailed to eligible participants ($N=1208$) 6–14 months after diagnosis to allow for completion of initial therapy. The survey and healthcare utilization form queried participants about their demographics, health status, impact of their cancer, quality of life, healthcare delivery, and treating physicians.^{19,22}

Of the 1208 patients identified as eligible for the study, 524 patients responded to the survey. The overall response rate was 43%, comparable to contemporary national surveys that query new respondents about health behaviors and attitudes.^{19,23,24} Characteristics of respondents and non-respondents were similar across cancer type, education, and time from diagnosis. However, Hispanic and non-Hispanic black individuals as well as males were slightly less likely to respond.¹⁹ Of the 524 respondents, 464 provided information about the name and location of the physician(s) who were treating or had treated their cancer at the time of the survey (up to a maximum of four physicians), as well as the name and location of the hospital(s) where they were receiving or had received treatment. This information was used to supplement treatment, physician, and hospital information routinely collected in the 2007–2008 SEER cancer registries and to obtain physician contact information to request medical records for data abstraction.

Physician characteristics

Physician characteristics were obtained by linking the 2008 American Medical Association Physician Masterfile with the physicians reported by the respondents or identified in the SEER cancer registry. The Physician Masterfile contains the most comprehensive information currently available on physician characteristics,^{25,26} including sex (female/male); physician age at patient treatment, calculated by subtracting the physician's birth year from 2008 (≤ 40 , 41–50, 51–64, ≥ 65); foreign born (yes/no), degree (DO, MD); pediatric specialty (yes/no); specialty (pediatric hematology/oncology, hematology/oncology, radiation/oncology, orthopedics, surgical, pediatric medical, medical, other/unknown); United States-trained (yes/no); percent of hours spent in hospital practice (0%, 1–50%, 51–100%); primary responsibilities (direct medical care, medical research/teaching, other/unknown); practice organization (solo or two-person practice, group practice, medical school, governmental hospital, other); whether they practice in multiple offices (yes/no); region of primary practice (Northeast, Midwest, South, West); and population size of the metropolitan statistical area where the practice is located ($<100,000$, 100,000–249,999, 250,000–999,999, $\geq 1,000,000$, unknown).

Hospital characteristics

For those who received care at more than one hospital, patients were assigned to the hospital where they received the most definitive surgery or, if no surgery was given, the most definitive therapy based on information in the medical records and SEER registry data. Using this information, hospital

characteristics were obtained about the primary treating facility from the 2008 American Hospital Association Annual Survey Database²⁷ and SEER, including number of hospital beds (1–199, 200–499, ≥500, or other, such as outpatient facilities), type of hospital (cancer center [NCI-designated or other type], community hospital, other), and whether the hospital had an approved residency program (yes/no).

AYA patient characteristics

Medical records from facilities listed on patients’ healthcare provider forms and from SEER registry data were abstracted to obtain tumor characteristics, staging, comorbidities, cancer type, and patient age at diagnosis. Patients’ perceptions of the quality of care received was assessed in the AYA HOPE survey using a 5-point Likert scale ranging from poor to excellent.

Analyses

In addition to basic descriptive statistics (frequencies and percentages; Tables 1 and 2), differences in physician and hospital characteristics were examined by patient age at diagnosis (15–21 [because pediatric hospitals in the United States typically admit individuals up to the age of 21 years²⁸], 22–30, 31–39; Table 3) and by cancer type (Table 4) using chi-square analyses. Because patients in the AYA HOPE Study could have been treated by multiple physicians, each physician observation was weighted (1/number of physicians treating the AYA patient). While not previously validated, this method reflects the proportional contribution of each physician to the treatment of the study population. For example, a physician who was part of a treating team with four physicians would have a weight of 0.25. Both weighted and unweighted frequencies and weighted percentages are reported. As a sensitivity analysis, cases with unknown physician or hospital characteristics were removed to examine whether this modified the relationship between these characteristics and patient age at diagnosis or cancer type. The findings remained unchanged. Thus, only the original analyses are presented. Analyses were conducted using SAS v9.3 (SAS Institute, Inc., Cary, NC). *p*-Values were two-sided, with *p* < 0.05 considered statistically significant.

