



BRIEF REPORT

Adverse childhood experiences and resilience in childhood and adolescent and young adult cancer patients

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1 | INTRODUCTION

Childhood and adolescent and young adult (AYA) cancer survivors report chronic diseases¹ and emotional distress² at higher rates compared to peers. Some of these long-term outcomes are partially explained by cancer treatments, which remain necessary to achieve cure.³ Others, such as chronic pain, can impact survivors regardless

of treatment exposures.⁴ Therefore, it is critical to identify modifiable risk factors upfront in childhood and AYA cancer patients to reduce suboptimal long-term outcomes they experience as survivors.

Adverse childhood experiences (ACEs) are traumatic events occurring prior to age 18 that can undermine a person's sense of safety and bonding.^{5,6} ACEs are associated with chronic health conditions,⁷ poor mental health,⁸ and substance misuse⁷ in the general population. However, resilience or harnessing resources to sustain well-being during adversity can mitigate effects of ACEs.^{9,10} Resilience has been studied

Abstract

Childhood and adolescent and 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 and 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; $X^2(3, N = 52) = 9.4, p = .02$. Further investigations of ACEs and resilience in larger cohorts are warranted to delineate associations with long-term health outcomes.

KEYWORDS

adolescent and young adult cancer, adverse childhood experiences, childhood cancer, feasibility, resilience

Abbreviations: ACE, adverse childhood experience; AYA, adolescent and young adult.

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in childhood and AYA cancer populations^{11–13} and can be cultivated, providing a target for intervention to improve outcomes for those with ACEs.

To our knowledge, the impact of ACEs on health outcomes of childhood and AYA cancer patients has not previously been investigated. The influence of resilience on ACEs and health outcomes has also not been explored. 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 (chronic health conditions, mental health issues, and substance misuse) in our cohort.

2 | METHODS

A convenience sample of patients 0–25 years old undergoing cancer treatment at the University of Chicago were approached. The University of Chicago is an urban, quaternary medical center, serving racial/ethnically and socioeconomically diverse patients.¹⁴ Participants 18 years and above provided informed consent, and participants 17 years and younger completed the study with a parent/caregiver. All questionnaires were completed electronically using a tablet during clinic appointments.

Demographic, biologic, and behavioral variables were collected through self-report questionnaires. These included endorsement/denial of chronic health conditions, mental health issues, and substance misuse. To assess ACEs, participants of 17 years and younger completed the “Pediatric ACEs Screening and Related Life-events Screener” either independent of a parent/caregiver (12–17 years) or with them (0–11 years).^{5,15} Participants of age 18 years and above completed the “ACE Questionnaire for Adults” alone.^{5,15} Both include 10 dichotomous items indicating presence/absence of each ACE. To assess resilience, participants less than or equal to 17 years old completed the “Child and Youth Resilience Measure” either independent of a parent/caregiver (12–17 years) or with them (0–11 years).¹⁶ Participants 18 years and above completed the “Adult Resilience Measure” alone.¹⁶ These measures categorize 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/clarity of the instruments, and interest in ACEs and resilience. It also assessed technical difficulties.

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

3 | RESULTS

Fifty-two of 56 eligible participants completed the study (two refused; two had incomplete questionnaires). Our final sample was

racial/ethnically diverse (non-Hispanic White: $n = 25$, 48%), with equal sex representation (female: $n = 27$, 52%) (Table 1).

Regarding feasibility/acceptability, most participants rated their study experience favorably (Table 2). Most felt prepared to answer study questions based on informed consent. Most felt comfortable and reported privacy in answering sensitive questions. None reported technical difficulties.

Descriptively, 26 participants (50%) reported ACEs (mean total number of ACEs 1.3 ± 1.7 ; range 0–7). The most common ACEs were emotional abuse (e.g., parent/caregiver repeatedly swore at/insulted/put down the participant; $n = 12$), parental separation/divorce ($n = 11$), and having a household member with substance misuse ($n = 8$). Participants' mean resilience score was 75 ± 9 (range 49–85), indicating “High” resilience. Categorical breakdowns were: five scored “Low” (10%), eight scored “Moderate” (15%), 10 scored “High” (19%), and 29 scored “Exceptional” (56%). Mean age at assessment differed between those with ACEs (16 ± 6 years) and those without (12 ± 8 years) [$t(47) = -2.1$, $p = .04$]. Those with ACEs were more likely to self-endorse mental health issues [0 ACEs: $n = 4$, 15%; ≥ 1 ACE: $n = 11$, 42%; $\chi^2(1, N = 52) = 4.6$, $p = .03$] and substance misuse [0 ACEs: $n = 6$, 23%; ≥ 1 ACE: $n = 14$, 54%; $\chi^2(1, N = 52) = 5.2$, $p = .02$]. Participants with ACEs had lower resilience compared to those without; five participants with ACEs scored “Low” (≤ 62) compared to zero without, and 10 participants with ACEs scored “Exceptional” (≥ 77) compared to 19 participants without [$\chi^2(3, N = 52) = 9.4$, $p = .02$]. There were no differences in sex, race/ethnicity, household income, insurance, and chronic health conditions between those with and without ACEs.

