

## **Adaptive challenges for Adolescents with Sickle Cell Disease and their Parents**

### **Abstract**

**Purpose** The purpose of this study is to explore and describe the adaptive challenges faced by adolescents with Sickle Cell Disease (SCD) and their parents, and the adaptive work they engage in to self-manage the disease. An understanding of these challenges will allow for the design of interventions aimed at supporting self-management of symptoms and disease complications for adolescents with SCD.

**Background/significance** SCD is an inherited blood disorder that predominantly affects African Americans in the United States. Adolescence is a critical period for patients with SCD.

Adolescents are at increased risk of mortality and poor health outcomes, including recurrent hospitalizations and increased risk of complications. A significant challenge for adolescents with SCD and nurses is the unpredictability and complex nature of these symptoms which vary widely between individuals and for the same individual across the disease trajectory. Adolescents in particular are susceptible to unpredictable complications as they undergo dramatic physical, emotional, and cognitive changes in the midst of the disease course. This unpredictability results in frequent and challenging encounters for the adolescent with the health care system. The focus of care for adolescents with SCD needs to be directed at improving their adaptive capacities to self-manage the disease. The Adaptive Leadership framework constitutes a novel model of care that emphasizes the ability of individuals to adapt both physically and psychologically to their disease. It is a dynamic model that implicates the trajectory of symptoms over time. It aims at maximizing adaptive capacities of adolescents with SCD and builds on a collaborative relationship between the adolescent and the nurse to monitor symptoms and plan adaptive work.

**Methods** A qualitative descriptive focus group design will be used to study adolescent and parent adaptive challenges to living with SCD. Separate adolescent (n=2) and parent/caregiver (2) focus groups with 6-8 participants each will be recruited from the Pediatric Sickle Cell Center at Duke Children's Hospital (Durham, NC). Participants will be recruited through provider or self-referral. Inclusion criteria for the adolescent groups are a diagnosis of SCD (HgbSS genotype), age 11-18 years old, English speaking, and ability to provide consent/assent. Inclusion criteria for the parent will be having an adolescent with SCD, English speaking, and ability to provide consent. Data analysis will include an inductive coding technique to identify codes and themes.

**Nursing relevance/Implication** This study will identify the adaptive challenges and the adaptive work of adolescents with SCD and their parents as they attempt to self-manage the disease. The findings will provide a framework for the classification of challenges faced by adolescents and their parents and will be useful to inform nursing interventions as nurses work collaboratively with adolescents and their parents to foster an adaptive approach to care management and delivery.

### **Lay language Abstract**

Sickle cell disease is a complex disease that affects predominantly African Americans in the United States. It is characterized by severe complications including pain crises, chronic pain, stroke, which are often unpredictable and vary among individuals and for the same individual across time. Adolescents who have sickle cell disease face many challenges as they attempt to self-manage the disease and are at high risk for poor health outcomes and death. A better understanding of these challenges from the perspective of the adolescents and their parents is needed so that directed at improving their adaptive capacities to self-manage the disease. The Adaptive Leadership framework constitutes a novel model of care that emphasizes the ability of individuals to adapt both physically and psychologically to their disease. It is a dynamic model that implicates the trajectory of symptoms over time. It aims at maximizing adaptive capacities of adolescents with SCD and builds on a collaborative relationship between the adolescent and the nurse to monitor symptoms and plan adaptive work. The study will use focus groups to understand the challenges that adolescents who have sickle cell disease and their parents face as they attempt to self-manage their disease. Findings from this study can help nurses design interventions aimed at supporting self-management of symptoms and disease complications for adolescents with SCD.