Results

Demographic patient and hospital characteristics

The majority of cancer patients in the AYA HOPE Study were male, non-Hispanic white, diagnosed in the early stages of their disease (American Joint Committee on Cancer stage I or II), diagnosed with germ cell cancer or HL, and received chemotherapy with or without surgery as part of their primary treatment. The average patient age at diagnosis was 28.2 years old. Overall patient satisfaction with the quality of care they received was positive, with more than 50% of patients rating quality of care as excellent and 82% indicating excellent or very good care (Table 1). Further, the majority of patients were treated in cancer centers (66%) as opposed to community hospitals, and in hospitals with an approved residency program (64%; Table 1). The study identified 903 physicians who treated 464 AYA patients. Seventeen percent of patients identified only one treating physician, while two, three, and four physicians were identified by 40%, 32%, and 11% of patients, respectively (Table 1).

TABLE 1. DEMOGRAPHIC AND HOSPITAL CHARACTERISTICS OF CANCER PATIENTS

	No. of patients (N = 464)	Percent
Demographic patient characteristics		
Number of treating physicians		
1	79	17.0
2	187	40.3
3	147	31.7
4	51	11.0
Sex		
Male	283	61.0
Female	181	39.0
Race/ethnicity		
Non-Hispanic white	380	81.9
Other	84	18.1
AJCC stage at diagnosis		
I/II	287	61.9
III/IV	112	24.1
Unknown/unstaged	65	14.0
Cancer type		
Acute lymphoblastic leukemia	20	4.3
Germ cell cancer	175	37.7
Hodgkin lymphoma	134	28.9
Non-Hodgkin lymphoma	112	24.1
Sarcoma	23	5.0
Age at diagnosis, in years (Mean [SD])	28.2 [6.7]	—
Treatment		
Radiation ± surgery	51	11.0
Chemotherapy ± surgery	231	49.8
Radiation and chemotherapy	115	24.8
Surgery only	53	11.4
Other	14	3.0
Overall self-perceived quality of care		
Excellent	257	55.4
Very good	125	26.9
Good	57	12.3
Fair/poor	16	3.4
Unknown	9	1.9
Hospital characteristics		
Number of hospital beds ^a		
1–199	93	20.0
200–499	208	44.8
≥500	141	30.4
Outpatient/unknown	22	4.7
Hospital type ^a		
Cancer center, NCI-designated or other type	308	66.4
Community hospital	108	23.3
Other/unknown	48	10.3
Hospital has residency program ^a		
Yes	299	64.4
No	165	35.6

Note. Percentages may not add to 100 due to rounding.

^aHospital characteristics where patient received the most definitive therapy.

AJCC, American Joint Committee on Cancer; NCI, National Cancer Institute; SD, standard deviation.

TABLE 2. DEMOGRAPHIC AND PRACTICE CHARACTERISTICS OF PHYSICIANS

	No. of physicians (N = 903)	Percent
Sex		
Male	699	77.4
Female	183	20.3
Unknown	21	2.3
Physician age at patient treatment (years)		
≤ 40	176	19.5
41–50	275	30.4
51–64	370	41.0
≥ 65	61	6.8
Unknown	21	2.3
United States–born		
No	177	19.6
Yes	592	65.6
Unknown	134	14.8
Degree		
MD	863	95.6
DO	40	4.4
Pediatric specialty		
Yes	44	4.9
No	859	95.1
Primary treating physician specialty		
Pediatric hematology/oncology	26	2.9
Hematology/oncology	240	26.6
Radiation/oncology	106	11.7
Orthopedics	13	1.4
Surgical	188	20.8
Pediatric medical	18	2.0
Medical	230	25.5
Other/unknown	82	9.1
United States–trained		
Yes	725	80.3
No	178	19.7
% hours spent in hospital practice		
0	506	56.1
1–50	206	22.8
51–100	170	18.8
Unknown	21	2.3
Primary responsibility		
Direct medical care	793	87.8
Medical research/teaching	50	5.5
Other/unknown	60	6.7
Practice organization		
Solo or two-person practice	123	13.6
Group practice	516	57.1
Medical school	45	4.9
Government hospital	96	10.6
Other/unknown	123	13.6
Multiple offices		
Yes	223	24.7
No	659	73.0
Unknown	21	2.3
Practice address region		
Northeast	9	1.0
Midwest	213	23.6
South	146	16.2
West	511	56.6
Unknown	24	2.6

(continued)

TABLE 2. (CONTINUED)

	No. of physicians (N = 903)	Percent
Size of MSA where practice is located		
<100,000	39	4.3
100,000–249,999	58	6.4
250,000–999,999	126	14.0
≥ 1,000,000	659	73.0
Unknown	21	2.3

Note. Percentages may not add to 100 due to rounding. MSA, Metropolitan Statistical Area.

