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904. OUTCOMES RESEARCH-NON-MALIGNANT CONDITIONS

Towards an Implicit Measure of Patient Engagement in Sickle Cell Disease: Relationships between Implicit Measures of Engagement and Previous Childhood Trauma Among Adolescents and Young Adults

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Background:

Historically, patient engagement among adolescents and young adults (AYAs, age 18-25) decreases, parallel with the shift from parental to patient responsibility for engagement, and the transition from pediatric to adult care. Simultaneously, among AYAs with sickle cell disease (SCD), increases in organ failure, visits for VOCs, and mortality occur during this period. One previously shown predictor of excess hospital and ED utilization is prior childhood trauma, including medical trauma from treatment, parental abuse, or neglect. We found no implicit and few explicit measures of SCD AYA engagement in self-care or cooperation with professional care. We did find that Adverse Childhood Experiences (ACEs) are linked to increased morbidity. Particularly Emergency Department (ED) visits for pain, among children and adolescents with SCD. So, as part of validating an empirically derived implicit measure of SCD AYA engagement, we tested the relationship of the new measure to a validated measure of previous childhood trauma.

Method:

We studied selected AYA patients (N=20) enrolled in an Adult Sickle Cell Medical Home. Childhood trauma was assessed using the Center for Disease Control's 13-item, Behavioral Risk Factor Surveillance System Adverse Childhood Experience (ACE) module, measuring self-reported exposure to 9 types of childhood adversities: emotional abuse, physical abuse, sexual abuse, household member mental illness, household member substance abuse, witnessing domestic violence, parental separation or divorce, and incarcerated family members. The implicit measure of patient engagement was the draft 4-item Tiers of Engagement (TOE) tool. The original TOE was developed for pediatric patients and assessed parental as well as patient engagement. The adult TOE assesses only AYA engagement. The TOE tool asks professionals of all disciplines caring for SCD patients to confer as a group during interprofessional meetings to subjectively assign ratings of one (ideal engagement) to three (poor engagement) to four different domains: medical, educational, mental, and social. The analysis of variance (ANOVA) test was used to analyze the relationship between the ACE score and each of the engagement sectors (medical, educational, mental, and social).

Results:

The graphs below show ANOVA results for the relationship of the ACE score to each TOE domain score. We found no significant relationships between ACE scores and TOE domain scores.

Conclusion:

We observed no significant relationships between childhood trauma and implicitly measured patient engagement among AYAs with SCD. Future research should measure the TOE in larger samples and identify whether the TOE score is related to explicit measures of SCD AYA engagement, or hypothesized predictors of SCD AYA engagement and healthcare utilization. Future research should also utilize the ACE measures to implement trauma-informed care in AYAs with SCD.

References:

Pernell B, Nagalapuram V, Lebensburger J, Lin CP, Baskin ML, Pachter LM. Adverse childhood experiences in children and adolescents with sickle cell disease: A retrospective cohort study. *Pediatr Blood Cancer*. 2022 Mar;69(3):e29494. doi: 10.1002/pbc.29494. Epub 2021 Dec 16. PMID: 34913574.

Centers for Disease Control and Prevention, B. R. F. S. S (2021). BRFSS Adverse Childhood Experience (ACE) module updated (as of 2021). Atlanta, GA: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. Retrieved November 11, 2022, from https://www.cdc.gov/violenceprevention/pdf/acestudy/BRFSS_ACEModuleQuestions_2021_508.pdf

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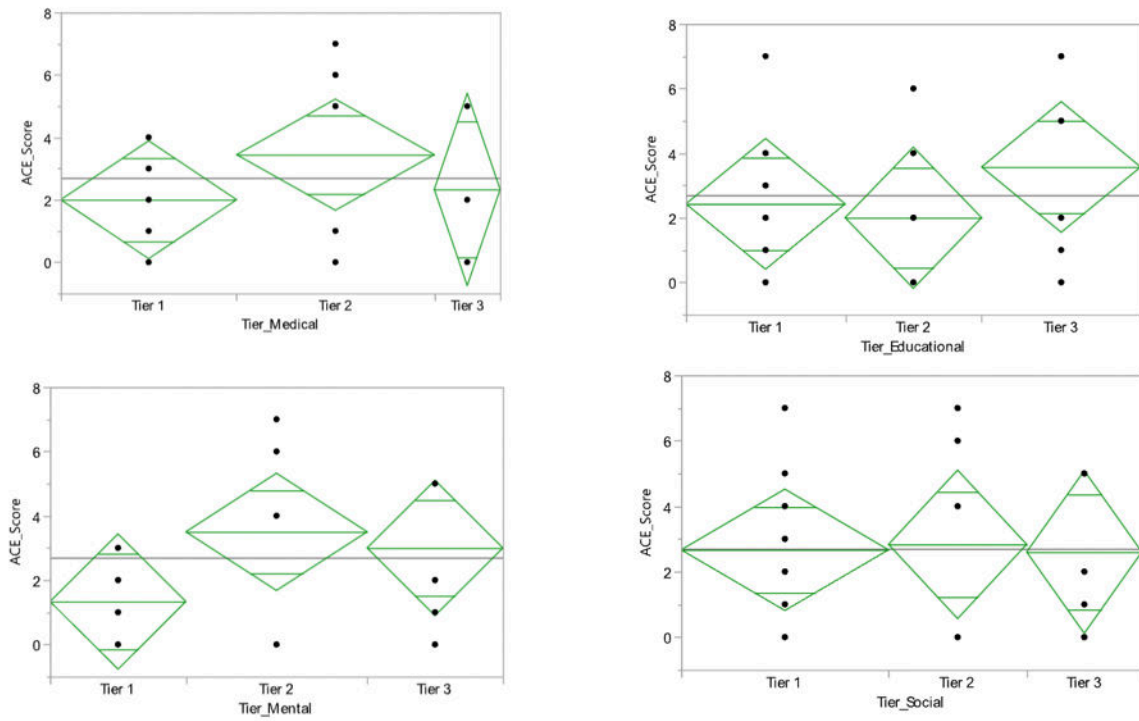


Figure 1

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