

Adverse Childhood Experiences (ACEs) and Resilience in Childhood and Adolescent/Young Adult (AYA) Cancer Patients

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Abstract

Childhood and adolescent/young adult (AYA) cancer survivors experience poor health outcomes in adulthood. Adverse Childhood Experiences (ACEs) also portend poor health outcomes for the general population. Resilience can mitigate effects of ACEs. We examined the feasibility of assessing ACEs and resilience in childhood/AYA cancer patients. We also described occurrences of ACEs, resilience, and poor health outcomes. Of 52 participants, most rated their study experience favorably, with privacy in answering sensitive questions. Half reported ACEs, and those with ACEs had lower resilience, $X^2(3, N=52)=9.39$, $p=0.02$. Further investigations of ACEs and resilience in larger cohorts are warranted to delineate associations with long-term health outcomes.

Introduction

Childhood and adolescent/young adult (AYA) cancer survivors report chronic health conditions, such as cardiovascular disease,¹ and emotional distress, including depressive symptoms,² at higher rates compared to peers. Some, but not all, of these outcomes are explained by cancer treatments, which remain necessary to achieve cure.³ Therefore, it is critical to identify and target modifiable risk factors to reduce sub-optimal outcomes.

Adverse Childhood Experiences (ACEs) are traumatic events that occur prior to age 18, and they can undermine a person's sense of safety, stability, and bonding.⁴ ACEs have been associated with increased rates of chronic health conditions,⁵ poor mental health,⁶ and substance misuse⁵ for the general population. However, resilience, defined as harnessing resources to sustain well-being during adversity, can mitigate the effects of ACEs.^{7,8} Resilience can be cultivated, providing a target for intervention to improve health outcomes of those with ACEs.

To date, the impact of ACEs on health outcomes of childhood and AYA cancer patients and survivors has not been investigated. The influence of resilience on ACEs and health outcomes has also not been explored for these populations. Therefore, the purpose of this pilot study was to evaluate the feasibility and acceptance of assessing the sensitive subjects of ACEs and resilience in childhood and AYA cancer patients. We also described the occurrence of ACEs, resilience, and poor health outcomes (such as chronic health conditions, mental health issues, and substance misuse) in our cohort.

Methods

A convenience sample of patients [?]25 years old undergoing cancer treatment at the University of Chicago were approached. The University of Chicago is an urban, quaternary medical center, which serves racial/ethnically- and socioeconomically-diverse patients.⁹ Participants >18 years old provided informed consent, and participants < 17 years old completed the study with a parent or primary caregiver. All questionnaires were completed electronically using a tablet during clinic appointments.

Demographic, biologic, and behavioral variables were collected through self-report questionnaires. This included endorsement/denial of chronic health conditions, mental health issues, and substance misuse. We used age-stratified measures to assess participant ACEs.^{4,10} Participants answered ten dichotomous items indicating presence/absence of each ACE that potentially occurred prior to the age of 18, and endorsements were summed to create a final ACE score. Resilience was assessed using age-stratified measures from the Resilience Research Centre.¹¹ These measures provide a categorization of social-ecological resilience based on a summed score: “Low” ([?]62), “Moderate” (63-70), “High” (71-76), or “Exceptional” ([?]77). Lastly, participants completed questionnaires for study feasibility/acceptability. These assessed their comfort during the study, sense of privacy, understanding and the clarity of the instruments, and interest in the topics of ACEs and resilience. It also asked if they experienced workflow or technical difficulties.

Descriptive statistics characterized demographic, biologic, behavioral and study feasibility/acceptability data. Two-sample *t*-tests and chi-squared tests evaluated differences in demographics, health behaviors and outcomes, and resilience based on ACEs exposure.

Results

52 out of 56 eligible participants completed the study (two actively refused; two did not complete all questionnaires). Our final sample was racial/ethnically diverse (non-Hispanic white: n=25,48.1%) with equal sex representation (female: n=27,51.9%) (**Table 1**). Leukemia was the most common diagnosis (n=30;57.7%).

Regarding feasibility/acceptability, most participants rated their overall study experience favorably (**Table 2**). A majority felt prepared to answer study questions based on their informed consent. Most participants felt comfortable and had enough privacy to answer sensitive questions. No workflow or technical difficulties were reported.

