UC Irvine UC Irvine Previously Published Works

Title

Attitudes Toward Cancer Clinical Trial Participation in Young Adults with a History of Cancer and a Healthy College Student Sample: A Preliminary Investigation

Permalink https://escholarship.org/uc/item/43v986kg

Journal Journal of Adolescent and Young Adult Oncology, 3(1)

ISSN 2156-5333

Authors

Grigsby, Timothy J Kent, Erin E Montoya, Michael J <u>et al.</u>

Publication Date

2014-03-01

DOI

10.1089/jayao.2013.0030

Copyright Information

This work is made available under the terms of a Creative Commons Attribution License, available at https://creativecommons.org/licenses/by/4.0/

Peer reviewed

Attitudes Toward Cancer Clinical Trial Participation in Young Adults with a History of Cancer and a Healthy College Student Sample: A Preliminary Investigation

Timothy J. Grigsby,¹ Erin E. Kent, PhD,² Michael J. Montoya, PhD,^{3–5} Leonard S. Sender, MD,^{6–8} Rebecca A. Morris, MSG, MPH,⁸ Argyrios Ziogas, PhD,^{6,9} and Hoda Anton-Culver, PhD^{6,7,9}

Purpose: Adolescents and young adults (AYAs) aged 15-39 at diagnosis have very low cancer clinical trial accrual rates. To date, no studies have examined attitudes toward clinical trial participation in this age range to determine if certain individuals are less likely to enroll if offered participation. The current study assessed attitudes toward participation using the Cancer Treatment Subscale of the Attitudes toward Cancer Trials Scales. *Methods:* Data were collected from a sample of leukemia and lymphoma survivors (n = 99) and a healthy college student sample (n = 397). Following a principal components analysis, two subscales—Personal Barriers/Safety and Personal Benefits-were retained for analysis.

Results: In the cancer survivor group, only 14 (13.3%) reported being offered participation in a cancer clinical trial, and only 8 of those 14 (7.6% of survivors) participated. Responses from leukemia and lymphoma survivors revealed no significant relationships between age, gender, race/ethnicity, clinical trial participation, insurance status, or social class with Personal Benefits or Personal Barriers/Safety. Healthy college females had more negative Personal Barriers/Safety attitudes compared to males after adjusting for race/ethnicity and social class (p=0.01), but no associations were present when examining Personal Benefits as an outcome.

Conclusion: This preliminary investigation suggests that drivers of attitudes toward clinical trial participation in AYAs are not well understood and may impact cancer trial participation. Future work should focus on defining attitudes toward cancer clinical trials in the AYA population and developing interventions to increase awareness, knowledge, and positive attitudes toward participating in cancer research.

Keywords: beliefs, attitudes, recruitment, clinical trials

ANCER CLINICAL TRIALS HAVE BECOME acknowledged as Chick consider trading cancer treatments among clinicians, researchers,¹ and some trial participants.² Enrollment in a clinical trial is important as it may engender benefits to the participant, including access to new treatment methods, increased knowledge of the healthcare system, an expanded healthcare provider team, and positive feelings associated with altruism.^{1,3}

Adolescents and young adults (AYAs) with cancer aged 15-39 at diagnosis have the lowest cancer clinical trial accrual rates of any age group. In the United States, accrual rates are estimated to be 10-20% for 15-19 year olds, less than 2% for 20-29 year olds, and less than 4% for 30-39 year olds.^{1,3} Whether or not a participant experiences survival advantages purely from participating in an experimental study remains unknown,^{4,5} but overall cancer survival rates in recent decades

¹Institute for Health Promotion and Disease Prevention, Department of Preventive Medicine, University of Southern California, Los Angeles, California.

²Outcomes Research Branch, Applied Research Program, Division of Cancer Control and Population Science, National Cancer Institute, Bethesda, Marvland.

Departments of ³Anthropology, ⁴Chicano/Latino Studies, ⁵Public Health, and ⁶Epidemiology; ⁷Chao Family Comprehensive Cancer Center; ⁹Genetic Epidemiology Research Institute; University of California, Irvine, Irvine, California. ⁸Hyundai Cancer Institute, CHOC Children's Hospital, Orange, California.

