

Adverse Childhood Experiences in Youth with Juvenile Idiopathic Arthritis

Tamar Rubinstein, Children's Hospital at Montefiore; Danielle Bullock, University of Minnesota

Project Summary/Abstract

Adverse Childhood Experiences (ACEs) are stressors such as abuse, parental incarceration, and food insecurity. ACEs are pervasive, with almost half of the children in the United States experiencing at least one ACE, and are strongly associated with chronic disease. ACEs have been associated with rheumatologic diseases in adults, including disease development, activity, damage, and chronic pain. While social determinants of health have increasingly been shown to impact outcomes for children with rheumatologic diseases, our understanding of the relationship between ACEs and pediatric rheumatologic diseases is still nascent. Our previous work shows that children with arthritis have a high prevalence of ACEs compared to other children both with and without chronic disease. However, whether ACEs are associated with disease activity or outcomes for children with specific rheumatologic diseases is still unknown. We propose to leverage the Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry and associated infrastructure in order to conduct the first known study to evaluate the impact of ACEs on youth with juvenile idiopathic arthritis. Aim 1 of this study proposes to assess the feasibility and data completeness of two approaches to ACE screening, with the goal of maximizing data completeness in a manner that is sensitive to the needs of patients and their families. Aim 2 of this study proposes to implement the identified optimal ACE screen developed in Aim 1 in order to cross-sectionally assess relationships between ACEs, disease activity, and patient-reported outcomes in youth with confirmed diagnoses of JIA who are enrolled in the CARRA Registry. Findings from this study could ultimately lead to the development and testing of novel interventions that improve clinical outcomes and children's lived experiences.

Lay Summary

Adverse Childhood Experiences (ACEs) are major stressors such as abuse, parental incarceration, and hunger. Almost half of children in the United States have experienced at least 1 ACE. ACEs are associated with chronic illness in childhood and adulthood. Studies show that ACEs are associated with worse disease outcomes among adults with rheumatologic diseases, but there have not yet been any studies of the effect of ACEs on children with rheumatologic diseases. The first part of this study will assess how to best screen for ACEs among children with juvenile idiopathic arthritis, with the goal of making sure that complete information is obtained in a way that is comfortable for families. The second part of this study will assess whether ACEs are associated with worse disease activity, pain, physical function, and quality of life in children and teenagers with juvenile idiopathic arthritis.