

Assessing Psychosocial Risk Factors in Children with Sickle Cell Disease

Nicole Frey,¹ Julia LaMotte,^{1,2} Jillian Bouck,^{1,3} Genese Parker,² Roua Daas,^{1,3} Seethal A. Jacob,^{1,2,3}

¹Indiana University School of Medicine; ²Riley Hospital for Children at IU Health Division of Pediatric Hematology/Oncology; ³Center for Pediatric and Comparative Effectiveness Research

Background and Objective:

Most patients with sickle cell disease (SCD) in U.S. identify as Black/African American. This is an important psychosocial risk factor to consider given well-documented systemic racism in medicine resulting in disparate health outcomes, particularly for individuals managing a chronic health condition like SCD. The purpose of our research is to determine the level of psychosocial risk factors in children with SCD at Riley Hospital and assess the utility of Psychosocial Assessment Tools (PATs) in this setting.

Methods:

The PAT is a validated caregiver-report screener administered as part of the clinical visit. Each PAT is scored by the SCD Social Worker to provide tailored resources to families. Scores are stratified into 3 risk tiers indicating level of psychosocial intervention necessary- Universal, Targeted, or Clinical. Descriptive analyses were performed to determine patient and caregiver demographics, experiences, beliefs, and overall risk categorization.

Results:

There were 141 completed PATs for analysis. Ninety-five percent of the patients identified as Black/African-American with an average age of 8.57 years (0-22 years). Most caregivers were Black, single women over 21 with at least a high school degree. Sixty-seven percent of patients fell into the Universal range, 29% in the Targeted range, and 4% in the Clinical range. The Family Structures/Resources Subscore had the highest average, and includes questions about insurance coverage, transportation, and money problems. Forty-six percent of families reported some form of financial difficulty, with housing, utility bills, and car costs as the most common.

Conclusion and Impact:

Implementation of a psychosocial risk screener in the SCD clinic identified financial challenges for almost half of families, allowing for timely resource support. Many of these families, however, were categorized as Universal, indicating that distribution of resources must not be based on total PAT score alone. Future steps include evaluating the effect of resource provision at SCD visits on improving barriers to care.