

Identifying Barriers to Equitable Access to Higher Education for Adolescent and Young Adult Cancer Survivors: An Exploratory Study

Lisa Carey, EdD
Kennedy Krieger Institute,
Johns Hopkins University School of Education

Lisa Jacobson, PhD
Kennedy Krieger Institute,
Johns Hopkins University School of Medicine

Kathy Ruble, PhD
Johns Hopkins School of Medicine

Juliana Pare-Blagoev, EdD
Johns Hopkins University School of Education

Clifton Thornton, PhD
Children's Hospital of Philadelphia

Background

Childhood cancer and treatment are known to impact cognition, often resulting in developmental disabilities such as ADHD, learning disabilities, and intellectual disability. Equitable access to quality education is a social determinant of health. Survivors often require academic accommodations (via special education / Section 504 plan) to access quality education, but struggle to obtain these supports due to communication gaps between medical and school teams.

This mixed-methods study explored cancer survivors' transition experience from high school to higher education. The study is an extension of a patient-centered quality improvement project focused on improving equitable access to education for childhood cancer survivors by disseminating relevant evidence to provider and parent stakeholders to improve the quality of patient care (PCORI EADI-14100).

Methods

An exploratory mixed-methods survey was disseminated via social media, in partnership with relevant cancer foundations, and via ads in clinics in three mid-Atlantic centers. Inclusion criteria required that participants 1) live in the US, 2) be ≥18 years of age, and 3) have a cancer diagnosis prior to age 25.

Survey items were developed through in-depth literature review, including addressing post-secondary outcomes, higher education, access to and use of academic accommodations, degree of difficulty in attending higher education, and presence of cancer late effects. The survey included two qualitative items which asked participants "What was helpful for you to succeed in college and/or what do you think would have been helpful for you during this period?" and "How did your cancer diagnosis/ treatment impact your time in college (for example your learning, classes or success)?"

Quantitative data were analyzed using descriptive and inferential statistics. Qualitative data were analyzed using descriptive in-vivo codes and pattern coding to generate category labels. Finally, quantitative and qualitative data were converged.

Results

- Participants (n=47; Mean age=23.1 years) from 14 states completed the survey (see Table 1).
- 97.7% reported a desire to attend higher education, with 81% attending some college and 44% not completing their degree due to challenges related to cancer and late effects of treatment (see Table 2).
- 17% of participants indicated that transitioning to higher education was too difficult due to cancer.
- Only 44.7% of participants received academic accommodations in college (see Table 3).

Qualitatively, participants reported specific barriers:

- lack of understanding by higher education faculty and staff
- lack of support from medical providers
- resulting in a large impact on academic success and quality of life

Discussion

- Prior evidence shows that accessing meaningful accommodations in higher education is difficult for students with disabilities.
- This exploratory study suggests cancer survivors receive inadequate supports to successfully navigate higher education, due in part to the siloed nature of healthcare and education.
- Qualitatively, survivors lacking supports were often forced to drop/retake classes or drop out, causing significant economic strain and negatively impacting educational attainment—a critical social determinant of health.
- Future interdisciplinary research examining barriers to higher education transition and access to disability accommodations is warranted, with a close look at the intersection between medical care and higher education supports.
- Findings highlight potential policy and practice changes to better support adolescents and young adults with cancer and other chronic illnesses.

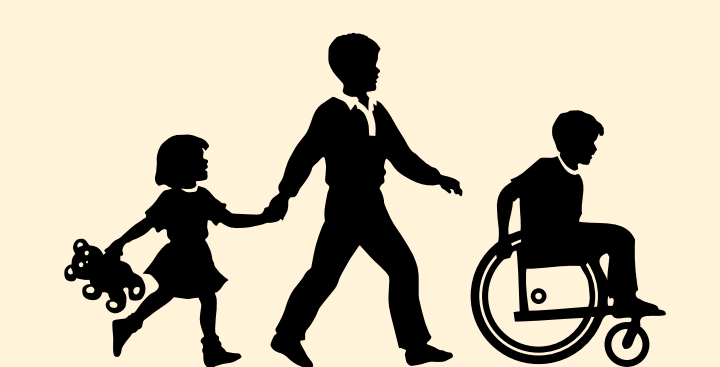
	N (%)
Age at Diagnosis	13.7 years (SD=5.6)
Childhood (<15 years)	21 (44.7%)
Adolescence (15-18 years)	16 (34%)
Young adult (>18 years)	10 (21.3%)
Current Age	23.1 years (SD=4.4)
Years Since Diagnosis	9.4 years (SD=7.4)
Race	
White	35 (74.5%)
Black	4 (8.5%)
Asian	3 (6.4%)
Multiracial	2 (4.3%)
American/Alaskan Native	1 (2.1%)
Other	1 (2.1%)
Declined answer	1 (2.1%)
Ethnicity	
Hispanic	5 (10.6%)
Non-Hispanic	42 (89.4%)
Gender	
Male	9 (19.2%)
Female	38 (89.4%)
Have late effects of cancer/treatment	40 (85%)

College plans after high school	N (%)
Cancer made it too hard	8 (17%)
Enrolled in college	38 (80.9%)
Path if not attending college	
Trade school/internship	1 (11.1%)
Joined workforce	2 (22.2%)
Home/unemployed	6 (66.6%)
Highest degree earned	
Associate degree	3 (7.7%)
Bachelor's degree	14 (35.9%)
Graduate degree	5 (12.8%)
Uncompleted degree	17 (44%)
Difficulty Rating (0-100 scale)	M (SD)
Having cancer made college difficult	59.4 (27)
Cognitive late effects made college difficult	67.7 (27.5)

		Age at Diagnosis			Total
		Childhood N (%)	Adolescence N (%)	Young Adult N (%)	
Received educational supports in high school	YES	14 (67%)	8 (50%)	2 (20%)	24 (51.1%)
	NO	7 (33%)	8 (50%)	8 (80%)	23 (48.9%)
Received educational supports in college	YES	10 (59%)	4 (33%)	7 (78%)	21 (55.3%)
	NO	7 (41%)	8 (67%)	2 (22%)	17 (44.7%)

FIGURE 1 QUALITATIVE DATA CATEGORIES

- MENTAL HEALTH CONCERNS
- PHYSICAL IMPACTS / LATE EFFECTS
- NEUROCOGNITIVE IMPACTS / LATE EFFECTS
- ALTERED COLLEGE COMPLETION TIMELINES
- LACK OF TRANSITION SUPPORT FROM HIGH SCHOOL STAFF
- EXPERIENCES WITH ACCOMMODATIONS
- ROLE OF HIGHER ED FACULTY/ STAFF IN COLLEGE EXPERIENCE



Kennedy Krieger Institute