Adults with Sickle Cell Disease

An Interdisciplinary Approach To Home Care and Self-Care Management With a Case Study

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The complexity of caring for adults with sickle cell disease (SCD) strains the confines of a care-segregated medical system. As treatment protocols have dramatically improved since 1990, many patients with SCD are now living well beyond their 6th decade of life. This improved survival rate presents opportunities and challenges for the home healthcare nurse in the management of adult patients with SCD. The home healthcare nurse is essential in the coordination of interdisciplinary health team members to reduce pain episodes and the potentially catastrophic complications of renal failure, pulmonary disease, and cardiovascular events. In addition, the home healthcare nurse serves as patient advocate for the transition from acute care to home, as well as advocate for healthcare maintenance of vision, musculoskeletal involvement, and social and psychological support. This article seeks to provide a viable network for home healthcare nurses to establish self-care management and support of the adult patient with SCD.

Overview of Sickle Cell Disease

Sickle cell disease (SCD) is caused by a genetic mutation resulting in defective hemoglobin (Hgb) synthesis. Patients with SCD inherit the mutated gene from both parents. Individuals inheriting the gene from a single parent harbor the sickle trait, but are typically asymptomatic. Approximately 8% of African Americans carry the trait; while 1 in 500 actually have SCD. Individuals with Mediterranean, Asian, Indian, and Middle Eastern descent may also carry the trait (National Institutes of Health [NIH], 2002). SCD is considered a chronic autosomal recessive disorder that is manifested as sickle cell anemia, sickle Hgb C disease, or sickle cell thalassemia disease (Jenerette & Phillips, 2006).

Symptoms of SCD are related to the thin, rigid, crescent-shaped Hgb cells, which carry inadequate oxygen and tend to clump in the vasculature. This clumping can lead to a vaso-occlusive crisis (VOC) with symptoms of profound pain, typically in the bones and joints. The sickle cells clump and occlude vessels, thereby starving the tissues of oxygen. This triggers an inflammatory response releasing histamines, enzymes, cytokines, and chemokines. This cycle of hypoxia and inflammatory mediator release can occur in any tissue in the body, including bone, bone marrow, and organs. Additional symptoms of VOC include a falling Hgb level, hypotension, tachycardia, fever, swollen joints, shortness of breath, and dehydration (Marlow & Chicella, 2002; Yale et al., 2000).

Precipitating factors for VOC are related to patients experiencing emotionally stressful events, dehydration, pregnancy, infection, and abrupt changes in temperature or altitude. The pain of VOC is reported by some patients as more severe than cancer pain (Marlow & Chicella, 2002) and is the most common reason for seeking emergency department (ED) care in adults (Jenerette & Phillips, 2006).

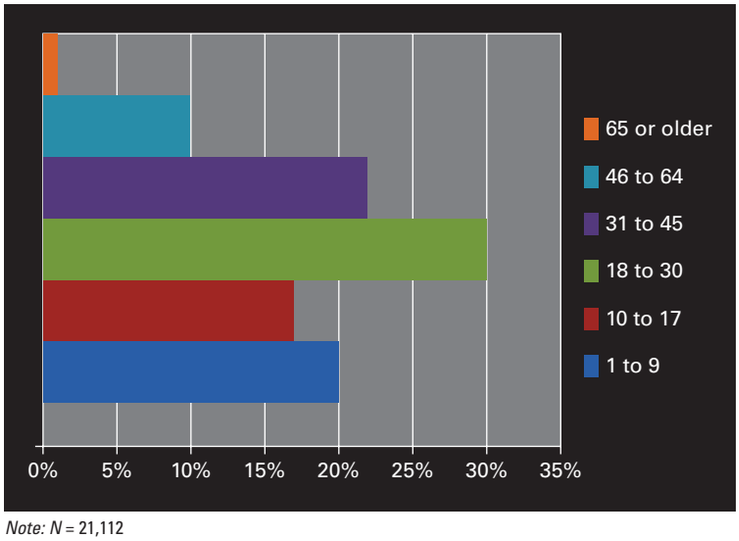
Unfortunately, ED healthcare providers often respond with inadequate pain control because of overestimating drug dependence and their perceptions of drug seeking behaviors by patients' with SCD (Yale et al., 2000). These misconceptions by ED providers, combined with lack of a regular primary care provider and poor self-care management of SCD, are factors contributing to the patient's repeated use of the ED for pain management (Todd et al., 2006).

