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Knowledge of Clinical Trial Availability and Reasons for Non-Participation Among Adolescent and Young Adult Cancer Patients: A Population-Based Study

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Abstract

PURPOSE—Adolescent and young adult (AYA) cancer patients are under-represented in clinical trials, but the reasons for this phenomenon are unknown.

PATIENTS AND METHODS—Questionnaire and medical record data from 515 AYA cancer patients (21 acute lymphocytic leukemia [ALL], 201 germ cell [GCT], 141 Hodgkin lymphoma [HL], 128 non-Hodgkin lymphoma [NHL], 24 sarcoma) from a population-based study were analyzed. We used multivariable models to determine characteristics associated with patient knowledge of the availability of clinical trials for their cancer. Reasons for not participating in a trial were tabulated.

RESULTS—63% of patients reported not knowing whether a relevant clinical trial was available, 20% reported knowing that a clinical trial was not available, and 17% reported that a trial was available. Among patients reporting an available trial, 67% were recommended for enrollment. Knowing about the availability of clinical trials was associated with having ALL (odds ratio [OR]=2.9, 95% confidence interval [CI]=1.1,7.8). Reporting that a clinical trial was available was positively associated with having ALL, HL, NHL and sarcoma (relative to GCT) and working full-time or in school full-time (OR=2.6, 95% CI=1.0, 6.7). Concerns about involvement in research (57%) and problems accessing trials (21%) were the primary reasons cited for not enrolling among patients who knew that a trial was available.

CONCLUSION—Improvement in AYA cancer patient clinical trial enrollment will require enhancing knowledge about trial availability and addressing this population's concerns about participating in medical research.

Keywords

clinical trials; cancer; adolescents; young adult

INTRODUCTION

Cancer is the leading cause of nonaccidental death among adolescents and young adults (AYA)[1]. Studies have shown that participation of AYA (ages 15-39 years) cancer patients in clinical treatment trials is strikingly lower than in younger or older patients.[1-4] Low clinical trial participation reduces opportunities to improve knowledge of cancer management, and has been correlated with the lack of improvement in outcome for AYA cancer patients.[5] Thus, understanding the factors that influence clinical trial participation among AYA cancer patients is essential to making progress in the treatment and survival of this population.

A recent population-based study of 1,358 AYA cancer patients found that participation in clinical trials was positively associated with management by a pediatric oncologist

and having health insurance, independent of demographic characteristics and tumor type.[6] However, previous studies have not addressed whether these characteristics or others influence an AYA patient's awareness of trials for which he or she might be eligible, or whether enrollment in a trial was recommended by a physician. In addition, no studies have assessed underlying reasons that AYA cancer patients with knowledge of available or recommended relevant clinical trials do not participate in them. We used data from the population-based AYA Health Outcomes and Patient Experience (AYA HOPE) Study[7] to address these gaps in knowledge.

METHODS

Overview of AYA HOPE study

Briefly, eligible patients were residents of seven geographically-defined U.S. regions covered by the U.S. National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) Program, aged 15-39 when diagnosed with germ cell tumor (GCT), non-Hodgkin lymphoma (NHL), Hodgkin lymphoma (HL), acute lymphocytic leukemia (ALL), or sarcoma (Ewing's sarcoma, osteosarcoma, or rhabdomyosarcoma) between July 1, 2007 and October 31, 2008.[7] Of the 1,309 eligible patients who were alive at the start of recruitment, 524 completed the baseline questionnaire 6-14 months after diagnosis, and medical record data through the first course of treatment were abstracted for 490. This analysis is based on 515 patients for whom self-administered questionnaire data were available (of the 524 completed questionnaires, one was lost, and the questionnaires of eight patients were missing responses to all questions regarding clinical trials).