This work was previously presented in part: Kent EE, Montoya MJ, Sender LS, Morris RA, Ziogas A, Anton-Culver HA. Comparison of attitudes toward cancer clinical trial participation between adolescents and young adults with leukemia and lymphoma and college students. Poster for the Society for Behavioral Medicine Conference, Washington, DC, April 27-30, 2011.

have not improved for AYAs in the United States at the same rate of other age groups.⁶ Recent findings suggest AYAs treated at institutions participating in clinical trials have improved survival over those treated at other sites,^{7,8} highlighting the importance of increasing AYAs' clinical trial participation.

A growing body of literature has analyzed the relation of basic demographic features of the AYA population (e.g., gender, insurance status, etc.) to low clinical trial accrual rates,^{1,8–10} but little, if any, work exists that attempts to understand how the perceptions, attitudes, and beliefs of the AYA survivors may contribute to these low accrual rates in addition to the age-related barriers they encounter throughout the cancer treatment process. Using the Attitudes toward Cancer Trials Scales developed by Schuber,¹¹ we sought to (1) examine factors associated with attitudes toward cancer clinical trials in young adult survivors of leukemia and lymphoma and a sample of healthy college students and (2) test for differences in attitudes between younger (aged 20–29) and older (aged 30–39) AYA cancer survivors.

Methods

Study design

This cross-sectional study surveyed leukemia and lymphoma survivors (an average of 31.1 months after diagnosis) recruited from the California Cancer Registry and college undergraduates from a large public university in the southwestern United States. The purpose of the study was to examine two understudied facets of AYA cancer: quality of life and attitudes toward clinical trials. For the cancer survivor sample, complete recruitment procedures are described in a manuscript on the quality of life findings.¹² In brief, cancer survivors were eligible to participate in the present study if they were 15–39 years old at cancer diagnosis; verified as having a primary leukemia or lymphoma diagnosis; were diagnosed between January1, 2006 and December 31, 2007; and resided in Orange, Imperial, or San Diego counties at the time of diagnosis. A total of 258 participants met the inclusion criteria. Of those, 110 (43%) participated, 33 declined to participate, and 120 were non-locatable. Response and participation rates in the current study are similar to other population-based research conducted with cancer survivors in this age group.¹³

The college student sample was recruited from a large public university in the southwest United States using an internet-based student research survey portal that allows undergraduate students to view and participate in ongoing research projects at the university. College students were excluded if they were 30 years or older (n = 10). Students completed surveys online. A total of 954 students responded at least in part to the survey. Of those, 397 met the age criteria and completed all items for use in the current analysis. The cancer survivor and healthy student sample were presented with the same survey items, which included demographic questions, items from the chosen study scale, and items about previous experience with cancer.

Predictors

Given the lack of previous research examining attitudes toward cancer clinical trials for AYAs, we examined the relationship between attitudes toward clinical trials with specific demographic features known to be associated with clinical trial participation in the AYA population.^{1–4,10} Predictors included in the final analyses were: gender, age, race/ ethnicity, family educational attainment, past participation in a clinical trial, insurance status, and social class at the time of the survey. We tested for possible age differences in cancer clinical trial attitudes, as previous research has suggested that being younger at diagnosis is related to increased rates of participation in clinical trials.¹⁰

Age was calculated using participants' self-reported date of birth. Participants self-reported their race/ethnicity; possible responses were: Non-Hispanic White, Hispanic/Latino, Asian/Pacific Islander, African American, or Other. Family educational attainment was measured with one question asking the participant to report the highest level of education for immediate family members (i.e., self, parent, sibling, spouse). Social class was measured with a single item asking participants how they felt their household compared financially to others in the United States, with the following possible responses: lower, working, middle, upper middle, or upper class. Past participation in a clinical trial was measured with two items asking participants if they had (1) been offered participation in a clinical trial, and (2) agreed to participate in a cancer clinical trial before the interview. Finally, insurance status was measured with a single item asking if the participant currently had health insurance.

Attitudes toward Cancer Trials Scales

The Cancer Treatment subscale of Schuber's Attitudes toward Cancer Trials Scales¹¹ (ACTS-CT) was used to measure attitudes toward cancer treatment trials. The ACTS-CT consists of four distinct components: Personal Benefits (4 items), Personal Barriers/Safety (5 items), Personal & Social Value (5 items), and Trust in the Research Process (4 items). Items were measured on a 7-point Likert scale with responses ranging from "strongly disagree" to "strongly agree." Negatively worded items were reverse-coded prior to summation for analysis. Descriptions of each item are listed in Table 1.