Acute Care Use and Rehospitalization

Adult patients with SCD visit the ED approximately 197,000 times a year with 30% of these visits resulting in hospital admission (Center for Disease Control and Prevention [CDC], 2010). The majority of hospitalizations for this patient population are due to pain crisis with increasing frequency of pain episodes in early adulthood (NIH, 2002).

One U.S. study of ED encounter data (n = 21,112) from eight geographically dispersed states was retrospectively analyzed to identify rates of acute care use and rehospitalization (Brousseau et al., 2010). The encounter rate, which included hospitalizations and ED visits, was 2.59 with the 18- to 30-year-old category experiencing the highest encounter rate, 3.61. The age groups of individuals included in the cohort are displayed in Figure 1.

Figure 1. Encounter rate by age groups.



Note: N = 21,112
Source: Data from Brousseau et al. (2010).

In terms of healthcare costs for acute care management of SCD from this retrospective study; Medicare and Medicaid were the primary payers for 60% of the care provided. The other primary payers for SCD care were private insurance (25%), uninsured (11%), and private pay (4%). Brousseau et al. (2010, p. 1293) also found that "one in three adult patients with

SCD seen in the ED was rehospitalized within 30 days." This was a significantly higher rehospitalization rate than the more common chronic diseases such as asthma (34%) or diabetes (20%; Brousseau et al., 2010). This vicious cycle of repeated ED treatments and frequent rehospitalization contributes to astronomical healthcare costs, especially with the increasing age of SCD patients seeking pain relief.

Unfortunately, the aggressively focused care for pain relief in the ED does little to prevent future flairs or to provide patient education and support for self-care management when the patient returns home. This leaves an enormous opportunity for home healthcare nurses (HHNs) to intervene and improve the quality of life for patients with SCD and their families.

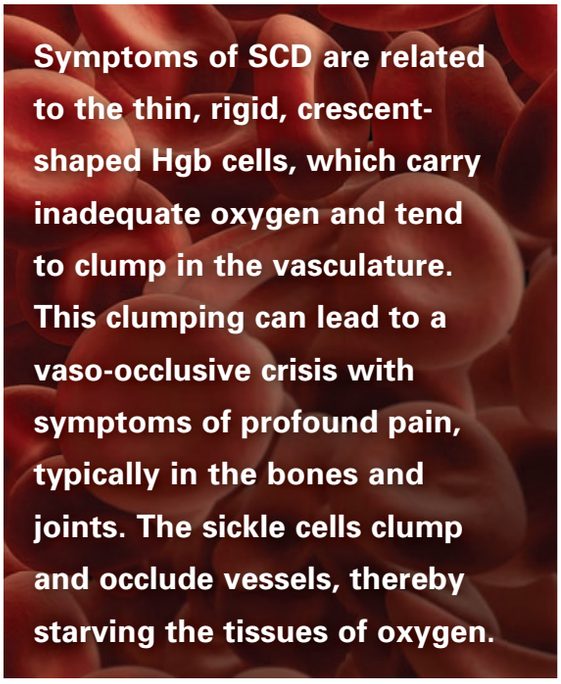
Complications of SCD

Pain is the hallmark symptom of SCD; however, complications from involvement with multiple organ systems also pose potential complications. It is therefore imperative for the HHN to understand the most significant complications that may arise for early detection and intervention. The HHN has an important role in patient and family education regarding complications and promoting self-care management practices to reduce complications.

Planning home care and developing goals together with the patient and family can improve overall health and well-being while reducing complications and unnecessary ED visits. By carefully weaving an interdisciplinary web of care, the HHN can assist the patient and family to reduce the complications that many patients with SCD endure as they transition from childhood into young adulthood and beyond. Some of the common complications noted particularly in adults with SCD are found in Table 1.