4 | 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 parents/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 childhood abuse, retrospective studies likely provide underestimates of incidence.¹⁷ However, certain survey methodology choices, such as utilization of anonymous surveys and creation of perceived confidential environments to disclose ACEs, can improve accuracy of reports.¹⁸ 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.^{5,19,20} Those with ACEs were older compared to those without. Though most of the ACEs literature uses retrospective cohorts of adults,²¹ prospective accounts of ACEs from children less than 18 years old retain the ability to predict poor health outcomes in their futures.¹⁷ Participants

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

	Participants (N = 52) n (%)
Sex	
Female	27 (52%)
Male	25 (48%)
Race/ethnicity	
Non-Hispanic White	25 (48%)
Non-Hispanic Black	14 (27%)
Hispanic	10 (19%)
Asian	3 (6%)
Age at primary malignancy diagnosis, in years (mean/SD/range)	13 ± 7 (0–25)
0–11 years	19 (37%)
12–17 years	15 (29%)
≥18 years	18 (34%)
Age at assessment, in years (mean/SD/range)	134 ± 7 (0–25)
0–11 years	18 (35%)
12–17 years	14 (27%)
≥18 years	20 (38%)
Primary malignancy diagnosis	
Leukemia	30 (57%)
CNS tumor	3 (6%)
Hodgkin lymphoma	6 (11%)
Non-Hodgkin lymphoma	2 (4%)
Neuroblastoma	4 (8%)
Wilms tumor	2 (4%)
Soft tissue sarcoma	1 (2%)
Bone tumor	2 (4%)
Other ^a	2 (4%)
Treatment type	
Surgery	16 (31%)
Radiation	7 (13%)
Chemotherapy	51 (92%)
Stem cell transplantation	4 (8%)
Other	3 (6%)
Health insurance	
Private	36 (69%)
Medicaid	14 (27%)
Other	2 (4%)
Annual household income	
Less than \$20,000	11 (21%)
\$20,000–\$49,999	5 (10%)
\$50,000–\$99,999	12 (23%)

(Continues)

TABLE 1 (Continued)

	Participants (N = 52) n (%)
\$100,000–\$149,999	7 (13%)
\$150,000–\$199,999	4 (8%)
\$200,000 or more	5 (10%)
Don't know/unsure	8 (15%)
Any chronic health condition	27 (52%)
Vision/eye problems	16 (31%)
Hearing problems	0 (0%)
Speech problems	3 (6%)
Any endocrine	1 (2%)
Any cardiac/vascular	3 (6%)
Any respiratory	3 (6%)
Any gastrointestinal/digestive	1 (6%)
Any renal	2 (4%)
Any brain/nervous system	3 (6%)
Any musculoskeletal	0 (0%)
Chronic pain	1 (2%)
Any psychiatric/mental health diagnosis	18 (35%)
Substance misuse	
Tobacco use ^b	8 (15%)
Risky alcohol use ^c	12 (23%)
Recreational/prescription drug use ^d	10 (19%)

^aFor the “Other” subcategory, both participants were diagnosed with testicular germ cell tumors.

^bEndorsed current or former tobacco product use. Of note, all positive endorsements occurred in the ≥18-year-old age subgroup.

^cEndorsed 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-year-old age subgroup.

^dAnswered affirmatively for “How many times in the past year have you used a recreational drug or a prescription medication for non-medical 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-year-old age subgroup and one positive endorsement occurred in the 12–17 age subgroup.