Physician characteristics

Physicians were predominately male (77%), 51–64 years old (41%), born in the United States (65%), MDs (95.6%), in non-pediatric specialties (95%), and United States–trained (80%; Table 2). Additionally, fewer than half practiced in a hospital setting (44%), while the majority were primarily engaged in direct medical care (88%) as opposed to medical research/teaching and were part of a group practice (57%). Most physicians practiced in a single office (73%) and in large metropolitan areas (73% practiced in cities with populations ≥ 1,000,000).

Physician and hospital characteristics by patient age

Although the number of patients treated by pediatric specialties was low overall (5%), of those, older patients were less often treated by pediatric physicians (0.4% 31–39 year olds vs. 23% 15–21 year olds, $p < 0.01$; Table 3). Furthermore, older patients were more likely to be treated by United States–trained physicians (83% 31–39 years olds vs. 80% 15–21 year olds, $p = 0.04$) and by physicians without research or teaching responsibilities (91% 31–39 year olds vs. 84% 15–21 year olds, $p < 0.01$). Younger patients were seen in hospitals with approved residency programs more often than older patients (60% 31–39 year olds vs. 70% 15–21 year olds, $p = 0.05$; Table 3).

Physician and hospital characteristics by patient cancer type

Physician characteristics also varied by patient cancer type (Table 4). A large proportion of pediatricians ($n = 44$) treated those with ALL (42% of physicians treating ALL patients had a pediatric specialty vs. 0.9% for germ cell cancers, $p < 0.01$). Patients with germ cell cancers were primarily treated by surgical specialists (39%), while hematologists/oncologists tended to treat HL (40%), NHL (41%), and sarcoma (24%) patients. Furthermore, patients with ALL and HL were more likely to be treated by physicians in non-hospital based practices (i.e., have 0% of hours spent in hospital practice, $p < 0.001$). Physicians with research/teaching responsibilities were more likely to treat patients with ALL and sarcoma compared with other types of cancer ($p < 0.01$ for both). The majority of physicians were employed by a group practice (57%). Furthermore, physicians based in a medical school were more likely to treat sarcomas compared with other cancer types ($p < 0.01$). Patients with HL and ALL were more likely to be treated in larger hospitals compared with other

