

Owing to the lack of specialized care and the unpredictable nature of acute pain episodes in adults with sickle cell disease (SCD), emergency departments have been largely used to provide care for these patients. The lack of specialized care for patients with SCD portends higher healthcare costs and lower health-related quality of life. Although study findings have shown that using multiple models for SCD care is feasible and cost-effective, nurses' awareness of evidence-based guidelines and care models for acute pain management in ambulatory settings is lacking.

#### AT A GLANCE

- Limited access to specialty care for adults with SCD leads to increased rates of acute care utilization, but a variety of models of care have the potential to fill this gap.
- Strong nursing assessment and communication skills are crucial to safe triage of acute pain in adults with SCD in the ambulatory setting.
- Nursing leadership must establish clear organizational policies and guidelines to support safe nursing practice when treating acute pain in patients with SCD in the ambulatory setting.

#### KEYWORDS

anemia; sickle cell disease; acute pain; pain management; nursing; ambulatory care

#### DIGITAL OBJECT

#### IDENTIFIER

10.1188/21.CJON.605-607

# Sickle Cell Disease

## Considerations for acute pain management in the hematology-oncology ambulatory setting

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It is estimated that about 100,000 individuals in the United States have sickle cell disease (SCD), a group of inherited blood disorders (Centers for Disease Control and Prevention [CDC], 2020a). Complications of SCD include acute pain, chronic pain, avascular necrosis, priapism, acute chest syndrome, stroke, splenic complications, infection, organ failure, and psychosocial difficulties (CDC, 2020b). Acute pain in SCD stems from vaso-occlusive crisis (VOC) and is difficult to predict. Because of a lack of SCD specialty clinics, patients often seek care in the emergency department (ED) (Shah et al., 2019). VOC has been associated with more than three-fourths of the about 134,000 SCD hospitalizations in the United States, with an average stay of five days, and 40% of ED visits leading to hospitalization in 2016 (Fingar et al., 2019). In addition to the lower health-related quality of life (HRQOL) reported by patients with SCD, inpatient care costs in 2016 totaled \$811.4 million (Fingar et al., 2019), and acute care utilization for this subpopulation continues to rise (Lanzkron et al., 2018).

Although the ED is well equipped to care for complex and medically unstable patients with SCD, analgesia administration in the ED may be delayed because of prioritization of life-saving care (Telfer & Kaya, 2017). In addition, patients with SCD are often characterized as opioid seeking and, as a consequence, do not often receive adequate or timely pain management (Telfer & Kaya, 2017). Inadequate acute pain management for

patients with SCD has been linked to increased hospitalization (Telfer & Kaya, 2017). Seeking care in the ED means fragmented clinical encounters with healthcare providers that impede shared decision-making, which increases the likelihood of negative illness experience (Telfer & Kaya, 2017).

Historically, the poor health outcomes and shorter life span observed in patients with SCD informed SCD centers' focus on pediatric care, but SCD care should be adapted to consider the increased number of adults (Kanter et al., 2020). Access to care for adults with SCD is still lacking, but using alternate care models, including cancer centers, may reduce disparity in care and outcomes (Andemariam & Jones, 2016). Kanter et al. (2020) outlined four care models based on the levels of access as classic comprehensive, embedded care, specialized medical home, and hub and spoke. Evidence supports feasibility and cost-effectiveness of these care models in integrated SCD infusion centers because they allow for increased access to specialty care. Increased access to specialty SCD care may reduce healthcare costs (Rousseau et al., 2020). This model was first shown in the seminal work of Benjamin et al. (2000). To ensure safe management of acute pain, it is of paramount importance for hematology-oncology nurses to be cognizant of the embedded model of care and its limitations while caring for patients with SCD. This article outlines pertinent components of SCD care delivery models for acute pain management in ambulatory hematology-oncology settings for adults with SCD.