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

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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 35 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