Current Treatment Protocols

There is no cure for SCD and treatment focuses on controlling pain, managing hydration status, preventing infection, and other complications that can precipitate VOC. Hydroxyurea, an antineoplastic agent, is often used for adults to manage complications of SCD. Hydroxyurea facilitates synthesis of red blood cells with fetal Hgb reducing the frequency and severity of painful episodes in about 50% of adults treated (Brawley et al., 2008; Gaspard, 2005; NIH, 2002). Brawley et al. (2008) suggests that responsiveness to hydroxyurea can take up to 6 months. However, data on the effectiveness of hydroxyurea is limited and more studies are needed to better understand the long-term effects of treatment and barriers that prevent widespread use for SCD.



Transfusion therapy is another treatment being used to prevent organ damage and improve the oxygen carrying capacity of the blood while decreasing the number of sickled cells present. Episodic transfusions are used to manage severe anemia and acute illness such as acute chest syndrome and sepsis (NIH, 2002). This type of transfusion is also helpful in improving tissue perfusion and restricting severity of VOC. Chronic transfusion therapy is a type of exchange transfusion or red cell pheresis used to remove sickled cells and replace them with normal red blood cells without burdening the vascular system with iron or excess viscosity (NIH, 2002). Transfusion therapy is not without complications, however. Fluid volume overload, hemolytic transfusion reactions, bloodborne infections, and iron overload are complications that warrant careful assessment before, during, and after transfusion therapy.

Stem cell transplant is yet another SCD treatment option being studied. As of 2002, 85% of 150 SCD patients with transplants produced stable results in children with a sibling donor.

Table 1. Complications of Sickle Cell Disease (SCD) in Adults

Pain
• Both chronic and acute can be crippling for some. • Acute pain is the result of vaso-occlusive crisis (VOC) in which sickled cells clump, blocking blood flow. This type of pain is similar to a myocardial infarction, another type of ischemic pain. • Chronic pain results from a lifetime of VOC episodes. These repeated assaults lead to tissue damage of bones, organs, and vessels.
Acute chest syndrome and other pulmonary complications
• Second only to pain as a reason for hospitalization, patients with acute chest syndrome often present with fever, chest pain, dyspnea, cough, and hypoxia that can rapidly progress to respiratory failure. • Hypoxia increases sickling leading to occlusion in the pulmonary vasculature. Treatment is supportive (oxygen and antibiotics) and transfusion therapy improves respiratory function. • Repeated episodes of acute chest syndrome or other pulmonary complications can lead to pulmonary hypertension, another frequent complication of adults with SCD.
Eye disease
• Annual eye exams are important and should begin in childhood to detect early optic changes that occur as a result of vascular occlusions in the eye (iris, conjunctivae, retina, and the optic artery/vein) retinopathy, retinal hemorrhages, detachments, and increased ocular pressure can all lead to loss of vision. Treatment is directed toward prevention of vision loss.
Stroke
• A major complication of SCD that does not discriminate, affecting both adults and children. • Gaps exist in the literature regarding prevention and treatment of strokes in adults with SCD. • Studies do suggest high blood pressure is a risk factor in adults with SCD.
Renal disease
• Is a consequence of normal pathology within the renal medulla. This area of the kidney is normally low in oxygenated blood and more acidic, two conditions that promote sickling and, therefore, lead to occlusions within the renal tissues. • This leads to chronic renal damage and associated abnormalities such as inability to concentrate urine and chronic hematuria, proteinuria, glomerular injury, and renal failure.
Bone and joint abnormalities
• Vaso-occlusive events occur frequently in the bones and joints leading to distorted bone growth, infection, and tremendous pain for patients with SCD. • Chronic anemia leads to bone marrow hyperplasia, growth deformities, and fractures. • Dactylitis (hand-foot syndrome) occurs in young children and presents as pain and swelling in the bones of the hands and feet. • Osteonecrosis is the result of ischemic events of the bone that mainly affect the femoral and humeral heads. Treatment is aimed at preserving the joint and at times arthroplasty although infection rates are high. • Bone infarctions also lead to aseptic avascular necrosis, osteomyelitis, and septic arthritis.
Chronic leg ulcers
• The etiology of leg ulcers in patients with SCD is poorly understood but is thought to be due to tissue hypoxia in the lower leg in addition to other contributing factors like infection and trauma. • The most effective treatment is bed rest with limb elevation and dressing application; although all methods are often time consuming, impractical, and costly.
Age/lifestyle-related illness in conjunction with SCD
• Diabetes, asthma, atherosclerotic vascular disease, and other chronic illness.