TABLE 3. CHARACTERISTICS OF PHYSICIANS AND HOSPITALS BY PATIENT AGE AT DIAGNOSIS

	n [weighted ^a n]	Patient age in years at diagnosis (percent)			p-Value
		15–21	22–30	31–39	
Total number [weighted ^a n]	1098 [464]	212 [92]	435 [185]	451 [187]	
<i>Physician characteristics</i>					
<i>Sex</i>					
Male	858 [369.3]	73.6	82.0	80.1	0.10
Female	218 [86.9]	25.1	16.2	18.1	
Unknown	22 [7.8]	1.3	1.8	1.7	
<i>Physician’s age at patient treatment (years)</i>					
≤40	207 [88.1]	14.4	19.5	20.7	0.53
41–50	354 [152.9]	33.7	30.5	35.0	
51–64	445 [187.8]	43.8	42.5	36.9	
≥65	70 [27.3]	6.9	5.6	5.7	
Unknown	22 [7.8]	1.3	1.8	1.7	
<i>United States–born</i>					
No	215 [87.8]	16.1	16.9	22.3	0.18
Yes	716 [307.4]	68.8	66.3	64.9	
Unknown	167 [68.8]	15.0	16.8	12.7	
<i>Degree</i>					
MD	1055 [449.8]	99.2	96.4	96.4	0.05
DO	43 [14.3]	0.8	3.6	3.6	
<i>Pediatric specialty</i>					
Yes	54 [23.3]	22.5	0.9	0.4	<0.0001
No	1044 [440.8]	77.5	99.1	99.6	
<i>Primary treating physician specialty</i>					
Pediatric hematology/oncology	34 [14.2]	15.1	0.1	—	<0.0001 ^b
Hematology/oncology	330 [148.3]	24.1	33.0	34.8	
Radiation/oncology	139 [55.7]	8.3	12.9	12.9	
Orthopedics	22 [9.3]	3.1	1.9	1.5	
Surgical	209 [93.2]	15.9	21.0	21.2	
Pediatric medical	20 [9.1]	7.3	0.8	0.4	
Medical	251 [100.9]	20.7	21.7	22.4	
Other/unknown	93 [33.5]	5.4	8.5	6.8	
<i>United States–trained</i>					
Yes	869 [369.7]	79.8	76.0	83.2	0.04
No	229 [94.3]	20.2	24.0	16.8	
<i>% hours spent in hospital practice</i>					
0	620 [264.5]	56.2	54.6	59.8	0.72
1–50	239 [103.3]	22.0	24.8	19.9	
51–100	217 [88.3]	20.6	18.8	18.5	
Unknown	22 [7.8]	1.3	1.8	1.7	
<i>Primary responsibility</i>					
Direct medical care	971 [410.3]	84.2	87.8	91.1	<0.0001
Medical research/teaching	61 [27.0]	11.8	5.1	3.6	
Other/unknown	66 [26.7]	4.0	7.1	5.3	
<i>Practice organization</i>					
Solo or two-person practice	139 [59.6]	11.1	13.0	13.5	0.22
Group practice	622 [256.5]	51.0	52.5	60.1	
Medical school	65 [28.2]	7.5	7.3	4.1	
Government hospital	134 [62.8]	15.6	14.6	11.4	
Other/unknown	138 [56.9]	14.8	12.5	10.8	
<i>Multiple offices</i>					
Yes	265 [113.7]	22.7	24.9	25.0	0.94
No	811 [342.5]	76.0	73.3	73.3	
Unknown	22 [7.8]	1.3	1.8	1.7	

(continued)

TABLE 3. (CONTINUED)

	n [weighted ^a n]	Patient age in years at diagnosis (percent)			p-Value
		15–21	22–30	31–39	
Practice address region					
Northeast	12 [4.8]	0.9	1.8	0.3	0.39
Midwest	255 [90.3]	16.7	19.6	20.7	
South	176 [74.8]	16.6	14.4	17.6	
West	630 [285.2]	64.3	61.8	59.7	
Unknown	25 [9.1]	1.5	2.4	1.7	
Size of MSA where practice is located					
<100,000	41 [15.8]	4.2	3.5	2.9	0.67
100,000–249,999	71 [31.3]	7.2	5.9	7.3	
250,000–999,999	150 [60.9]	10.1	12.1	15.6	
≥ 1,000,000	814 [348.1]	77.3	76.6	72.4	
Unknown	22 [7.8]	1.3	1.8	1.7	
Hospital characteristics					
Number of hospital beds					
1–199	211 [93]	25.0	20.5	17.1	0.24
200–499	490 [208]	42.4	44.9	46.0	
≥ 500	344 [141]	27.2	31.4	31.0	
Outpatient/unknown	53 [22]	5.4	3.2	5.9	
Hospital type					
Cancer center, NCI-designated, or other type	746 [308]	65.2	63.8	69.5	0.11
Community hospital	247 [108]	25.0	27.0	18.7	
Other/unknown	105 [48]	9.8	9.2	11.8	
Hospital has residency program					
Yes	707 [299]	69.5	66.5	59.9	0.04
No	391 [165]	30.4	33.5	40.1	

Note. Sample size = 1098 physician observations for 464 patients. Percentages may not add to 100 due to rounding.

^aWeighted by the number of physicians who treated a patient.

^bDue to small numbers, *p*-value calculation excludes pediatric hematology/oncology. NCI, National Cancer Institute.

patients (i.e., those with ≥ 500 beds, *p* < 0.01). Finally, 95% of ALL patients were treated at a cancer center, compared with 56% of patients with germ cell cancer (*p* < 0.01). ALL (85%) and sarcoma (87%) patients were more likely to be treated in hospitals with residency programs compared with those with germ cell (59%) or other cancers (*p* < 0.01).