To explore the psychometric structure of the ACTS-CT in this young adult population, we used principal components analysis for the young adult survivors included in the analysis and explored possible differences by comparing the results to an internet-based survey of healthy college students, as well as to Schuber's original findings. Items were rotated orthogonally to aid in the interpretation of the components loadings, preceded by Kaiser normalization to give equal weight to the items. Two of the four ACTS-CT components were excluded from the final analysis due to weak factor loadings (loadings: Personal & Social Value, 0.47-0.79; Trust in the Research Process, 0.45–0.69). Components 1 (Personal Barriers/Safety) and 2 (Personal Benefits) were included in the final analyses. Table 2 displays the item descriptions, item means, and subscale Cronbach's alphas for the components retained for the final analysis. Final component scores used in subsequent regression modeling represent the averages of the items within the components.

Statistical analysis

Ordinary least squares regression models were run separately on the Personal Barriers/Safety and Personal Benefits component mean scores of the cancer survivor and college

Component	Variable name	Description				
Components retained for final and	alysis					
1. Personal Benefits	Improved treatment	I'd get improved cancer treatment if I took part in cancer study.				
	Better chance	People who join cancer studies have a better chance of beating their cancer.				
	Best treatment	Joining a cancer study would mean I'd receive the best existing cancer treatment.				
	Better health care	By joining a cancer study, I would receive better health care.				
2. Personal Barriers/Safety	A lot more trouble	Taking part in a cancer study is a lot more trouble than just getting the usual treatment.				
	Less safe	Getting treatment in a cancer study is less safe than getting the usual treatment.				
	Unsafe treatment	Treatments received in a cancer study could be unsafe for myself.				
	More health problems	My taking part in a cancer study could lead to more health problems.				
	More difficult treatment	Joining a cancer study would make cancer treatme more difficult.				
Components removed from final a	ınalysis					
3. Personal & Social Value	Should know more about studies	In general, people should know more about cancer studies.				
	Little importance	Cancer studies are of little importance to me.				
	Access is important Helping fight cancer	Access to cancer treatment studies is important to n People who take part in cancer studies are helping of us fight cancer.				
	Safety watched closely	I feel certain my safety would be watched closely in a cancer study.				
4. Trust in the Research Process	Doctors and nurses are truthful	Doctors and nurses tell patients the truth about wh to expect during a cancer study.				
	Treated like a guinea pig	If I took part in a cancer study, I would be treated like a guinea pig.				
	Doctors and nurses mislead	Doctors and nurses mislead their patients who are involved in cancer studies.				
	Would be safe to join	It would be safe for me to join a cancer study for treatment.				

TABLE 1. OBSERVED VARIABLES AND HYPOTHESIZED COMPONENTS FOR THE CANCER TREATMENT SUBSCALE OF THE ATTITUDES TOWARD CANCER TRIALS SCALE IN AN ADOLESCENT AND YOUNG ADULT POPULATION

student groups. Multiple linear regression analyses were conducted separately on the survivor and student groups. Group differences between younger and older survivors were tested using the independent samples Student's *t*-test. Results were considered significant at p < 0.05. All analyses were conducted in SAS 9.2 (Cary, NC).

Results

Demographic and socioeconomic information for the young adult cancer survivors and college students included in the final analysis are presented in Table 3. Of the respondents, 397 college students and 99 cancer survivors had complete information; those with missing data were excluded from final regression analyses. Approximately 53% of the cancer survivor sample and nearly 86% of the college student sample was female. The majority of cancer survivors self-reported their race/ethnicity as Non-Hispanic White (61.9%), while the majority of the college student sample self-identified as Asian/Pacific Islander (50.7%). However, this number was collapsed into the "Other" category for analysis, as only 11% of cancer survivors reported their race/ethnicity as Asian/Pacific Islander. Most college students reported coming from

a middle class background (48.9%), while the majority of cancer survivors reported coming from middle (36%) or lower and working (36%) social classes. The mean score for the Personal Barriers/Safety component was 4.6 (standard deviation [SD]=1.2) for the cancer survivor group and 4.2 (SD=0.8) for the college student sample. For the Personal Benefits component, cancer survivors had an average score of 3.6 (SD=1.4), whereas the college student sample had an average score of 4.4 (SD=0.9).