Source: Authors. Data from McCaffery & Passero, 1999; and NIH, 2002.

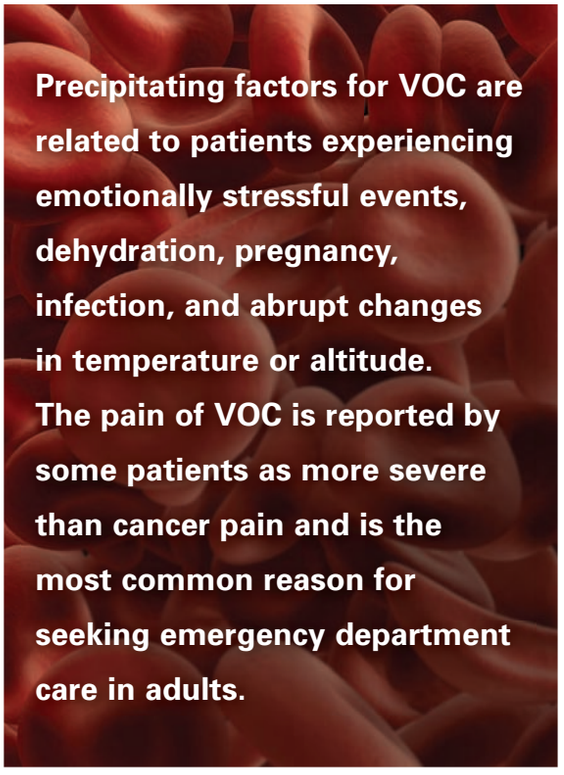
Unfortunately, studies are limited for adults with SCD because of the increased risk of death due to graft-versus-host disease (NIH, 2002). HHNs may have the opportunity to care for patients experiencing current SCD treatment protocols. The side effects and complications from these protocols would be critical to include in the overall plan of care by the interdisciplinary team.

HHN Assessment

To develop a self-care management plan, a thorough assessment of the patient and their lifestyle choices is necessary. Self-care management, which includes lifestyle changes, is believed to favorably influence health status and quality of life (Jenerette & Phillips, 2006). Because pain is the hallmark feature of SCD, the HHN needs to first evaluate past and present pain management strategies and experiences.

The Guidelines for Standard of Care of Acute Painful Episodes in Patients with Sickle Cell Disease (Ballas et al., 2000) outlines pain assessment for adults using verbal responses, visual analogue scales, and a daily pain diary. In addition, identifying location of pain using a scaled body drawing, assessment of coping strategies (Coping Strategies Inventory), and assessment of social and environmental factors that influence pain is also necessary. It is suggested that these assessments take place when the patient is pain-free (Ballas et al., 2000). Teaching the patient and family members about pain assessment, coping strategies, and providing them with tools to use may prove helpful with self-management in the home environment (Ballas et al., 2000). Diaries are one such tool that may be used to assess pain and the patient's pain response (e.g., the Initial Pain Assessment Tool, Supplemental Digital Content 1, http://links.lww.com/HHN/A9; the Pain Rating Scales, Supplemental Digital Content 2, http://links.lww.com/HHN/A10; and the Pain Control Record, Supplemental Digital Content 3, http://links.lww.com/HHN/A11).

One study used daily diaries to help patients and family members better understand pain self-management and identified modalities and medications that best control pain without interrupting activities of daily living (ADLs) (Dampier et al., 2002). Dampier et al. (2002) used diaries to capture not only pain occurrence and intensity, but also quality, location, and duration of pain, and to distinguish between sickle and nonsickle pain.



In 1996, the World Health Organization (WHO) developed a Three-Step Analgesic Ladder for use in cancer pain relief (Supplemental Digital Content 4, http://links.lww.com/HHN/A12). This three-step ladder model has since been adopted by the Pennsylvania Department of Health for the pharmacologic management of adult sickle cell pain (Ballas et al., 2000; Jost & Roila, 2010). The model addresses preventative and ongoing treatment of pain rated on a 10-point numerical scale using medications either alone or in combination.