Discussion

In this population-based study of AYA cancer patients with germ cell cancers, HL and NHL, ALL, and sarcomas, it was found that the majority of patients were treated by non-pediatric, community-based physicians in non-research/training practices, although select physician characteristics significantly varied by patient cancer type and age at diagnosis. Because of varying treatment settings and opportunities to fall into the gap between pediatric and adult oncology, future program development must be tailored to the unique needs of this AYA population.^{17,29} Further, as this group may be treated by a number of specialists or general practitioners, care for the AYA cancer population must be carefully coordinated to reduce the risk of potential loss to follow-up. This will require a multidisciplinary team of specialists and care coordinators.^{7,29,30}

It was found that the types of physicians who treat AYAs varied by patient age at diagnosis. In particular, treatment by

a physician in a pediatric specialty diminished greatly with age. Although no study, to the authors' knowledge, has evaluated these physician patterns in the older AYA population, Albritton et al. found that among 15–19 year olds in the Utah Cancer Registry, utilization of a pediatric cancer center dropped significantly with increasing age and was only minimally influenced by type of diagnosis or distance from a pediatric cancer center.¹⁵ In a study of the Georgia Cancer Registry, Howell et al. found that 15–19 year olds were less likely to be referred to a Children's Oncology Group institution, that is, a hospital participating in NCI-supported clinical trials aimed at childhood and adolescent cancers, than children <15 years of age, potentially exposing them to worse outcomes within some cancer subtypes.¹⁶ The present work goes beyond these studies to examine treatment patterns across the entire AYA age spectrum, finding continued patterns of decreasing use of pediatric physicians with increasing age. As pediatric protocols tend to involve more aggressive treatment plans that can be associated with better prognosis compared to non-pediatric protocols,^{13,16} future research should continue to examine optimal treatment settings that produce the highest quality of life and long-term outcomes for AYAs.

Additionally, it was found that only a small percentage of physicians who treated AYA cancer patients were involved in medical research or worked within a medical school setting, a pattern that was inversely associated with patient age at

TABLE 4. CHARACTERISTICS OF PHYSICIANS AND HOSPITALS BY PATIENT CANCER TYPE

	n [weighted ^a n]	Patient cancer type (percent)					p-Value
		ALL	Germ cell	Hodgkin lymphoma	Non-Hodgkin lymphoma	Sarcoma	
Total number [weighted ^a n]	1098 [464]	43 [20]	396 [175]	337 [134]	266 [112]	56 [23]	
<i>Physician characteristics</i>							
Sex							
Male	858 [369.3]	68.8	84.0	79.3	76.3	73.2	0.053
Female	218 [86.9]	29.6	14.7	19.9	20.8	23.6	
Unknown	22 [7.8]	1.7	1.3	0.8	3.0	3.3	
Physician's age at patient treatment (years)							
≤40	207 [88.1]	10.0	18.9	23.1	17.1	12.3	0.23
41–50	354 [152.9]	34.2	33.3	34.0	33.0	22.9	
51–64	445 [187.8]	44.2	40.1	37.7	40.3	57.6	
≥65	70 [27.3]	10.0	6.3	4.4	6.7	4.0	
Unknown	22 [7.8]	1.7	1.3	0.8	3.0	3.3	
United States–born							
No	215 [87.8]	10.8	20.2	19.0	19.9	11.2	0.27
Yes	716 [307.4]	75.8	66.5	66.6	61.2	78.3	
Unknown	167 [68.8]	13.3	13.2	14.4	18.9	10.5	
Degree							
MD	1055 [449.8]	98.3	96.7	95.3	98.3	100.0	0.17 ^b
DO	43 [14.3]	1.7	3.3	4.7	1.7	—	
Pediatric specialty							
Yes	54 [23.3]	41.7	0.9	4.5	4.0	12.7	<0.0001
No	1044 [440.8]	58.3	99.1	95.5	96.0	87.3	
Primary treating physician specialty							
Pediatric hematology/ oncology	34 [14.2]	24.6	0.4	2.5	2.9	8.3	<0.0001 ^c
Hematology/oncology	330 [148.3]	27.1	21.6	39.9	41.1	23.6	
Radiation/oncology	139 [55.7]	1.7	11.2	14.7	10.6	17.8	
Orthopedics	22 [9.3]	—	0.2	0.4	1.4	29.7	
Surgical	209 [93.2]	1.7	39.1	10.1	8.6	5.1	
Pediatric medical	20 [9.1]	17.1	0.5	1.9	1.1	4.3	
Medical	251 [100.9]	25.0	22.2	22.6	22.5	6.9	
Other/unknown	93 [33.5]	2.9	4.7	7.9	11.7	4.3	
United States–trained							
Yes	869 [369.7]	79.2	79.6	79.9	78.3	86.2	0.83
No	229 [94.3]	20.8	20.4	20.1	21.7	13.7	
% hours spent in hospital practice							
0	620 [264.5]	62.9	54.9	61.8	56.6	42.0	<0.0001
1–50	239 [103.3]	23.3	29.1	18.6	16.1	20.3	
51–100	217 [88.3]	12.1	14.7	18.8	24.3	34.4	
Unknown	22 [7.8]	1.7	1.3	0.8	3.0	3.3	
Primary responsibility							
Direct medical care	971 [410.3]	65.8	93.3	87.7	88.5	75.0	<0.0001
Medical research/ teaching	61 [27.0]	30.0	2.1	5.6	5.0	18.1	
Other/unknown	66 [26.7]	4.2	4.6	6.7	6.5	6.9	
Practice organization							
Solo or two-person practice	139 [59.6]	7.5	16.1	8.8	13.3	13.8	<0.0001
Group practice	622 [256.5]	62.9	57.7	59.5	49.3	35.1	
Medical school	65 [28.2]	8.3	4.6	4.9	6.7	19.6	
Government hospital	134 [62.8]	12.1	9.9	15.0	17.0	17.8	
Other/unknown	138 [56.9]	9.2	11.8	11.8	13.8	13.8	
Multiple offices							
Yes	265 [113.7]	19.6	25.8	23.6	23.3	29.7	0.53
No	811 [342.5]	78.8	72.9	75.6	73.7	67.0	
Unknown	22 [7.8]	1.7	1.3	0.8	3.0	3.3	