Within the cancer survivor group, only 14 of the survivors (13.3%) reported being offered participation in a cancer clinical trial, and only 8 of those 14 (7.6%) participated. There were no statistically significant differences in age, race/ethnicity, gender, or social class between those who were and were not offered an opportunity to participate in a cancer clinical trial.

Multivariable regression

Young adult cancer survivor sample. Table 4 presents parameter estimates for the fully adjusted regression models of both components. Relative to upper middle and upper class cancer survivors, there was a marginally significant

	Components						
Component name, item number, and brief description	Item mean ^a	SD	Subscale corrected item-total correlation	Subscale α if item deleted			
Component 1: Personal Barriers/Safety (s	ubscale $\alpha = 0.86$)						
1. Unsafe treatment	4.13	1.54	0.71	0.82			
2. Less safe than usual treatment	4.41	1.40	0.72	0.82			
3. More difficult treatment	4.85	1.56	0.61	0.84			
4. More health problems	4.38	1.63	0.55	0.85			
5. Treated like a guinea pig	4.87	1.71	0.66	0.83			
6. A lot more trouble	4.42	1.54	0.63	0.84			
Component 2: Personal Benefits (subscale	$\alpha = 0.85$						
7. Better health care	3.50	1.75	0.73	0.81			
8. Better chance	3.85	1.65	0.75	0.81			
9. Best treatment	3.85	1.54	0.65	0.83			
10. Improved cancer treatment	3.15	1.60	0.69	0.82			
11. Access is important	5.10	1.56	0.54	0.85			
12. Safety watched closely	4.84	1.76	0.47	0.86			

TABLE 2. ITEM MEANS AND CRONBACH'S α Reliability of Subscales Retained for Final Analysis (N=99)

^aHigher values indicate more agreement with item.

SD, standard deviation.

TABLE 3. DEMOGRAPHIC AND SOCIOECONOMIC COMPARISON OF THE YOUNG ADULT CANCER SURVIVORS AND COLLEGE STUDENTS AT TIME OF SURVEY

Variable	College students		Cancer survivors aged 20–29		Cancer survivors aged 30–39	
	n	%	n	%	n	%
Gender						
Male	57	14.4	18	47.4	31	46.3
Female	340	85.6	20	52.6	36	53.7
Age at study ^a						
Mean (SD)	20.4	(2.5)	25.3	3 (2.7)	36.0	5 (4.1)
Race/ethnicity ^b						~ /
Non-Hispanic White	82	20.7	25	65.8	40	59.7
Hispanic/Latino	63	15.9	6	15.8	20	29.8
Other/unknown	252	63.5	7	18.4	7	10.5
Family educational attainment						
High school graduate or less	23	5.8	2	5.2	12	17.9
Some college	78	19.7	2 8	21.1	12	17.9
College graduate or higher	273	68.7	28	73.7	43	64.2
Unknown	23	5.8		_		_
Social class ^c						
Lower/working	118	29.7	13	34.2	25	37.3
Middle	194	48.9	10	26.3	28	41.8
Upper middle/upper	85	21.4	14	36.8	11	16.4
Unknown			1	2.6	3	4.5
Insurance status at study			-		-	
Any	369	92.6	36	94.7	63	94.0
None/unknown	28	7.1	2	5.3	4	6.0
Invited to participate on a cancer of			-	0.0	·	0.0
No			32	84.2	59	88.1
Yes			6	15.8	8	11.9

^aDistributions vary significantly between cancer survivor age groups at p < 0.05.

^bOptions for race/ethnicity item included Non-Hispanic White, Hispanic/Latino, Asian/Pacific Islander, African American, and Other. The "Other" category included Asian/Pacific Islander, African American, and Native American, as well as those that did not indicate their race/ethnicity on the survey. Due to low numbers in the cancer survivor groups, it was not feasible to compare these groups directly.

 ${}^{c}p = 0.05$. ^dOf the 14 invited to participate in a cancer clinical trial, only 8 participated. SD, standard deviation.