WHO Step 1 addresses treatment of mild pain, rated 1-4 on a NRS. The ladder recommends nonopioid or nonsteroidal anti-inflammatory drugs (NSAIDs) in combination with an adjuvant, such as antihistamines, tricyclic antidepressants, benzodiazephines, anticonvulsants, antiemetics, and laxatives (Ballas et al., 2000; Jost & Roila, 2010). Step 2 is for treatment of moderate pain, rated 5-7 on NRS, and suggests a combination of a nonopioid or NSAID with a weak opioid or strong opioid in a low dose with the addition of an adjuvant (Ballas et al., 2000; Jost & Roila, 2010). For treatment of severe pain, rated 8-10, on the scale, the WHO Step 3 protocol suggests oral administration of morphine or other strong opioid

with an adjuvant; however, parenteral administration of opioids can be used at one-third of the oral immediate release equivalent dose (Ballas et al., 2000; Jost & Roila, 2010). Oral alternatives to morphine may include oxycodone or hydromorphone available in modified or immediate release formulations (Jost & Roila, 2010).

Patients are encouraged to begin self-care management and treatment at any step based on their severity of pain and past experiences. The HHN may also suggest other nonpharmacologic modalities that may help in controlling pain escalation such as heating pads, relaxation, and diversion (Ballas et al., 2000).

According to Jenerette and Lauderdale (2008), prevention of VOC pain is critical to successful self-management. Therefore, the HHN may support lifestyle activities to reduce pain crisis that include maintaining adequate hydration, exercising moderately, avoiding temperature extremes, getting adequate rest, managing stress, and eating a reasonably balanced diet (Dorman, 2005; Willens, 2010). (See Table 2.)

Interdisciplinary Network

According to Dr. Lorna Bennett, clinical services manager of the Sickle Cell and Thalassaemia Center in London (quoted in Northen, 2008),

Table 2. Nursing Care Plan: Acute Sickle Cell Pain Related to Tissue Injury Secondary to Vaso-occlusive Crisis (VOC)

Assessment	Interventions	Desired Outcomes
Listen: verbal patient report is the gold standard when assessing pain.	Establish a trusting, caring relationship with the patient and family. Maintain an unbiased attitude and "believe what your patient tells you regarding his/her pain."	Patient and family will share concerns with nurse.
Evaluate patient and family's attitude toward pain management.	Teach the patient and family how to assess pain, a variety of methods for managing pain, how to reduce or control adverse effects of analgesics. Teach the patient and family to treat pain before it becomes severe and to be alert for signs of sickle cell complications that may lead to a crisis such as overexertion, dehydration, weather extremes, illness, and fatigue.	The patient and his family will demonstrate assessment and management of pain as evidenced by maintenance of a pain diary, verbal reporting of pain, regular use and documentation of analgesics and nonpharmacologic measures for pain, and regular reassessment of pain following interventions.
Assess for nonverbal behaviors: guarding, facial grimace, tense movements, rubbing a body part, and rocking or writhing.	Encourage the patient to keep a pain diary, recording time, activity, description of pain and rating, medication or other measures taken, and reassessment of pain following intervention.	Patient and family will demonstrate ability to choose the correct analgesic based on pain assessment.
Monitor patient's assessment of acceptable pain rating.	Help the patient to understand that pain may always be present at some level. It is important for the patient to decide what an acceptable pain rating is and then work with providers to manage accordingly.	The patient and family will notify the HHN or primary care provider on call when pain is unrelieved, chest pain or dyspnea occurs, or temperature is greater than 100° F.
Assess behavior changes: (restlessness, depressed mood or sadness, irritability, aggressive or agitated behavior) may indicate unrelieved pain or uncontrolled adverse effects. Assess physiologic responses to pain: increased blood pressure, heart rate, and respiratory rate pallor, diaphoresis, dilated pupils. All of these may be less apparent in patients with chronic pain.	Teach a variety of measures for relieving pain: massage and contralateral stimulation, application of heat (cold is contraindicated for VOC), low-impact exercise (walking, stretching, Pilates, yoga), relaxation, meditation and prayer, imagery, music, painting, or other creative outlets for distraction.	Use a combination of medications (polypharmacy) to manage pain based on assessment and rating (see WHO Three Step Approach): patient will report an acceptable pain rating of 3-4 on a 0-10 NRS.

