

Testing the Theory of Self-Care Management for Vulnerable Populations in Sample of Adults with Sickle Cell Disease

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Sickle cell disease (SCD) and its manifestations offer a lifetime of pain and hospitalizations. SCD most often affects Blacks, a vulnerable minority population. Even though modern medicine is able to detect SCD, these patients often receive inadequate health care and may lack the skills needed to improve self-care management, health status, and quality of life. SCD patients often report dissatisfaction with the care that they receive. Dissatisfaction is often related to inadequate pain relief. Inadequate pain relief results in poor quality of life. Also, medical interventions may not be adequate, as patients need to learn to increase their self-care management.

The aim of this research was to describe factors that predict quality of life in persons with SCD. This aim was achieved by testing the Theory of Self-Care Management for Vulnerable Populations, a middle range theory that focuses on increasing health status and quality of life in vulnerable populations.

Persons over the age of 18 with SCD (N=232) were recruited from two outpatient clinics. They completed questionnaires that assess vulnerability, assertiveness, coping behaviors, knowledge, self-efficacy, social support, self-care, health status, and quality of life. Descriptive data was used to describe the demographic characteristics of person's with SCD. The research questions were answered using Structural Equation Modeling (SEM) to estimate the measurement model and the structural equation model. Based on the SRMC, the standardized root mean squared covariance residual, the vulnerability model had the best fit, followed by health outcomes, self-care management, and intra-personal resources. The average SRMC for the four measurement models was 0.08 indicating an overall assessment of moderate to fair fit of the measurement models underlying the Theory of Self-Care Management for Vulnerable Populations. The fit indices support the underlying structural model of the final respecified Theory of Self-Care Management for Vulnerable Populations as moderate to fair. The results of the study identify potential interventions that may increase self-care management, health status, and quality of life in persons with SCD. Additionally, the results indicate the need to further describe the concept of vulnerability, including its antecedents and defining characteristics.