

## **Pain in Children with Sickle Cell Disease: Integrating Parent, Family, and Cultural Perspectives in Care**

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Caring for children with sickle cell disease (SCD) is unique given the intense and unpredictable nature of pain episodes and the complex social, cultural, and economic issues that impact access and provision of care. Culturally sensitive assessment is critical to understanding the impact of pain on children and families; however, this goal may be complicated by patient and parent mistrust of medical systems and by protocols that do not fully capture risk and resiliency in children and families.

Eight focus groups with 53 parents of children ages 7 to 12 with SCD were conducted across three sites (Cincinnati, Columbus, and Cleveland Rainbow and Babies Children's Hospitals) to examine areas important to intervention research: (1) barriers and facilitators to pain management, particularly at home where the majority of pain episodes occur; and (2) impact of pain and related sequelae on patient and family coping.

All transcripts were coded for major and minor themes that emerged during group discussion using standardized coding procedures. Transcripts were further coded for within-site and cross-site consensus of themes.

Consensus ratings reveal that parents primarily defer to children's verbal and nonverbal cues in encouraging home management strategies including medication, distraction, and relaxation, and for deciding when to go to the emergency room. Other factors such as intuition and spirituality, previous experiences, day/ timing, staff training issues, and physician recommendations also impact decision-making. Families also rely on support and prayer in coping with pain and related consequences. Staff training around cultural issues and disease impact would foster sensitivity in care. Enhancing support and educational services for patients and families, and furthering school and community education are areas for future intervention.

This study has informed initiatives to increase sensitivity in care and assessment. Implications for understanding pain in a broader context and for ensuring culturally-sensitive intervention will be highlighted.