Variable	Models							
	Personal Barriers/Safety, $r^2 = 0.17$				Personal Benefits, $r^2 = 0.11$			
	β	SE	t	р	β	SE	t	р
Intercept	78.01	6.39	12.21	< 0.0001	51.75	7.35	7.04	< 0.0001
Age group 20–29 30–39	-6.06	3.64 Re	– 1.66 ference	0.10	-4.48	4.20 Re	- 1.07 ference	0.29
<i>Gender</i> Female Male	-3.82	3.40 Re	- 1.12 ference	0.26	-1.71	3.91 Re	-0.44 ference	0.66
Race/ethnicity Hispanic/Latino Other/unknown Non-Hispanic White	-1.03 -3.33	4.13 5.16 Re	-0.25 -0.65 ference	0.80 0.52	7.90 -6.81	4.75 5.94 Re	1.66 - 1.15 ference	0.10 0.25
Invited to participate in a			1 4 4	0.15	1.00	5.06	0.01	0.04
No Yes	-7.48	7.48 5.18 – 1.44 0.15 Reference			1.23 5.96 0.21 0.84 Reference			
Self-reported social class Lower/working Middle Upper middle/upper	4.03 - 8.46	4.52 4.50 Re	0.89 – 1.88 ference	0.37 0.06	3.53 -3.47	5.20 5.18 Re	0.68 -0.67 ference	0.50 0.51

TABLE 4. PARAMETER ESTIMATES OF FULL REGRESSION MODELS ON PERSONAL BARRIERS/SAFETY AND PERSONAL
BENEFITS COMPONENTS OF THE ACTS-CT, RESPONSES FROM YOUNG ADULT CANCER SURVIVORS (N=99)

Note: r^2 = adjusted *r*-squared (squared multiple correlation), β = unstandardized regression coefficients, *SE* = standard error, *t* = Student's independent sample *t*-test statistic.

ACTS-CT, Attitude toward Cancer Clinical Trials Scales-Cancer Treatment subscale.

negative association between middle class social status and average Personal Barriers/Safety attitudes, indicating that lower social class standing may be related to poorer perceptions of the barriers and safety of clinical trials (p = 0.06). There was no association between Personal Barriers/Safety attitudes for lower or working social class standing and Personal Barriers/Safety attitudes relative to upper middle and upper class participants (p=0.37). Additionally, no associations were present between the other variables included in the final model and average Personal Barriers/Safety attitudes. For the Personal Benefits subscale, there were no statistically significant associations with age group, gender, race/ethnicity, clinical trial participation, or social class.

College student sample. Females reported lower scores on the Personal Barriers/Safety component compared to males (p=0.01) after adjusting for race/ethnicity and selfreported social class. There were no statistically significant associations between gender, race/ethnicity, or social class and average Personal Benefits subscale scores. However, scores were marginally higher for Hispanic/Latino participants relative to non-Hispanic White participants (p=0.06; Table 5).

Group differences

Subscale mean scores were calculated and compared between the two survivor age groups: those aged 20–29 and those aged 30–39. On the Personal Barriers/Safety subscale, younger survivors had a mean score of 63.4 (standard error [SE]=3.5) while older survivors had a higher average score of 69.4 (SE=3.1). The difference was not statistically significantly different (p=0.10). Similarly, younger survivors had lower average scores on the Personal Benefits subscale (mean [M]=47.4; SE=4.0) compared to older survivors (M=51.9; SE=3.6), but the difference was not significant (p=0.29).

Discussion

This preliminary investigation represents the first study to examine the attitudes toward cancer clinical trials of young adult cancer survivors and healthy college students, and yielded several important findings. Cancer clinical trial participation rates among the survivors in our study were similar to those found for a recent study that examined patterns of care among AYA patients and found that 14% of AYA patients studied were enrolled on a clinical trial.¹⁰ For survivors, we observed a marginally significant difference in attitudes toward Personal Barriers/Safety of trials by social class, but there were no other relationships between the predictors and participants' attitudes toward clinical trial participation. For college students, females had worse perceptions of Personal Barriers/Safety than males, but there were no associations between race/ethnicity or social class and the outcomes of interest. In general, item means in the present study were lower than those found in Schuber's study,¹¹ indicating slightly more negative attitudes toward cancer clinical trials in the present young adult survivor sample. However, Schuber's study sample was older (M = 47)years old), with 58% having a bachelor's degree or higher. It is possible that the age difference between the two studies' samples affected the item mean response differences.