Clinical trial availability and participation measures

The self-administered questionnaire explained that “Clinical trials are research studies that may include surgery, radiation, chemotherapy, drugs or other treatments. Clinical trials are sometimes called experimental studies or protocols.” Each patient was asked whether there were “...clinical trials or experimental studies available for their type or stage of cancer” with possible answers being “Yes,” “No,” or “Don't Know.” Among those who responded “Yes”, the questionnaire asked whether their doctor ever recommended a clinical trial and whether they had participated in one. Those patients who reported that a clinical trial was available but had not participated were asked to agree or disagree with each of 9 possible reasons for their non-participation. Finally, trained abstractors reviewed medical records and recorded the protocol sponsor and identification number, if any, on which each patient was registered. We excluded protocols that were not treatment-based according to the clinicaltrials.gov. No attempt was made to discern patient or physician knowledge or preferences for clinical trial participation via review of medical records.

Other characteristics included in the analysis

Medical records provided information on each patient's co-morbid conditions, health insurance status from diagnosis through treatment (insured vs. not insured), hospital type (NCI-designated cancer center, other cancer center, pediatric, academic, community, as well as combinations of these designations), hospital bed size (<300, 300-499, 500+), hospital residency program approval (yes, no), physician sub-specialty (medical oncology

[including hematology, hematology/oncology, oncology and pediatric oncology] vs. not medical oncology [including radiation oncology, general surgery, orthopedic surgery, internal medicine, other, or unknown]). We coded up to four physician specialties; patients treated by a medical oncologist were classified in that group for analysis. Data on hospital size and residency programs were based on American Hospital Association publications at time of diagnosis. For patients receiving treatment at multiple facilities, only the facility where most definitive treatment was given was coded. The self-administered questionnaire provided information on race/ethnicity (White-Hispanic, White-Non-Hispanic, Other) and employment/education status at diagnosis (full-time work, full-time school, not full-time work or school). Finally, cancer registry records provided data on each patient's cancer type, sex, age at diagnosis, and stage at diagnosis (AJCC I, II, III, IV or unstaged).

Statistical analyses

The main outcome measures were knowledge of availability of, and recommendations to enroll in, clinical trials. We classified patients as knowing the availability status of clinical trials (i.e., knowing whether a relevant clinical trial was available) if they responded “Yes” or “No” to the question regarding whether clinical trials were available for their type or stage of cancer, and not knowing the availability status of clinical trials if they responded “Don't know.” Among those who knew the availability status of clinical trials for their type or stage of cancer, we classified patients as reporting that a clinical trial was available vs. reporting that a clinical trial was not available. Analyses of the frequency of reported reasons for non-participation in clinical trials were restricted to patients who reported knowing that a clinical trial was available but who did not participate in a trial (either by self-report or medical record abstraction). We grouped the reasons into two categories representing access to, or concerns about involvement in clinical trials. A patient thus could be classified as reporting an “Access Reason,” a “Concern Reason,” or both. Multivariable logistic regression models were used to estimate odds ratios (OR) and corresponding 95% confidence intervals (CI), between patient, physician, and treating institution characteristics and whether the patient knew about the availability of clinical trials and whether clinical trials were available (among patients who knew about the availability of clinical trials). There were too few patients who reported that a relevant clinical trial was available to conduct multivariable analyses of characteristics related to having a physician recommend enrollment. Models that included stage at diagnosis and cancer type excluded patients with missing stage information and ALL patients since these malignancies are not staged. Associations between patient characteristics and reasons for non-participation in clinical trials were not assessed due to the small number of subjects from which reasons were elicited.

RESULTS

Among participating patients (n=515), GCT was the most common tumor type followed by HL and NHL (Table 1); together these patients comprised over 90% of the study population. Approximately 70% of the patients had relatively early stage disease (AJCC stage I or II) and approximately two-thirds were male. The majority of the patients were 25+ years of age diagnosis (69%) and non-Hispanic white (59%). Almost all participants were insured (97%). Approximately one-half of patients were seen by a medical oncologist, but <2% were

managed at a pediatric institution (data not shown). Approximately two-thirds were cared for at a cancer center; a minority was seen at NCI-designated cancer centers.

