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Parental Problem-Solving Abilities and the Association of Sickle Cell Disease Complications with Health-Related Quality of Life for School-Age Children

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Abstract Children with sickle cell disease (SCD) are at risk for poor health-related quality of life (HRQOL). The current analysis sought to explore parent problem-solving abilities/skills as a moderator between SCD complications and HRQOL to evaluate applicability to pediatric SCD. At baseline, 83 children ages 6–12 years and their primary caregiver completed measures of child HRQOL. Primary caregivers also completed a measure of social problem-solving. A SCD complications score was computed from medical record review. Parent problem-solving abilities significantly moderated the association of SCD complications with child self-report psychosocial HRQOL ($p = .006$). SCD complications had a direct effect on parent proxy physical and psychosocial child HRQOL. Enhancing parent problem-solving abilities may be one approach to improve HRQOL for children with high SCD complications; however, modification of parent perceptions of HRQOL may require direct intervention to improve knowledge and skills involved in disease management.

Keywords Pediatric sickle cell disease · Problem-solving skills · Health-related quality of life

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Introduction

Children with sickle cell disease (SCD) are at risk for poor health-related quality of life (HRQOL) (Palermo, Schwartz, Drotar, & McGowan, 2002) due to medical, sociodemographic and psychosocial factors (Kral, Brown, & Hynd, 2001). Palermo et al. (2002) found that children and adolescents with SCD were rated by their caregivers to have lower physical, psychological, and social HRQOL, with associated limitations in self-esteem, school and social participation, and general psychological adjustment compared to healthy peers. Consistent with this finding, HRQOL among children with SCD has been rated as significantly lower based on caregiver and child report compared to normative samples (Panepinto, O'Mahar, DeBaun, Loberiza, & Scott, 2005). Lower physical HRQOL has been associated with pain episode frequency (Dampier et al., 2010; Fisak, Belkin, von Lehe, & Bansal, 2012), disease severity (Panepinto et al., 2005), other SCD complications (Panepinto, Pajewski, Foerster, Sabnis, & Hoffmann, 2009), and family and neighborhood distress (Palermo, Riley, & Mitchell, 2008) as well as being female and older in age (Palermo et al., 2002).