

0072

Cognition in Children with Sickle Cell Disease

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Approximately 300,000 infants are born with sickle cell disease (SCD) every year, which is an inherited blood disorder found mostly in people of African American, Hispanic or Middle Eastern descent (WHO, 2006). SCD is associated with an increased risk for neurological complications that can impact academic attainment. Research indicates that these children have substantial deficits at school age and may benefit from early intervention services (Thompson, Gustafson, Bonner, & Ware, 2002; Hogan et al, 2002). However, there is minimal research assessing development of children with SCD during infancy and early childhood.

The purpose of this study is to:

- Describe development in children 1-24 months with SCD
- Determine the efficacy of a parent education training on parental knowledge of SCD and typical developmental milestones

This is a prospective cohort study. Participants are children 1-24 months of age with a confirmed diagnosis of SCD and their caregivers. Children are excluded for known neurological complications or significant medical history. Caregivers are encouraged to attend monthly Parent Education Programs (PEP) that focus on positive child-parent interactions and information about SCD. Children were assessed quarterly using the Bayley Scales of Infant Development III (BSID) for one year and caregivers completed the Infant/Toddler Home Inventory upon enrollment and study completion.

Results: Available prior to WFOT Congress.

We expect to find that children with SCD have a greater risk of being classified in a lower developmental category than age matched norms using the Bayley Scales of Infant Development III (BSID; Bayley, 2006). In this study, particular focus is going to be placed on the documentation of developmental delays in infancy and early childhood in children with SCD. Feasibility of a caregiver education program within this population will also be determined. We hope to provide the necessary background information for future studies investigating the efficacy of providing early intervention services.