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.^{22,23} Though previous studies show childhood cancer survivors engage in similar rates of substance misuse compared to peers,²⁴ AYA cancer patients who report multidrug use are more likely to report mental health issues as well.²⁵ Participants with ACEs also had lower resilience scores compared to those without. Research has demonstrated that early adversity can be mitigated through teaching resilience.^{26,27}

TABLE 2 Feasibility/acceptability responses

	Participants (N = 52) n (%)
Rate your overall experience in the research study, where 0 is the worst possible experience, and 5 is the best possible experience	
0 (worst)	0 (0%)
1	0 (0%)
2	0 (0%)
3	6 (11%)
4	16 (31%)
5 (best)	30 (58%)
How comfortable did you feel completing these surveys?	
Very uncomfortable	2 (4%)
Somewhat uncomfortable	0 (0%)
Neither uncomfortable nor comfortable	5 (10%)
Somewhat comfortable	11 (21%)
Very comfortable	34 (65%)
How important do you feel it is for your cancer treatment team to know about your adverse childhood experiences (ACEs) in order to take care of you?	
Very unimportant	3 (6%)
Somewhat unimportant	3 (6%)
Neither unimportant nor important	9 (17%)
Somewhat important	12 (23%)
Very important	25 (48%)
How important do you feel it is for your cancer treatment team to know about your personal and community resilience factors in order to take care of you?	
Very unimportant	1 (2%)
Somewhat unimportant	1 (2%)
Neither unimportant nor important	9 (17%)
Somewhat important	16 (31%)
Very important	25 (48%)
Did the informed consent and discussions you had before participating in the research study prepare you for your experience in the study?	
No	1 (2%)
Yes, somewhat	3 (6%)
Yes, mostly	6 (11%)
Yes, completely	42 (81%)
I would be interested in learning more about ACEs	
No	9 (17%)
Unsure	20 (38%)
Yes	23 (45%)
I would be interested in learning more about personal and community resilience factors	
No	8 (15%)
Unsure	21 (40%)
Yes	23 (45%)

(Continues)

TABLE 2 (Continued)

	Participants (N = 52) n (%)
Did you have enough physical privacy to complete this study?	
Never	0 (0%)
Sometimes	1 (2%)
Usually	5 (10%)
Always	46 (88%)

Though studies mapping neurobiological pathways connecting ACEs, resilience, and health outcomes are ongoing,²⁸ research in the general population using “strength-based” interventions (e.g., focusing 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.^{29,30} Existing interventions promoting resilience in childhood and AYA cancer patients³¹ could be adapted for those with ACEs, encouraging posttraumatic growth after cancer therapy.³²

Limitations include the cross-sectional design of this study as well as our use of a convenience sample. Parental/caregiver involvement in this study may have influenced responses from participants under age 18. Future studies utilizing larger, well-characterized cohorts of childhood and AYA cancer patients and survivors could distinguish the impact of ACEs and resilience from treatment-related effects on 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.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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REFERENCES

1. Diller L, Chow EJ, Gurney JG, et al. Chronic disease in the Childhood Cancer Survivor Study cohort: a review of published findings. *J Clin Oncol*. 2009;27(14):2339-2355.