Source: Authors. Data derived from Berman & Snyder, 2012.

community-based home care makes a significant difference in health outcomes for individuals with SCD. In addition to physical management, patients benefit from psychological, social, and educational support. Physical therapists (PTs), occupational therapists, nurses, and social workers are uniquely educated to provide necessary support in the home care setting.

The home healthcare interdisciplinary team can play a vital role in education and support for the adult patient with SCD. As partners in care, it is essential for patients and their families to accurately assess and intervene in pain and engage in self-care management behaviors for a greater quality of life. Establishing relationships based on mutual trust and compassion may foster improved relationships with healthcare providers in the future and allow the patient to be viewed as a valuable and expert member of the home healthcare team.

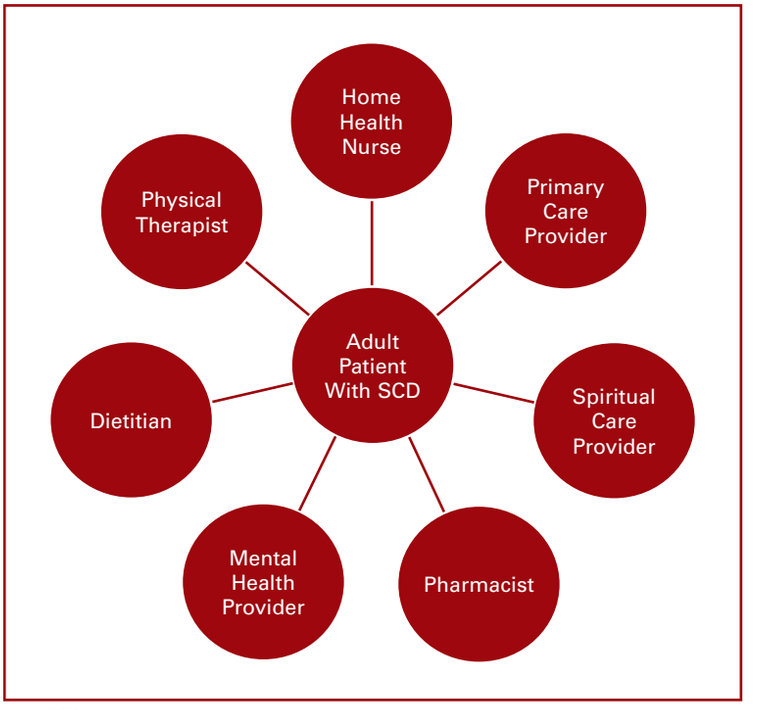
Encouraging patients to keep a diary with detailed information about intensity, quality, location, duration of pain, medications taken, and the response received, will be helpful as the patient learns self-care management. A diary will also provide the home healthcare team with information that will help them tailor an individualized plan for the patient based on trends. The patient's self-care program includes contacting the home care agency should symptoms occur that they are not able to manage successfully. The patient's effective self-management and the availability of the home care team when needed should result in fewer hospitalizations.

The interdisciplinary team, coordinated by the HHN, includes the following discipline's roles and responsibilities noted from the literature. (See Figure 2.)

1. HHN:

- Complete an assessment of the patient's and family's knowledge of sickle cell disease (SCD) and provide education in the areas of pain assessment, intervention, and reassessment;
- Educates patient to avoid extremes in temperature, especially cold, as it can trigger sickle cell formation;
- Educates patient to get adequate rest at night and take short rest periods during the day, especially during times of stress (exams, when ill);
- Educates patient to avoid travel in aircraft with cabins that are not pressurized, avoid travel to areas of high altitude, avoid persons that are ill, and use precautions during flu season (hand washing, masks);
- Educates patient when to seek medical care—that is, temperature higher than 100° F, chest pain, dyspnea, weakness, severe headache, pain not alleviated when following World Health Organization (WHO) ladder steps, or any signs of infection or illness;
- Educates young adults regarding preventive health maintenance (flu and pneumonia vaccinations, immunizations, safe contraception and protection from sexually transmitted diseases, and the risks associated with alcohol use and illegal drug use) ; and

Figure 2. Interdisciplinary web for the home healthcare team.



