Sickle Cell Disease in Adults: Developing an Appropriate Care Plan

Nadine Matthie, PhD, RN, CNL, and Coretta Jenerette, PhD, RN, CNE

Background: Sickle cell disease (SCD) is primarily characterized by pain. This chronic pain with acute exacerbations is the most common reason for hospital visits, admissions, and readmissions, particularly in young adults (aged 18–39 years). People who present to the hospital for pain crises often report that nurses lack knowledge of SCD and, consequently, they do not provide appropriate, timely care.

Objectives: Because pain episodes often result in hospital admissions, this article highlights prominent issues that staff nurses need to know.

Methods: Using a review of the literature and case studies, the authors provide recommendations to improve care of adults with SCD.

Findings: No objective signs of a sickle cell pain crisis exist. Patients react to pain in different ways and use various coping mechanisms in response. Suspected opioid addiction should not affect the provision of nursing care. Pain must be treated appropriately to decrease the potential for prolonged admissions and/or readmissions. Patients are to be acknowledged as experts and collaborated with in developing an appropriate plan of care. Advocacy on behalf of the patient is important for better communication with providers. With this knowledge, nurses will be better equipped to provide the appropriate and timely care required to manage pain crises experienced by individuals living with SCD.

Nadine Matthie, PhD, RN, CNL, was a postdoctoral fellow at the time of this writing and Coretta Jenerette, PhD, RN, CNE, is an associate professor, both in the School of Nursing at the University of North Carolina in Chapel Hill. The authors take full responsibility for the content of the article. The study was supported, in part, by a grant (No. T32NR007091) from the National Institute of Nursing Research. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of the article have been disclosed by the independent peer reviewers or editorial staff.

Key words: sickle cell disease; sickle cell anemia; sickle cell pain; clinical management; pain; staff nurses

Digital Object Identifier: 10.1188/15.CJON.562-567

Adults with sickle cell disease (SCD) average more than 197,000 annual visits to the emergency department (ED), with 29% of visits resulting in hospital admissions (Yusuf, Atrash, Grosse, Parker, & Grant, 2010). These visits often are less than ideal. Patients with SCD and their families report feeling that race affects healthcare quality and interpersonal relationships with caregivers, and results in negatively different treatment (Nelson & Hackman, 2013). When they sought pain treatment at hospitals, they reported being stigmatized as drug seekers (Jenerette, Brewer, & Ataga, 2014) and that their experiences often involved mistrust by providers, lack of patient control, and neglect (Prabhakar, Haywood, & Molokie, 2010). Patients with SCD also encountered underestimation, misunderstanding, and inadequate management of their pain (Zempsky, 2010). They experienced long delays in receiving pain medications and providers who lacked an understanding of SCD (Lattimer et al., 2010). Lattimer et al. (2010) also reported that patients with SCD felt that they were not always treated with respect and dignity, they were inadequately involved in decisions about their care, they received conflicting information from staff, nurses did not provide clear answers to their questions, finding someone with whom to discuss concerns was difficult, and their fears and anxieties were not always discussed by the nurses. In addition, some patients reported that their family was not given enough information to help with their recovery (Lattimer et al., 2010).

Every staff nurse must know certain things about SCD and integrate them into practice to provide appropriate and timely care.