(continued)

TABLE 4. (CONTINUED)

	n [weighted ^a n]	Patient cancer type (percent)					p-Value
		ALL	Germ cell	Hodgkin lymphoma	Non-Hodgkin lymphoma	Sarcoma	
<i>Practice address region</i>							
Northeast	12 [4.8]	1.3	0.6	1.5	1.3	—	<0.0001 ^b
Midwest	255 [90.3]	23.3	20.0	24.4	13.8	10.9	
South	176 [74.8]	28.8	10.6	20.8	18.2	9.8	
West	630 [285.2]	45.0	67.1	52.1	63.8	76.1	
Unknown	25 [9.1]	1.7	1.8	1.2	3.0	3.3	
<i>Size of MSA where practice is located</i>							
<100,000	41 [15.8]	2.5	2.8	4.6	3.0	4.3	0.12 ^b
100,000–249,999	71 [31.3]	10.8	4.4	9.0	6.3	9.8	
250,000–999,999	150 [60.9]	13.3	11.4	15.7	15.4	—	
≥1,000,000	814 [348.1]	71.7	80.0	69.9	72.3	82.6	
Unknown	22 [7.8]	1.7	1.3	0.8	3.0	3.3	
<i>Hospital characteristics</i>							
<i>Number of hospital beds</i>							
1–199	211 [93]	30.0	18.9	23.1	19.6	4.3	<0.0001 ^d
200–499	490 [208]	30.0	47.4	28.1	49.1	56.5	
≥500	344 [141]	40.0	30.3	31.3	28.6	26.1	
Outpatient/unknown	53 [22]	—	3.4	7.5	2.7	13.0	
<i>Hospital type</i>							
Cancer center, NCI-designated, or other type	746 [308]	95.0	56.0	73.1	70.5	60.9	<0.0001 ^d
Community hospital	247 [108]	—	32.6	19.4	20.5	8.7	
Other/unknown	105 [48]	5.0	11.4	7.5	8.9	30.4	
<i>Hospital has residency program</i>							
Yes	707 [299]	85.0	58.9	60.4%	69.6	87.0	<0.0001
No	391 [165]	15.0	41.1	39.6	30.4	13.0	

Note. Sample size = 1098 physician observations for 464 patients. Percentages may not add to 100 due to rounding.

^aWeighted by the number of physicians who treated a patient.

^bDue to small cell sizes, *p*-values exclude patients with sarcoma.

^cDue to small cell sizes, *p*-values exclude patients seen by orthopedics.