Note: SCD = sickle cell disease.
Source: Authors. Data derived from Dorman, 2005, p. 36; NIH, 2002.

- Educates patient and family that pain can be treated with nonpharmacologic methods, such as behavior modification, heat application and massage, distraction, and relaxation.

2. Primary care provider:

- Pain management by WHO standards to include monitoring of opioid use at home;
- Flu vaccine annually, pneumococcal vaccine every 5 years;
- Folic acid and vitamins to enhance red blood cell development;
- Routine medical evaluations every 2-6 months with blood counts, reticulocyte counts, and urinalysis; annual tuberculosis screening (more frequent visits if complications are identified);
- Annual ophthalmology examination (more frequent if complications present);
- Pre- and postconception education and genetic counseling; and
- Establish a database with health history, current home therapy, pain management history to facilitate care in the home, emergency department, or hospital when needed.

3. Dental care:

- Routine cleanings; and
- Annual preventive care and prophylaxis as needed.

4. Pharmacist:

- Provide education about different medications (nonopioids, opioids, and adjuvant use), side effects, management, interactions, proper storage, and refill information; and
- Assist team with managing dosages, side effects, interactions, and refills.

5. Dietitian:

- Evaluates body weight, height, and body mass index; educates regarding attaining or maintaining ideal body weight;
- Provides weight reduction strategies when needed to reduce complications, such as avasculaor necrosis and diabetes;
- Counsels on a balanced diet to maintain optimal weight and health status;
- Educates about avoiding caffeine and sodas; and
- Importance of staying hydrated

6. Physical therapist:

- Pain management with heat application and/or massage;
- Transcutaneous electrical nerve stimulation; and
- Low-impact exercise (stretching, yoga, Pilates, walking).

7. Spiritual health provider:

- Spiritual assessment, personal beliefs, coping skills;
- Spiritual strength and coping strategies;
- Promote use of meditation or prayer to increase spiritual awareness and diminish anxiety and hopelessness; and
- Foster development of self-efficacy.

8. Mental health provider:

- Mental health assessment;
- Using stress reduction techniques to prevent pain trigger;
- Coping skills;
- Antidepressants;
- Self-hypnosis; and
- Cognitive and behavioral pain management strategies.

Use of the network of interdisciplinary care is essential to enhance patient's quality of life and reduce hospitalizations. The interdisciplinary web is represented in the following case study.

Case Study

Ben Y. is a 22-year-old college student with a history of multiple hospitalizations for pain management related to VOC. He lives with his girlfriend in a small, single-family home in an urban area.

Medical History

Ben has a history of ED visits and hospitalizations for pain management related to VOC. On this occasion, Ben was playing soccer with friends and became overheated and dehydrated, experiencing pain afterward. One of his friends

accidentally stepped on his right foot during the game. He took ibuprofen during the night but by the following afternoon Ben presented to the ED with a complaint of moderate to severe joint pain, particularly in his left hip and right foot. A complete blood count revealed chronic hemolytic anemia and serum electrolytes confirmed dehydration. The goals of care are hydration, pain management, and education. He was treated with an intravenous solution of D_5W for rehydration and Duramorph for pain and was transferred to the inpatient area. A computed tomography scan showed no evidence of organ damage and the x-ray of his right foot was negative. After 2 days, Ben's pain resolved except for mild pain upon exertion in his left hip. He rated this pain as 4 on a scale of 10. The PT who treated Ben for his left hip pain explained to Ben that he had inadvertently compensated for the acute pain in his right foot by changing his gait. Because he favored his left leg when ambulating, Ben had developed tendonitis in his left hip.