The lack of strong component scores for the Personal & Social Value and Trust in the Research Process components indicated that these constructs may not be well-defined in the

Variable	Models							
	Personal Barriers/Safety, $r^2 = 0.02$				Personal Benefits, $r^2 = 0.03$			
	β	SE	t	р	β	SE	t	р
Intercept Gender	63.65	2.13	29.83	< 0.0001	61.23	2.38	25.77	< 0.0001
Female Male	-4.07	1.63 Re	-2.49 ference	0.01	-1.87	1.82 Re	- 1.02 eference	0.31
Race/ethnicity Hispanic/Latino Other/unknown Non-Hispanic White	1.83 -1.13	1.95 1.47 Re	0.94 -0.77 ference	0.35 0.44	4.10 1.66	2.18 1.63 Re	1.88 1.02 eference	0.06 0.31
Self-reported social class Lower/working Middle Upper middle/upper	0.31 0.67	1.66 1.49 Re	0.18 0.45 ference	0.85 0.65	-1.39 2.63	1.84 1.66	-0.75 1.59	0.45 0.11

 TABLE 5. PARAMETER ESTIMATES OF FULL REGRESSION MODELS ON THE PERSONAL BARRIERS/SAFETY AND PERSONAL BENEFITS COMPONENTS OF THE ACTS-CT, RESPONSES FROM HEALTHY COLLEGE STUDENTS (N=397)

Note: r^2 = adjusted *r*-squared (squared multiple correlation), β = unstandardized regression coefficients, *SE* = standard error, *t* = Student's independent sample *t*-test statistic.

ACTS-CT, Attitudes toward Cancer Clinical Trials Scales-Cancer Treatment subscale.

young adult survivor population compared to perceptions about safety and personal benefits. Further qualitative work with AYA cancer survivors is needed to understand these processes in the hope of developing an age-appropriate attitudes scale.

Developing an age-appropriate attitudes toward cancer clinical trials scale for the AYA population is necessary to understanding the unique challenges that reflect low trial participation in this age group. For example, a previous study that used a different scale to measure attitudes toward clinical trials—the Index of Attitude toward Clinical Trial Participation—assessed public perceptions in the United States of cancer clinical trials and found that roughly 70% of healthy 18–24 year olds had a positive attitude about cancer clinical trials.¹⁴ However, after taking into account trial availability and factors that may disqualify individuals from participation (e.g., insurance status, existing comorbidities, etc.), the remainder of participants—the percentage of people who scored negatively on the scale—was found to be consistent with the proportion that typically declines participation.

We found racial/ethnic differences in beliefs about clinical trials to be more evident in the college student sample than in the survivors. Compared to Non-Hispanic White participants, students reporting race/ethnicity as Hispanic/Latino had more positive views about the personal benefits of trials. Most of the individuals included in the "Other" race/ethnic category were Asian/Pacific Islander. Both Hispanic/Latino and Asian/Pacific Islander ethnic groups have much lower cancer clinical trial enrollment rates than Non-Hispanic Whites,⁹ but it is unclear why our findings are not concordant with previous research. Recent findings using qualitative methods have suggested that low scientific and health literacy factors correlate with less favorable attitudes toward cancer clinical trials and with poor communication with health providers by Hispanic/Latino and African American adult populations.¹⁵ General distrust in the medical research process among minority groups,¹⁶ treatment burden,¹⁷ tangible and available resources,¹⁸ and disparate cultural perceptions of "Western medicine"¹⁹ are worthwhile avenues of investigation when attempting to increase clinical trial accrual rates with ethnically diverse populations.

Several intrapersonal, socio-contextual and structural factors are also worthy of discussion when attempting to increase clinical trial recruitment for AYA patients. First, in a review analyzing barriers to cancer clinical trial participation, Ross and colleagues found concerns about incurring additional demands such as travel, unreimbursed costs, uncertainty of the treatment, concerns about the consent process, and preference for a particular treatment were the most commonly-cited issues among patients.³ The review also found that a patient was less likely to participate in a trial if a close friend or relative harbored negative feelings about participation. Second, the consent process for cancer clinical trials has been of particular concern given the substantial increase in length over time^{20,21} and questions as to how much participants comprehend the consent documents.²² While social support-based interventions may buffer the adverse effects of low health literacy among some participants,²³ more work is needed with AYA populations to understand and improve issues related to treatment burden and knowledge of the clinical trial process. Finally, the availability of trials varies across cancer sites and pediatric vs. adult treatment settings.²⁴ The Children's Oncology Group recently published a strategic plan that highlights new efforts to increase clinical trial availability in AYAs through collaborations between adult and pediatric cooperative groups, which will hopefully address this structural barrier.