For descriptive data, 26 participants (50%) reported ACEs (mean total number of ACEs 1.3 ± 1.7 ; range 0-7). The most common ACEs endorsed were emotional abuse (e.g., parent/caregiver had repeatedly sworn at/insulted/put down the participant; n=12), parental separation/divorce (n=11), and having a member of their household engaged in substance misuse (n=8). The mean resilience score for participants was 75.2 ± 9.0 (range 49-85), indicating overall “High” resilience. Categorical breakdowns were as follows: five scored “Low” (9.6%), eight scored “Moderate” (15.3%), ten scored “High” (19.2%), and 29 scored “Exceptional” (55.8%). Mean age at assessment was different between those with ACEs (15.8 ± 6.0 years) and those without (11.8 ± 7.8 years) [*t* (46.77) = -2.07, *p* = 0.04]. Those with ACEs were more likely to self-endorse mental health issues [zero ACEs: n=4,15.4%; [?]1 ACE: n=11,42.3%; X^2 (1,N=52) = 4.59, *p* = 0.03] and substance misuse [zero ACEs: n=6,23.3%; [?]1 ACE: n=14,53.8%; X^2 (1,N=52) = 5.20, *p* = 0.02]. Participants with ACEs had lower resilience compared to those without ACEs, with five participants with ACEs scoring “Low” ([?]62) compared to zero without ACEs and ten participants with ACEs scoring “Exceptional” ([?]77) compared to 19 participants without ACEs [X^2 (3,N=52) = 9.39, *p* = 0.02]. We did not find differences in sex, race/ethnicity, annual household income, insurance type, and chronic health condition endorsement between those with and without ACEs.

Discussion

Assessing the sensitive topics of ACEs and resilience was acceptable to our racial/ethnically- and socioeconomically-diverse cohort of childhood and AYA cancer patients and their caregivers. Feasibility and participant acceptance are common concerns in research with sensitive subject matter, such as ACEs. Prior research has shown that even in well-documented cases of serious childhood abuse, retrospective studies likely provide underestimates of their incidence.¹² However, certain survey methodology choices, such as the

utilization of anonymous surveys and the creation of perceived confidential environments to disclose ACEs have been shown to improve accuracy of reports.¹³ This provided rationale for administering electronic surveys to assess ACEs and resilience. Results from our study showed most participants were comfortable and prepared to answer survey questions following informed consent. This suggests that future studies of ACEs and resilience in larger cancer populations are feasible.

For our descriptive results, 50% of patients reported at least one ACE, similar to larger general population cohorts.^{4,14,15} Those with ACEs were older compared to those without. Though most of the ACE literature uses retrospective cohorts of adults,¹⁶ prospective accounts of ACEs from children less than 18 years old retain the ability to predict poor health outcomes in their futures.¹² Participants with prior ACEs were more likely to endorse mental health issues and substance misuse compared to those without. Prior studies investigating relationships between ACEs and mental health demonstrated that repeated exposures to high-stress experiences in early childhood can lead to long-term disruptions in neuropsychiatric development.^{17,18} Though previous studies show childhood cancer survivors engage in similar rates of substance misuse compared to peers,¹⁹ AYA cancer patients who report multi-drug use are more likely to report mental health issues as well.²⁰ Participants with ACEs also had lower resilience scores compared to those without. Research has demonstrated that early adversity can be mitigated through teaching resilience.^{21,22} Though studies mapping neurobiological pathways connecting ACEs, resilience, and health outcomes are ongoing,²³ research in the general population using “strength-based” interventions (e.g. those that focus on positive attributes of a person/group rather than negative) to cultivate resilience in children and AYAs with ACEs have shown increased health-promoting behaviors.^{24,25}

Limitations include the cross-sectional design of this study as well as our use of a convenience sample. Future studies utilizing larger, well-characterized cohorts of childhood and AYA cancer patients and survivors could better delineate associations of ACEs and resilience with long-term health outcomes. Assessment of ACEs could also be incorporated into future pediatric and AYA clinical trials to examine their associations with various poor health outcomes. These data would inform interventions to aid those who have experienced ACEs to reduce additional morbidity and premature mortality for this high-risk population.

Conflict of Interest Statement

All authors report no financial disclosures nor conflicts of interest.

