

## **SELF-CARE AND SICKLE CELL DISEASE**

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Sickle Cell Disease, a chronic illness affecting mostly Blacks, results in a lifetime of physical and psychological difficulties and complications which ultimately lead to an early death. This vulnerable, minority group is frequently hospitalized for complications of SCD. Patients with Sickle Cell Disease (SCD) tend to receive inadequate care, little guidance in managing their illness, and report dissatisfaction with healthcare delivery. This neglect places them at risk for increased negative health outcomes. To even live to adulthood, patients with SCD must learn how to self manage this chronic illness in order to persevere. Effective self care strategies will lead to improved quality of life, better health maintenance and greater patient satisfaction. The caring behaviors of healthcare providers are important to facilitate the development of effective self care behaviors by SCD patients. Patients who have experienced caring behaviors from healthcare providers have more effective self care behaviors. Improved self care skills result in increased quality of life and health.

**Purpose:** The purpose of this descriptive pilot study is to explore patients' perceptions of nurses' caring behaviors; patients' level of satisfaction with provided healthcare, patients' skills in self care and their attitudes towards learning more self care strategies.

**Method:** The sample will consist of all SCD patients who consent to participate from a population of 200 adult SCD patients at an out-patient clinic in North Texas. Subjects will complete The Caring Behavior Assessment (CBA), Chronic Illness Assessment Interview –Sickle Cell Disease (CIAI-SCD), and Sickle Cell Self- Efficacy Scale. Data will be collected in December, 2004 and January, 2005 and analysis will be initiated in January. The results will be reported in the poster presentation.