Knowledge of, and Opportunities for Participation in, Clinical Trials

The majority of patients (324/515, 63%) did not know whether or not a clinical trial was available (Table 2). Patients who had ALL or who were younger at diagnosis (<30 years) were more likely to know whether a clinical trial was available than patients with other cancer types or older subjects, respectively. ALL patients were more likely than GCT patients to know whether a relevant trial was available (age-adjusted OR=2.9, 95% CI = 1.1, 7.8) (Table 3); there was no statistically significant difference between GCT and other cancer types. In a multivariable model that excluded ALL patients, age at diagnosis, stage, employment or educational status (Table 3) were not significantly associated with knowing about availability of relevant clinical trials.

Among those patients who knew whether a clinical trial was available, 45% (86/191) reported that a clinical trial was available for their type and stage of cancer. These individuals constituted 17% of all study participants. ALL and sarcoma patients were more likely than patients with other cancers to report that a trial was available, as were patients (other than those with ALL) whose disease was stage III or IV, or who were working full-time or in school full-time at diagnosis, whose treating physician was a medical oncologist, or at an institution with a residency training program (Table 2). In a multivariable model excluding ALL (due to small numbers), patients with HL, NHL, and sarcoma were more likely than GCT patients to know that a clinical trial was available, as were patients who had stage III or IV disease, were treated at an institution with a residency training program, or were working full-time or being in school full-time (Table 3). No association was observed between reporting that a clinical trial was available and diagnosis age or being treated by a medical oncologist.

Of the 86 patients who reported that a trial was available for their type and stage of cancer, 78 responded to the question regarding whether a clinical trial was recommended to them by their doctor; 67% of the responders said that a trial was recommended (Table 2). Patients who had a trial recommended tended to be younger at diagnosis and full-time students, have ALL or GCT, or have none or one co-morbid conditions.

Of 490 patients for whom medical record abstracts were completed, 27 (5.5%) had a clinical trial protocol number. Of the 515 patients who completed the self-administered questionnaire, 31 (6%) replied that they had participated in a clinical trial; these individuals comprised 36% of the patients who indicated that they knew of a clinical trial for their cancer. Among the 478 patients with data on clinical trial participation from both sources, the agreement between the two measures was low (Kappa = 0.16). Only 22.2% (6/27) of patients whose medical record indicated clinical trial participation also reported being a clinical trial participant on their questionnaire; a much smaller percent (4.9%, 24/490) of patients whose medical record did not indicate clinical trial participation reported they were clinical trial participants via the questionnaire.

Reasons for Not Participating in a Clinical Trial

Among the 44 patients who reported knowing that a clinical trial was available, but who did not participate in a trial (according to either the medical record or self-report), approximately two-thirds reported one or more reason for not participating (Table 4). The majority (56.8%) of trial non-participants reported one or more concerns; approximately one-fifth reported one or more access reasons, and a small proportion (11.4%) reported both types of reasons. The most frequently reported concern was that the experimental treatment had not been sufficiently tested (38.6%), followed by worry about side effects (31.8%). The most commonly reported access issue was being too sick to enroll in a trial (18.2%).

DISCUSSION

Our study sought to understand reasons for the low proportion of AYA cancer patients that participate in clinical trials,[2,3,5] focusing on patient knowledge of, and physician recommendation to enroll in, available trials. We found that almost two-thirds of patients reported not knowing whether a clinical trial was available, and among those who knew about clinical trial availability, slightly more than one-half reported that a trial was not available. Thus, only a relatively small proportion of all patients (~17%) reported knowing that a relevant trial was available. This figure is larger than the nine percent reported by the only prior study that assessed, among adult cancer patients of unspecified age, awareness of clinical trial availability.[8]

Since patient knowledge of clinical trial availability is necessary for clinical trial enrollment, we might expect some of our findings to parallel, but be weaker than, those of Parsons et al. and Collins et al., who studied factors associated with clinical trial participation in a much larger number of AYA patients with many of the same types of cancer as in our study.[6,9] Our observation that knowledge about clinical trial availability was strongly associated with having ALL, lymphomas, and sarcomas (compared to GCT) is consistent with both of these studies and the generally more aggressive nature, and thus challenging management, of these malignancies. Parsons et al. also found that clinical trial enrollment by AYA cancer patients was strongly and independently associated with being managed by a pediatric oncologist.[6] As only 4% of our patients were seen in pediatric institutions, our relatively small sample size prevented us from assessing whether being managed by a pediatric oncologist is similarly associated with knowledge of available clinical trials.

