Parent and Provider Perspectives on a Developmental Screening and Therapy Referral Program for Children 0-3 Years With Sickle Cell Disease

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PURPOSE: Sickle cell disease (SCD) is an inherited blood disorder associated with developmental delays. Within the Unites States, most people with SCD identify as Black or African American. SCD causes the red blood cells to break apart, and the broken cells can cause inflammation and blockage of blood vessels. Children with SCD experience many side effects including pain and stroke. A lesser-known side effect can be developmental delay that can begin to emerge in the first few years of life. Early intervention can help reduce the impact of developmental delay and potentially improve long term outcomes. Screening for developmental delay in the first years of life can support early detection of developmental delays and referral to therapy services. Prior studies suggest that home-based early intervention can ameliorate the impact of delays and improve outcomes, yet few with SCD are referred to these beneficial services. The purpose of this study was to examine strategies to increase participation in screening and early intervention for children with SCD.

DESIGN: A cross-sectional descriptive design was used to gather qualitative data from early intervention providers and caregivers.

METHOD: Early intervention (EI) providers and caregivers of children 3-5 years with SCD completed a semi-structured interview and survey. Caregivers completed the Knowledge of Infant Development Inventory (KIDI); EI Providers completed the Implementation Climate Scale (ICS). Thematic analysis identified major themes of the interviews. Results were analyzed concurrently to identify patterns across the dataset. A follow-up survey asked EI providers to rank order incentives to increase adoption of evidence based practices.

RESULTS: Eleven caregivers and eight EI providers participated. All caregivers and three (38%) of EI providers identified as Black or African American. Three main themes were identified: 1) high acceptability of a screening and referral program, 2) awareness of systemic disparities, and 3) need for caregiver buy-in. All participants described a need to support caregiver buy-in and desired SCD specific education, including the risk and prevalence of developmental delays, common indicators of delay, and way to improve child outcomes. Knowledge related to child development is limited among caregivers (KIDI; mean = 79%, SD = 9%). EI providers expressed high interest in increasing EI utilization, ICS scores indicated very low incentive (mean = 0.08, SD = 0.22) for implementing evidence-based practices. The most preferred incentive was the ability to make a decision about something (e.g., topic of meeting).

CONCLUSION: The findings from this study add to our understanding of what is important to caregivers and would help participation in a developmental screening and referral program. This study also identified that leaders in early intervention are open to new programming that includes SCD, however there is little programmatic support. These findings support the need for a screening and referral program for children with SCD, with a focus on caregiver engagement and education about child development and SCD.

IMPACT STATEMENT: These outcomes will add to the development and implementation of a developmental screening program that offers caregiver education about SCD and early intervention programming and guidance for early intervention providers when they receive referrals for children with SCD.

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