The findings of this preliminary investigation should be interpreted with caution given the limitations described below. First, this was an exploratory study that relied on a small convenience sample of young adult cancer survivors and undergraduate students. As such, the generalizability of the findings is limited until the results can be replicated in a large representative community sample of healthy young adults and cancer survivors. Second, only leukemia and lymphoma survivors were included in the analysis, as these are two of the most common cancer types in this age range. However, differences in attitudes are expected among different cancer types; survivors of cancers that have more clinical trials open and accessible may view trials more favorably. Among the survivors sampled, it was not possible to validate clinical trial eligibility and accrual against the survey. Survivor bias may have had an impact on participation, given that individuals who are sicker may be less likely to participate. Family history of cancer was not collected from the college student sample, and this may have affected the results, as individuals with perceived elevated cancer risk or awareness may have different attitudes about cancer clinical trials.²⁶ The age distributions of the survivor and college student sample differed significantly (college students: M = 20.4, SD = 2.5; survivors aged: 20-29 M = 25.3, SD = 2.7). Thus, some of the differences in attitudes toward clinical trials may be attributable to age and life stage rather than the experience of having cancer. Finally, although the current study sought attitudes toward rather than knowledge about cancer clinical trials, it is also possible that individuals in both groups were not properly educated about trials and may have responded differently if better informed.

Conclusion

Despite the aforementioned limitations, this study contributes to the understanding of previously observed AYA cancer trial enrollment disparities. We found evidence suggesting that young adults, in general, reported positive attitudes toward clinical trials, though slightly more negative when compared to a previous sample of older cancer survivors.¹³ There was also evidence suggesting that further investigation is needed to construct a scale that addresses the personal value of participation and trust in the research process. These subscales were not validated in this sample of AYA cancer survivors. This would improve our understanding of AYAs' attitudes and allow for the evaluation of cancer trial attitudes as a possible mediator or moderator between AYAs' cancer clinical trial participation with demographic variables such as age, gender, and socioeconomic status.

We also observed that very few survivors reported having been offered participation in a cancer clinical trial and even fewer reported participation. Being offered participation predicted more positive attitudes about the safety of trials, although this was not statistically significant. The creation of programs that improve patients' education about the importance of cancer clinical trials have the potential to benefit future patients. Increasing positive attitudes toward the research process in conjunction with more clinical trial availability could lead to increased clinical cancer trial enrollment among the AYA population.

Acknowledgments

This project was carried out as part of Erin Kent's doctoral dissertation at the University of California, Irvine. Support for this work was provided by a UC MEXUS dissertation grant and a Centers for Disease Control and Prevention R36 Public Health Dissertation (Grant R36DP002012-01). Support for Timothy Grigsby is provided by a T32 fellowship from the National Institutes of Health (Grant CA009492). The authors thank undergraduate research assistants Marym

Mohammady and Priyanka Saxena and clinical research coordinator Isabel Guzman for their assistance with study recruitment and coordination.

Author Disclosure Statement

No competing financial interests exist.