The proportion of AYA cancer patients in our study that participated in a therapeutic clinical trial, whether measured through medical record abstracts or through questionnaire data, was approximately 6%. This figure is similar to a recent multi-institution cancer center-based study that relied on medical record review,[9] but substantially lower than the 14% reported by Parsons et al. based on a combination of medical record review and physician verification letters.[6] However, the study population in Parsons et al. included a larger proportion of patients with ALL and sarcoma, two types of AYA cancers that have particularly poor prognosis and for which treatment trials are more likely to be available and of interest to patients. Indeed, 37% of ALL and 32% of sarcoma patients in that study had participated in clinical trials.[6] In our study, medical record-documented participation in clinical trials also varied by cancer type: ALL and sarcoma patients participated in high proportions (38% and

28%, respectively) compared to patients with other cancers (<5%). Such variation illustrates the limitation of drawing inferences about AYA cancer patient clinical trial participation without reference to specific cancer types. Finally, eligible patients that did not participate in AYA HOPE because they were too ill with their disease or had died prior to recruitment likely represent a group of patients with more severe disease at diagnosis, and who may have been more likely to have known about, been invited to join, and participated in, a clinical trial.

To our knowledge, our study is the first to measure clinical trial participation using both subject reports and medical records. The poor concordance we observed between these two sources of data could have multiple explanations. Under-reporting of participation by patients relative to their medical records probably is due primarily to incorrect memory, as it seems unlikely that a medical record would mistakenly indicate that a patient was enrolled in a clinical trial when he or she was not. Over-reporting of participation by patients relative to medical records could be due to incomplete documentation in medical records or failure of our study to obtain the specific records containing clinical trial registration information. Alternatively, patients may have recalled participation in a research study that was not a clinical trial, thought that being on a specific treatment protocol meant being enrolled in a trial, or participated in a clinical trial for disease recurrence rather than the primary tumor. Future studies seeking to understand in greater depth the reasons for low clinical trial participation by eligible AYA patients will need to be designed such that those who do and do not enroll can be identified with greater confidence.

Our study is also the first to address the extent to which AYA cancer patients are reluctant to participate in trials when given the opportunity, and reasons for non-participation.[10] Our findings suggest that the major reason that AYA cancer patients do not participate in clinical trials when opportunities exist is concern about being a participant in medical research, as opposed to problems with access. Studies of cancer patients of wider age range also report that concerns about being a research subject are major reasons for electing not to participate,[10,11] and that these issues are rarely discussed.[12] To our knowledge no strategies for addressing such concerns and improving clinical trial enrollment have been evaluated.

There are several important limitations to our study. A relatively low proportion of eligible cancer patients participated in AYA HOPE; however, while participants in this study were more likely to be female and less likely to be of Hispanic or Black race/ethnicity (versus non-Hispanic white) compared to all eligible patients, they did not differ by age, census tract-based measures of education or median family income, or cancer type.[7] Nonetheless, it is possible that our estimates of knowledge of clinical trial availability or recommendation would be higher or lower if eligible AYA cancer patients who did not participate would have had different responses to our questions about these topics. Our sample size was relatively small and thus we likely lacked statistical power to identify more completely those factors that are associated with being aware of, or being recommended to enroll in, clinical trials. The small sample size also prevented us from determining whether characteristics of our patients were associated with the commonly cited reasons for non-participation. Another limitation is that we do not know which specific trials were available to, and appropriate for, the patients in our study because there is no comprehensive source of such detailed

information. And, if no trials were available, physicians may not have informed patients of this fact, leading us to overestimate the proportion of patients not knowing about clinical trial availability and underestimating the proportion who knew that a trial was not available. Finally, study patients completed questionnaires up to 14 months following diagnosis, possibly affecting their memories of clinical trial information. For example, patients may have forgotten their awareness of a trial when their initial treatment was planned, or become more aware of relevant trials during the ensuing months, leading to under- and overestimates of knowledge of trials, respectively. To the extent that such misclassification of their true knowledge of trials or recommendation by physicians is unrelated to the factors we investigated, the associations we report would be spuriously weak and some associations may have gone undetected.