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TABLE 1 Demographic, biologic, treatment, and behavioral characteristics for study participants

	Participants (N = 52) n (%)
Sex	
Female	27 (51.9%)
Male	25 (48.1%)
Race/Ethnicity	
Non-Hispanic white	25 (48.1%)
Non-Hispanic black	14 (26.9%)
Hispanic	10 (19.2%)
Asian	3 (5.8%)
Age at primary malignancy diagnosis, in years (mean / SD / range)	12.9 ± 7.1 (0 - 25)
0-11 years old	19 (36.5%)
12-17 years old	15 (28.9%)
[?]18 years old	18 (34.6%)
Age at assessment, in years (mean / SD / range)	13.8 ± 7.2 (0 - 25)
0-11 years old	18 (34.6%)
12-17 years old	14 (26.9%)
[?]18 years old	20 (38.5%)
Primary malignancy diagnosis	
Leukemia	30 (57.7%)
CNS tumor	3 (5.8%)
Hodgkin lymphoma	6 (11.5%)
Non-Hodgkin lymphoma	2 (3.9%)
Neuroblastoma	4 (7.7%)
Wilms tumor	2 (3.9%)
Soft tissue sarcoma	1 (1.9%)
Bone tumor	2 (3.9%)
Other*	2 (3.9%)
Treatment type	
Surgery	16 (30.8%)
Radiation	7 (13.5%)
Chemotherapy	51 (91.8%)
Stem cell transplantation	4 (7.7%)
Other	3 (5.8%)
Health insurance	
Private	36 (69.2%)
Medicaid	14 (26.9%)
Other	2 (3.9%)
Annual household income	
Less than \$20,000	11 (21.2%)
\$20,000 to \$49,999	5 (9.6%)
\$50,000 to \$99,999	12 (23.1%)
\$100,000 to \$149,999	7 (13.5%)
\$150,000 to \$199,999	4 (7.7%)

\$200,000 or more	5 (9.6%)
Don't know/Unsure	8 (15.4%)
Any chronic health condition	27 (51.9%)
Vision/Eye problems	16 (30.8%)
Hearing problems	0 (0%)
Speech problems	3 (5.8%)
Any endocrine	1 (1.9%)
Any cardiac/vascular	3 (5.8%)
Any respiratory	3 (5.8%)
Any GI/digestive	1 (1.9%)
Any renal	2 (3.8%)
Any brain/nervous system	3 (5.8%)
Any musculoskeletal	0 (0%)
Chronic pain	1 (1.9%)
Any psychiatric/mental health diagnosis	18 (34.6%)
Substance misuse	
Tobacco use**	8 (15.4%)
Risky alcohol use***	12 (23%)
Recreational/Prescription drug use****	10 (19.2%)

*For the “Other” subcategory, both participants were diagnosed with testicular germ cell tumors

**Endorsed current or former tobacco product use. Of note, all positive endorsements occurred in the [?]18 years old age subgroup.

***Endorsed one or more episodes of consuming five or more drinks in a day (men/boys) or four or more drinks in a day (women/girls). Of note, all positive endorsements occurred in the [?]18 years old age subgroup.

****Answered affirmatively for “How many times in the past year have you used a recreational drug or a prescription medication for nonmedical reasons? [Recreational drugs include methamphetamines (speed, crystal), cannabis (marijuana, pot), inhalants (paint thinner, aerosol, glue), tranquilizers (Valium), barbiturates, cocaine, ecstasy, hallucinogens (LSD, mushrooms), or narcotics (heroin)]” Of note, 9/10 positive endorsements occurred in the [?]18 years old age subgroup and one positive endorsement occurred in the 12-17 age subgroup.

TABLE 2 Feasibility/Acceptability responses

Rate your overall experience in the research study, where 0 is the worst possible experience, and 5 is the best possible experience

1

2

3

4

5 (best)

How comfortable did you feel completing these surveys? Very uncomfortable

Somewhat uncomfortable

Neither uncomfortable nor comfortable

Somewhat comfortable

Very comfortable

How important do you feel it is for your cancer treatment team to know about your Adverse Childhood Experiences (ACEs)?

Somewhat unimportant
Neither unimportant nor important
Somewhat important
Very important

How important do you feel it is for your cancer treatment team to know about your personal and community resilience factors?

Somewhat unimportant
Neither unimportant nor important
Somewhat important
Very important

Did the informed consent and discussions you had before participating in the research study prepare you for your experiences?

Yes, somewhat
Yes, mostly
Yes, completely

I would be interested in learning more about Adverse Childhood Experiences (ACEs). No

Unsure
Yes

I would be interested in learning more about personal and community resilience factors. No

Unsure
Yes

Did you have enough physical privacy to complete this study? Never

Sometimes
Usually
Always