2. Prasad PK, Hardy KK, Zhang N, et al. Psychosocial and neurocognitive outcomes in adult survivors of adolescent and early young adult cancer: a report from the Childhood Cancer Survivor Study. *J Clin Oncol*. 2015;33(23):2545-2552.
3. Suh E, Stratton KL, Leisenring WM, et al. Late mortality and chronic health conditions in long-term survivors of early-adolescent and young adult cancers: a retrospective cohort analysis from the Childhood Cancer Survivor Study. *Lancet Oncol*. 2020;21(3):421-435.
4. Long-term follow-up guidelines for survivors of childhood, adolescent and young adult cancers, version 5.0. Children's Oncology Group; 2018. Accessed October 14, 2022. www.survivorshipguidelines.org
5. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: the Adverse Childhood Experiences (ACE) Study. *Am J Prev Med*. 1998;14(4):245-258.
6. Giano Z, Wheeler DL, Hubach RD. The frequencies and disparities of adverse childhood experiences in the U.S. *BMC Public Health*. 2020;20(1):1327.
7. Campbell JA, Walker RJ, Egede LE. Associations between adverse childhood experiences, high-risk behaviors, and morbidity in adulthood. *Am J Prev Med*. 2016;50(3):344-352.
8. Edwards VJ, Holden GW, Felitti VJ, Anda RF. Relationship between multiple forms of childhood maltreatment and adult mental health in community respondents: results from the adverse childhood experiences study. *Am J Psychiatry*. 2003;160(8):1453-1460.
9. Poole JC, Dobson KS, Pusch D. Childhood adversity and adult depression: the protective role of psychological resilience. *Child Abuse Negl*. 2017;64:89-100.
10. Shonkoff JP, Garner AS, Siegel BS, et al. The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*. 2012;129(1):e232-e246.
11. Sharp K, Tillery R, Long A, Wang F, Pan H, Phipps S. Trajectories of resilience and posttraumatic stress in childhood cancer: consistency of child and parent outcomes. *Health Psychol*. 2022;41(4):256-267.
12. Okado Y, Long A, Phipps S. Profiles and predictors of resilient functioning in youths with pediatric cancer history. *J Psychosoc Oncol*. 2021;39(4):493-508.
13. Harper FWK, Albrecht TL, Trentacosta CJ, Taub JW, Phipps S, Penner LA. Understanding differences in the long-term psychosocial adjustment of pediatric cancer patients and their parents: an individual differences resources model. *Transl Behav Med*. 2019;9(3):514-522.
14. Cancer patient demographics. University of Chicago. Accessed August 12, 2020. <https://www.uchicagomedicine.org/cancer/about-us/patient-demographics>
15. Screening tools: several versions are available for different patient populations. ACEs Aware. Accessed November 11, 2019. <https://www.acesaware.org/screen/screening-tools>
16. Child and youth resilience measure & adult resilience measure. Resilience Research Centre. Accessed July 15, 2020. <https://cyrm.resilienceresearch.org>
17. Reuben A, Moffitt TE, Caspi A, et al. Lest we forget: comparing retrospective and prospective assessments of adverse childhood experiences in the prediction of adult health. *J Child Psychol Psychiatry*. 2016;57(10):1103-1112.
18. Bethell CD, Carle A, Hudziak J, et al. Methods to assess adverse childhood experiences of children and families: toward approaches to promote child well-being in policy and practice. *Acad Pediatr*. 2017;17(7s):S51-S69.
19. Merrick MT, Ford DC, Ports KA, Guinn AS. Prevalence of adverse childhood experiences from the 2011–2014 behavioral risk factor surveillance system in 23 states. *JAMA Pediatr*. 2018;172(11):1038-1044.
20. Child and Adolescent Health Measurement Initiative (CAHMI), Data Resource Center for Child and Adolescent Health, 2016–2017. National Survey of Children's Health Interactive Data Query. 2019. Accessed August 13, 2020. www.childhealthdata.org
21. Petruccelli K, Davis J, Berman T. Adverse childhood experiences and associated health outcomes: a systematic review and meta-analysis. *Child Abuse Negl*. 2019;97:104127.
22. Garner AS, Shonkoff JP. Early childhood adversity, toxic stress, and the role of the pediatrician: translating developmental science into lifelong health. *Pediatrics*. 2012;129(1):e224-e231.
23. Johnson SB, Riley AW, Granger DA, Riis J. The science of early life toxic stress for pediatric practice and advocacy. *Pediatrics*. 2013;131(2):319-327.
24. Marjerrison S, Hendershot E, Empringham B, Nathan PC. Smoking, binge drinking, and drug use among childhood cancer survivors: a meta-analysis. *Pediatr Blood Cancer*. 2016;63(7):1254-1263.
25. Asvat Y, King AC, Smith LJ, Lin X, Hedeker D, Henderson TO. Substance use behaviors in adolescent and young adult cancer patients: associations with mental and physical health. *Psychooncology*. 2020;29(6):1068-1076.
26. Rutter M. Psychosocial resilience and protective mechanisms. *Am J Orthopsychiatry*. 1987;57(3):316-331.
27. Masten AS. Ordinary magic. Resilience processes in development. *Am Psychol*. 2001;56(3):227-238.
28. McLaughlin KA, DeCross SN, Jovanovic T, Tottenham N. Mechanisms linking childhood adversity with psychopathology: learning as an intervention target. *Behav Res Ther*. 2019;118:101-109.
29. Chandler GE, Roberts SJ, Chiodo L. Resilience intervention for young adults with adverse childhood experiences. *J Am Psychiatr Nurses Assoc*. 2015;21(6):406-416.
30. Giovannelli A, Mondì CF, Reynolds AJ, Ou SR. Adverse childhood experiences: mechanisms of risk and resilience in a longitudinal urban cohort. *Dev Psychopathol*. 2020;32(4):1418-1439.
31. Rosenberg AR, Bradford MC, McCauley E, et al. Promoting resilience in adolescents and young adults with cancer: results from the PRISM randomized controlled trial. *Cancer*. 2018;124(19):3909-3917.
32. Meyerson DA, Grant KE, Carter JS, Kilmer RP. Posttraumatic growth among children and adolescents: a systematic review. *Clin Psychol Rev*. 2011;31(6):949-964.

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