The principal strengths of our study are that it is population-based, covers multiple U.S. geographic areas, and includes an ethnically-diverse set of patients of the cancer types that are particularly common in the AYA population.

Our findings suggest that enhancing AYA cancer patient clinical trial participation requires improving communication about the availability of relevant trials to each patient. Successful communication, however, depends heavily on physicians who are the gatekeepers to enrollment[13-15]. Unfortunately, multiple substantial barriers severely reduce cancer physician awareness of, and involvement in, clinical trials.[16] While addressing such barriers has been recognized as a critical component of improving the impact of cancer clinical trials[16], our study also points to the need for developing, testing, and implementing strategies that help address legitimate AYA cancer patient concerns about participating in medical research.

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Table 1

Selected characteristics of AYA cancer survivors, AYA HOPE Study

Characteristic		
	N	**%**
Cancer Type		
Acute lymphocytic leukemia	21	(4.1)
Germ cell tumor	201	(39.0)
Hodgkin lymphoma	141	(27.4)
Non-Hodgkin lymphoma	128	(24.9)
Sarcoma	24	(4.7)
AJCC stage		
I	203	(43.5)
II	126	(27.0)
III	73	(15.6)
IV	65	(13.9)
Unknown or Not applicable	48	
Sex		
Male	327	(63.5)
Female	188	(36.5)
Age at Diagnosis, yrs		
15-19	66	(12.8)
20-24	91	(17.7)
25-29	131	(25.4)
30-34	115	(22.3)
35-39	112	(21.7)
Race/Ethnicity		
White, Hispanic	108	(21.0)
White, Non-Hispanic	304	(59.0)
Black	44	(8.5)
Asian or Pacific Islander	50	(9.7)
Other	9	(1.7)
Employment and educational status prior to diagnosis		
Full-time working	312	(60.6)
Full-time student	119	(23.1)
Part-time working	24	(4.7)
Part-time student	22	(4.3)
Homemaker	17	(3.3)
Unemployed/Disabled	20	(3.9)
Other/Unknown	1	(0.2)
Health insurance		

Characteristic		
	N	%
Not insured	16	(3.1)
Insured	499	(96.9)
Number of comorbid conditions		
0	372	(72.2)
1	82	(15.9)
2+	61	(11.8)
Provider Sub-Speciality		
Medical Oncology	219	(51.2)
Not Medical Oncology	209	(48.8)
Unknown	87	
Hospital type		
NCI Cancer Center	85	(17.8)
Other Cancer Center, Academic	26	(5.5)
Other Cancer Center, Non-Academic	195	(40.9)
Non-Cancer Center, Academic	41	(8.6)
Non-Cancer Center, Non-Academic	130	(27.3)
Unknown	38	
Residency Training Program		
No	169	(35.1)
Yes	312	(64.9)
Missing/unknown	34	
Bed size		
<300	181	(39.5)
300-499	134	(29.3)
500+	143	(31.2)
Unknown	57	

Table 2

Clinical trial availability and doctor's recommendation for participation reported by AYA cancer survivors according to selected characteristics, AYA HOPE Study