^dDue to small cell sizes, *p*-values exclude patients with ALL.

ALL, acute lymphoblastic leukemia.

diagnosis. Further, the majority of treating physicians spent no time in a hospital, a finding that did not differ by patient age. Combined, these findings could have significant implications for access to clinical trials, and thus access to state-of-the-art therapy and more favorable long-term outcomes. In prior work, the authors found the lowest rates of clinical trial participation were in older AYAs (35–39 vs. 15–19 year olds) and AYAs treated by non-pediatric specialties, with care coordination and access issues (e.g., distance to facilities offering trials) and patient/physician knowledge about available trials found to be possible contributing factors.³¹ Whether the fact that older AYAs are rarely treated by physicians in medical research or teaching positions or that work in a hospital setting could also contribute to a relative lack of clinical trial access has yet to be studied.

The present study additionally identified differences by cancer in the types of physicians who treated AYAs. Not surprisingly, physicians with surgical specialties predominately treated germ cell cancers; hematologists/oncologists predominantly treated HL, NHL, and sarcomas; and physicians with pediatric specialties tended to treat ALL (likely due to the lower age at diagnosis of ALL patients in this study). Further, physicians with research/teaching responsi-

bilities and those based in medical schools were more likely to treat patients with ALL and sarcoma, while those treating patients with sarcoma and NHL were more likely to be hospital-based compared with other specialties. Finally, 95% of ALL patients were treated at a cancer center, compared with 56% of patients with germ cell cancer.

For any particular cancer type, the treatment location, specialty, and expertise of treating physicians can provide a compelling reason for patients to seek out or be referred to specific providers. Several previous studies have demonstrated a survival advantage for children treated by specialists in pediatric oncology centers when diagnosed with a traditional pediatric malignancy.^{6,32–34} In a study of Ewing sarcoma patients, adolescents >15 years of age treated at pediatric centers experienced improved survival compared to those treated at non-pediatric centers, despite receiving the same treatment protocol.³⁵ A study from the National Cancer Database found that adolescents 15–19 years old with non-Hodgkin lymphoma, leukemia, liver cancer, and bone tumors experienced improved survival if they were treated at an NCI Children's Oncology Group institution.³² Further, in a study from the Georgia Cancer registry, Bleyer demonstrated that adolescents with traditionally pediatric cancers have

improved outcomes if cared for by pediatric specialists. Additionally, Bleyer found that adolescents diagnosed with more common adult types of cancer have improved outcomes if treated on adult treatment regimens or if their care is coordinated by an adult-treating oncologist.³⁶ While studies to compare health outcomes across different provider characteristics and treatment locations are challenging due to the small number of AYA patients with each cancer type, continued research on this topic is needed (particularly for cancers not represented in this study) in order to create evidence-based guidelines to enhance current recommendations for providing optimal AYA cancer care.^{29,37}

This study provides valuable insights into the characteristics of physicians treating AYA cancer patients, although some limitations are acknowledged. First, due to the timing of data collection, all patients may not have completed therapy at the time of survey and, as a result, some treating physicians may not have been reported. However, no significant differences were found in physician characteristics by time between diagnosis and survey. Second, it was not possible to identify the primary treating physician or how many times patients were seen by each physician. However, a diverse combination of medical records, cancer registry data, and patient-reported treatment was used to obtain a comprehensive picture of the treating physicians. Future studies should also incorporate information about non-physician providers (e.g., nurse practitioners), as these multidisciplinary teams may provide new opportunities for innovative treatment and medical education models in AYA oncology. Third, it was not possible to conduct multivariable analyses of physician characteristics by cancer type and patient age at diagnosis due to sample size limitations. However, this study provides a starting point for clinicians and policy makers to understand the diverse treatment environment in which AYAs with cancer are treated to ensure that work continues toward improving long-term outcomes in this population.

Conclusion

Overall, this study provides insights into the characteristics of physicians who treat AYAs with cancer. Although most AYAs with cancer were treated by non-pediatric physicians in non-academic settings, select physician characteristics significantly varied by patient cancer type and age at diagnosis. These findings can be used to develop effective programming and care coordination to ensure AYAs receive optimal cancer care and supportive services that are age appropriate and tailored to their diagnosis. Future research should focus on examining whether physician characteristics impact patient retention for follow-up care and cancer outcomes in AYA cancer patients.

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