

Attitudes Among Healthcare Providers and Patients Diagnosed With Sickle Cell Disease: Frequent Hospitalizations and Stressors

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Sickle cell disease (SCD) is a chronic condition that affects thousands of people worldwide. The purpose of this study is to illustrate some of the challenges and perceptions of people diagnosed with SCD. The aims were to describe stressors, problematic symptoms, sources of support, and interactions with healthcare providers. This descriptive study, using mostly open-ended questions and conceptual analysis, included a sample of patients with SCD who were older than 18 years in ambulatory (57%) and inpatient (43%) clinics. Participants completed a 20-minute interview. Pain or SCD crisis were the chief reasons for hospitalization, and a wellness checkup was the chief reason people returned to an ambulatory clinic. Most (74%) were able to perform chores. Family was reported to cause the most stress in the home and also provide the most help. Pain is a pervasive aspect of life, limiting activities of daily living. Negative interactions with healthcare providers are common; therefore, advocacy is necessary for patients with SCD.

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Sickle cell disease (SCD) affects about 80,000 people in the United States and is the most common inherited blood disorder (U.S. National Library of Medicine, 2012). SCD affects 1 in every 500 births of African Americans (Centers for Disease Control and Prevention, 2011a), with the mean age of death being 33 years for men and 36 years for women (Lanzkron, Carroll, & Haywood, 2013). People diagnosed with SCD have a life expectancy of 20–30 years less than those without SCD (Centers for Disease Control and Prevention, 2011b). An SCD diagnosis often brings challenges with employment, school, and other activities. The vignettes throughout this article are based on the experiences of many patients and are meant to illustrate the lived experience. The purpose of this article is to illustrate some of the challenges and perceptions of people who are diagnosed with SCD. SCD can affect every facet of daily living, including relationships, health care, and finances. People with SCD are often referred to and managed by hematologists for pain and

symptom management, so nurses must be aware of and sensitive to the hardships of living with SCD.

My name is J.R., and I'm 28 years old. I was diagnosed with sickle cell at birth. My first crisis was at age 6 weeks. I just don't understand why there's nothing that can be done to help—just pain medicine and intravenous fluids. Sickle cell has been known for more than 100 years now. Is it because it's a black person's disease?

Background

SCD is manifested systemically with great variation in frequency and severity (Ballas et al., 2010). Periodic vaso-occlusive pain crises are the most common reason for a patient to be hospitalized; however, 62 complications involving 12 basic systems have been identified (Ballas et al., 2010). They include neurologic, renal, liver, and pulmonary complications, along