	Knew about availability of clinical trials [1]				A clinical trial was available [2]				Doctor recommended participation in a clinical trial [3]			
	Yes		No		Yes		No		Yes		No	
Characteristic	(n=191)		(n=324)		(n=86)		(n=105)		(n=52)		(n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%
Cancer Type												
Acute lymphocytic leukemia	13	(61.9) [4]	8	(38.1)	9	(69.2)	#	#	7	(100.0)	0	(0.0)
Germ cell tumor	66	(32.8)	135	(67.2)	18	(27.3)	48	(72.7)	12	(70.6)	5	(29.4)
Hodgkin lymphoma	53	(37.6)	88	(62.4)	29	(54.7)	24	(45.3)	17	(63.0)	10	(37.0)
Non-Hodgkin lymphoma	48	(37.5)	80	(62.5)	21	(43.8)	27	(56.3)	11	(61.1)	7	(38.9)
Sarcoma	11	(45.8)	13	(54.2)	9	(81.8)	#		5	(55.6)	#	
AJCC stage												
I	66	(32.5)	137	(67.5)	17	(25.8)	49	(74.2)	11	(68.8)	5	(31.3)
II	53	(42.1)	73	(57.9)	27	(50.9)	26	(49.1)	15	(62.5)	9	(37.5)
III	30	(41.1)	43	(58.9)	16	(53.3)	14	(46.7)	10	(71.4)	#	
IV	19	(29.2)	46	(70.8)	12	(63.2)	7	(36.8)	7	(58.3)	5	(41.7)
Unknown	23		25		14		9		9		#	
Sex												
Male	114	(34.9)	213	(65.1)	48	(42.1)	66	(57.9)	28	(62.2)	17	(37.8)
Female	77	(41.0)	111	(59.0)	38	(49.4)	39	(50.6)	24	(72.7)	9	(27.3)
Age at Diagnosis, yrs												
15-19	31	(47.0)	35	(53.0)	18	(58.1)	13	(41.9)	14	(87.5)	#	
20-24	34	(37.4)	57	(62.6)	11	(32.4)	23	(67.6)	9	(100.0)	0	(0.0)
25-29	56	(42.7)	75	(57.3)	26	(46.4)	30	(53.6)	13	(56.5)	10	(43.5)
30-34	38	(33.0)	77	(67.0)	13	(34.2)	25	(65.8)	5	(38.5)	8	(61.5)
35-39	32	(28.6)	80	(71.4)	18	(56.3)	14	(43.8)	11	(64.7)	6	(35.3)
Race/Ethnicity												

	Knew about availability of clinical trials [1]				A clinical trial was available [2]				Doctor recommended participation in a clinical trial [3]			
	Yes		No		Yes		No		Yes		No	
Characteristic	(n=191)		(n=324)		(n=86)		(n=105)		(n=52)		(n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%
White, Hispanic	49	(45.4)	59	(54.6)	27	(55.1)	22	(44.9)	14	(63.6)	8	(36.4)
White, Non-Hispanic	106	(34.9)	198	(65.1)	41	(38.7)	65	(61.3)	26	(66.7)	13	(33.3)
Black	18	(40.9)	26	(59.1)	10	(55.6)	8	(44.4)	8	(88.9)	#	
Asian or Pacific Islander	16	(32.0)	34	(68.0)	8	(50.0)	8	(50.0)	#		#	
Other	#		7	(77.8)	0	(0.0)	#		0	(0.0)	0	(0.0)
Employment and educational status prior to diagnosis												
Full-Time Work	108	(34.6)	204	(65.4)	49	(45.4)	59	(54.6)	27	(58.7)	19	(41.3)
Full-Time School	54	(45.4)	65	(54.6)	27	(50.0)	27	(50.0)	20	(87.0)	#	#
Neither Full-Time Work or Full-Time School	29	(34.5)	55	(65.5)	10	(34.5)	19	(65.5)	5	(55.6)	#	#
Health insurance												
Not insured	5	(31.3)	11	(68.8)	#		#		#	#	#	#
Insured	186	(37.3)	313	(62.7)	84	(45.2)	102	(54.8)	51	(67.1)	25	(32.9)
Number of comorbid conditions												
0	139	(37.4)	233	(62.6)	60	(43.2)	79	(56.8)	39	(68.4)	18	(31.6)
1	26	(31.7)	56	(68.3)	12	(46.2)	14	(53.8)	9	(75.0)	#	
2+	26	(42.6)	35	(57.4)	14	(53.8)	12	(46.2)	#		5	(55.6)
Physician Specialty												
Not Medical Oncology	75	(35.9)	134	(64.1)	24	(32.0)	51	(68.0)	14	(66.7)	7	(33.3)
Medical Oncology	89	(40.6)	130	(59.4)	44	(49.4)	45	(50.6)	25	(61.0)	16	(39.0)
Unknown	27		60		18		9		13		#	
Treating Institution Characteristics												
Hospital type												
NCI Cancer Center	31	(36.5)	54	(63.5)	15	(48.4)	16	(51.6)	11	(78.6)	#	#
Other Cancer Center, Academic	5	(19.2)	21	(80.8)	#	(40.0)	#	(60.0)	0	(0.0)	#	#
Other Cancer Center, Non-Academic	72	(36.9)	123	(63.1)	29	(40.3)	43	(59.7)	16	(66.7)	8	(33.3)
No Cancer Center, Academic	20	(48.8)	21	(51.2)	13	(65.0)	7	(35.0)	9	(69.2)	#	#