References

- Ferrari A, Montello M, Budd T, et al. The challenges of clinical trials for adolescents and young adults with cancer. Pediatr Blood Cancer. 2008;50(5 Suppl):1101–4.
- Schutta KM, Burnett CB. Factors that influence a patient's decision to participate in a phase I cancer clinical trial. Oncol Nurs Forum. 2000;27(9):1435–8.
- Ross S, Grant A, Counsell C, et al. Barriers to participation in randomised controlled trials: a systematic review. J Clin Epidemiol. 1999;52(12):1143–56.
- Kumar A, Soares H, Wells R, et al. Are experimental treatments for cancer in children superior to established treatments? Observational study of randomised controlled trials by the Children's Oncology Group. BMJ. 2005; 331(7528):1295.
- Peppercorn JM, Weeks JC, Cook EF, et al. Comparison of outcomes in cancer patients treated within and outside clinical trials: conceptual framework and structured review. Lancet. 2004;363(9405):263–70.
- Soliman H, Agresta SV. Current issues in adolescent and young adult cancer survivorship. Cancer Control. 2008; 15(1):55–62.
- Bleyer A, Montello M, Budd T, et al. National survival trends of young adults with sarcoma: lack of progress is associated with lack of clinical trial participation. Cancer. 2005;103(9):1891–7.
- Howell DL, Ward KC, Austin HD, et al. Access to pediatric cancer care by age, race, and diagnosis, and outcomes of cancer treatment in pediatric and adolescent patients in the state of Georgia. J Clin Oncol. 2007;25(29):4610–5.
- Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. JAMA. 2004;291(22):2720–6.
- Parsons HM, Harlan LC, Seibel NL, et al. Clinical trial participation and time to treatment among adolescents and young adults with cancer: does age at diagnosis or insurance make a difference? J Clin Oncol. 2011;29(30): 4045–53.
- Schuber PA. Measuring attitudes toward participation in cancer treatment and cancer prevention trials: the Attitudes Toward Cancer Trials Scales (ACTS). J Nurs Meas. 2008; 16(2):136–52.
- Kent EE, Sender LS, Morris RA, et al. Multilevel socioeconomic effects on quality of life in adolescent and young adult survivors of leukemia and lymphoma. Qual Life Res. 2013;22(6):1339–51.
- Harlan LC, Lynch CF, Keegan TH, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. J. Cancer Surviv. 2011;5(3)305–14.
- Comis RL, Miller JD, Aldige CR, et al. Public attitudes toward participation in cancer clinical trials. J Clin Oncol. 2003;21(5):830–5.
- Evans KR, Lewis MJ, Hudson SV. The role of health literacy on African American and Hispanic/Latino perspectives on cancer clinical trials. J Cancer Educ. 2012;27(2): 299–305.

- Corbie-Smith G, Thomas SB, St George DM. Distrust, race, and research. Arch Intern Med. 2002;162(21): 2458–63.
- 17. Henry DH, Viswanathan HN, Elkin EP, et al. Symptoms and treatment burden associated with cancer treatment: results from a cross-sectional national survey in the U.S. Support Care Cancer. 2008;16(7):791–801.
- Fisher JA, Kalbaugh CA. Challenging assumptions about minority participation in US clinical research. Am J Public Health. 2011;101(12):2217–22.
- Mayo RM, Sherrill WW, Sundareswaran P, Crew L. Attitudes and perceptions of Hispanic patients and health care providers in the treatment of Hispanic patients: a review of the literature. Hispanic Health Care Int. 2007; 5(2):64–72.
- Berger O, Gronberg BH, Sand K, et al. The length of consent documents in oncological trials is doubled in twenty years. Ann Oncol. 2009;20(2):379–85.
- Albala J, Doyle M, Appelbaum PS. The evolution of consent forms for research: a quarter century of changes. IRB. 2010;32(3):7–11.
- 22. Joffe S, Cook EF, Cleary PD, et al. Quality of informed consent in cancer clinical trials: a cross-sectional survey. Lancet. 2001;358(9295):1772–7.

- Lee SY, Arozullah AM, Cho YI. Health literacy, social support, and health: a research agenda. Soc Sci Med. 2004; 58(7):1309–21.
- 24. Downs-Canner S, Shaw PH. A comparison of clinical trial enrollment between adolescent and young adult (AYA) oncology patients treated at affiliated adult and pediatric oncology centers. J Pediatr Hematol Oncol. 2009;31(12):927–9.
- Freyer DR, Felgenhauer J, Perentesis J. Children's Oncology Group's 2013 blueprint for research: adolescent and young adult oncology. Pediatr Blood Cancer. 2013;60(6):1055–8.
- Lerman C, Rimer BK, Daly M, et al. Recruiting high risk women into a breast cancer health promotion trial. Cancer Epidemiol Biomarkers Prev. 1994;3(3):271–6.

Address correspondence to: Erin E. Kent, PhD Outcomes Research Branch, Applied Research Program Division of Cancer Control and Population Science National Cancer Institute 9609 Medical Center Drive Rockville, MD 20850

Email: erin.kent@nih.gov