Am J Clin Oncol. Author manuscript; available in PMC 2022 March 02.

	Knew about availability of clinical trials [1]				A clinical trial was available [2]				Doctor recommended participation in a clinical trial [3]			
	Yes		No		Yes		No		Yes		No	
Characteristic	(n=191)		(n=324)		(n=86)		(n=105)		(n=52)		(n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%
No Cancer Center, Non-Academic	56	(43.1)	74	(56.9)	23	(41.1)	33	(58.9)	12	(54.5)	10	(45.5)
Unknown	7		31		#	#	#	#	#	#	0	
Residency Training Program												
No/Unknown	60	(35.5)	109	(64.5)	17	(28.3)	43	(71.7)	9	(52.9)	8	(47.1)
Yes	125	(40.1)	187	(59.9)	66	(52.8)	59	(47.2)	40	(69.0)	18	(31.0)
Missing	6		28		3		3		3		0	
Bed size												
<300	74	(40.9)	107	(59.1)	31	(41.9)	43	(58.1)	21	(70.0)	9	(30.0)
300-499	45	(33.6)	89	(66.4)	21	(46.7)	24	(53.3)	11	(73.3)	#	#
500+	56	(39.2)	87	(60.8)	26	(46.4)	30	(53.6)	15	(60.0)	10	(40.0)
Unknown	16		41		8		8		5		#	

[1] For the patient's type and stage of cancer

[2] For the patient's type and stage of cancer. Calculated among the 191 patients who responded “Yes” regarding knowledge of availability of clinical trial

[3] Calculated among the 78 patients who reported knowing that a clinical trial was available; 8 additional such patients did not respond to this item on the questionnaire

[4] Row percentages are calculated separately for each clinical trial knowledge question

Data not shown due to cell size <5

Table 3

Adjusted odds ratios for associations between AYA cancer patient characteristics and knowledge of clinical trial availability, AYA HOPE Study

Outcome/Model	Model terms		OR (95% CI)[1]
Knew about availability of clinical trials for their cancer[3]			
Model including acute lymphocytic leukemia			
	Cancer type	Germ cell tumor	1.0 --[2]
		Non-Hodgkin lymphoma	1.3 (0.8, 2.1)
		Hodgkin lymphoma	1.2 (0.8, 1.9)
		Sarcoma	1.6 (0.7, 3.8)
		Acute lymphocytic leukemia	2.9 (1.1, 7.8)
	Age at diagnosis (yrs)	15-19	1.0 --
		20-24	0.8 (0.4, 1.6)
		25-29	1.0 (0.5, 1.9)
		30-34	0.7 (0.4, 1.3)
		35-39	0.5 (0.3, 1.0)
Model excluding acute lymphocytic leukemia			
	Cancer type	Germ cell tumor	1.0 --
		Non-Hodgkin lymphoma	1.3 (0.8, 2.2)
		Hodgkin lymphoma	1.2 (0.7, 1.9)
		Sarcoma	1.7 (0.5, 5.6)
	Age at diagnosis (yrs)	15-19	1.0 --
		20-24	0.9 (0.4, 1.8)
		25-29	1.1 (0.5, 2.1)
		30-34	0,7 (0.4, 1.5)
		35-39	0.6 (0.3, 1.2)
	AJCC Stage at diagnosis	I or II	1.0 --
		III or IV	0.9 (0.6, 1.4)
	Employment and educational status prior to diagnosis	Neither Full-Time Work or Full-Time School	1.0 --
		Full-Time Work or Full-Time School	1.3 (0.8, 2.2)
Reported that clinical trials were available for their cancer[4]			
Model including acute lymphocytic leukemia			
	Cancer type	Germ cell tumor	1.0 --
		Non-Hodgkin lymphoma	2.4 (1.0, 5.6)
		Hodgkin lymphoma	3.8 (1.7, 8.6)
		Sarcoma	14.1 (2.6, 78)

Outcome/Model	Model terms		OR (95% CI)[1]
		Acute lymphocytic leukemia	6.9 (1.7, 28.6)
	Age at diagnosis (yrs)	15-19	1.0 --
		20-24	0.6 (0.2, 1.7)
		25-29	1.3 (0.5, 3.6)
		30-34	0.7 (0.2, 2.1)
		35-39	2.1 (0.7, 6.8)
	Employment and educational status prior to diagnosis	Neither Full-Time Work or Full-Time School	1.0 --
		Full-Time Work or Full-Time School	2.6 (1.0, 6.7)
Model excluding acute lymphocytic leukemia			
	Cancer type	Germ cell tumor	1.0 --
		Non-Hodgkin lymphoma	3.5 (1.1, 11.3)
		Hodgkin lymphoma	5.1 (1.7, 15.4)
		Sarcoma	19.7 (1.8, 220)
	Age at diagnosis (yrs)	15-19	1.0 --
		20-24	0.3 (0.1, 1.5)
		25-29	1.0 (0.3, 3.7)
		30-34	0.6 (0.1, 2.2)
		35-39	1.3 (0.3, 5.7)
	AJCC Stage at diagnosis	I or II	1.0 --
		III or IV	2.4 (1.0, 5.7)
	Employment and educational status prior to diagnosis	Neither Full-Time Work or Full-Time School	1.0 --
		Full-Time Work or Full-Time School	3.7 (1.0, 13.7)
	Provider specialty	Not Medical Oncology	1.0 --
		Medical Oncology	1.2 (0.5, 2.9)
	Residency training program	No/Unknown	1.0 --
		Yes	2.1 (0.9, 4.8)

[1] OR= odds ratio, CI = confidence interval. ORs are mutually adjusted for all of the terms in each model

[2] Reference category for OR calculation

[3] vs. not knowing whether clinical trials were available for their cancer

[4] vs. reported that clinical trials were not available for their cancer, among the 191 patients who responded “Yes” regarding knowledge of availability of clinical trial

Table 4

Reported reasons for clinical trial non-participation among AYA cancer patients, AYA HOPE study

Reason	N (%)*
Any	29 (65.9)
Concern about involvement with clinical trials	
Worried that treatment was insufficiently tested	17 (38.6)
Worried about side effects	14 (31.8)
Worried about being treated like guinea pig	7 (15.9)
Worried about receiving placebo	7 (15.9)
Worried about having to switch doctors	7 (15.9)
Did not think a trial would help	6 (13.6)
Any concern reason	25 (56.8)
Problems with access to clinical trials	
Were too sick to enroll in a trial	8 (18.2)
Could not find a trial nearby	6 (13.6)
Insurance would not pay for all or part of trial	#
Any access reason	9 (20.5)
Both concern and access reason	5 (11.4)

*Percentages are based on 44 patients who reported knowing that a clinical trial was available for their type and stage of cancer, but who did not participate in a trial (either by self-report or medical record abstraction). Percentages for individual reasons or groups of reasons do not sum to 100% because patients were asked to select all reasons that applied.

#Data not shown due to cell size <5