Current Concern

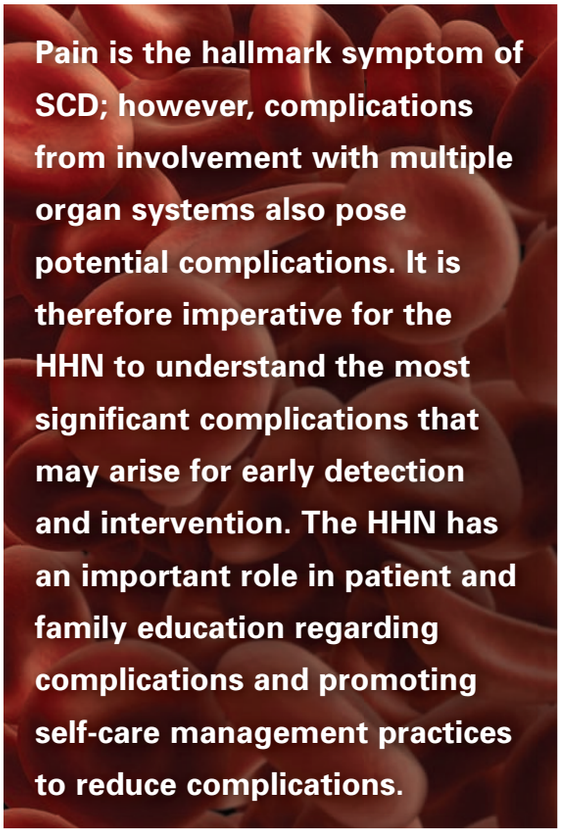
Although the current crisis has been effectively managed, Ben is concerned about the likelihood of another painful crisis. After receiving authorization from Ben's insurance company, the hospital case manager contacted a home care agency for aftercare to address the need for effective self-management to avoid precipitating an SCD-related crisis and left hip pain.

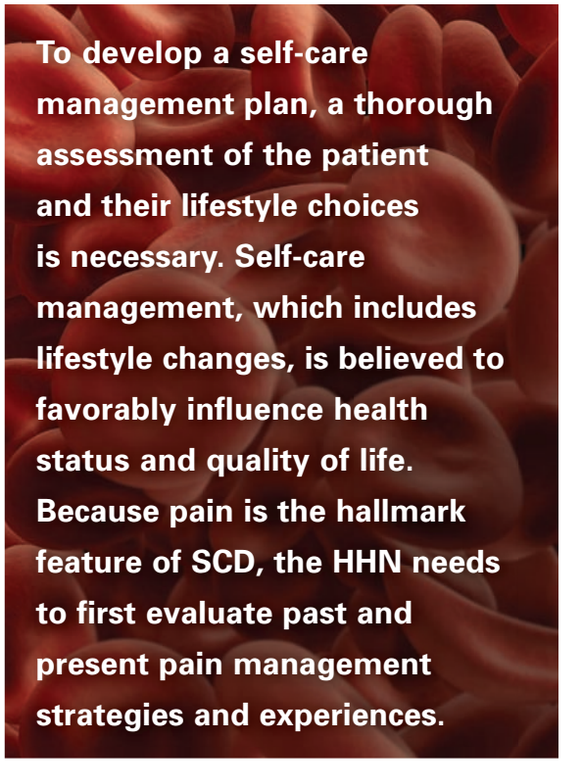
The Home Care Assessment

During the start of care assessment, the home care admissions registered nurse (RN) learned that Ben was reluctant to take the oral analgesic ordered upon hospital discharge for fear of becoming addicted to opioids. Typical of many college students, Ben had a habit of staying up late, sleeping at odd hours, and eating an insufficient diet.

Plan of Care

The HHN established a teaching plan with Ben and his girlfriend targeting self-management. The RN provided instructions in etiology, risk factors, and signs and symptoms. An interdisciplinary approach, including his regular physician, his HHN and a PT provided optimal management of Ben's disease at home (Yale et al., 2000). Working collaboratively with Ben, the RN established a behavioral modification program including adequate hydration, a consistent bedtime that insured 8 hours of sleep each night, and a nutritious diet. The RN completed a comprehensive pain assessment to provide a baseline of Ben's pain characteristics and coping, history, and management. The RN explaind Ben's rights about pain control and introduced the numeric rating scale (NRS) that will be used to self-assess his pain. A pain-control record was also provided, allowing Ben to assess how well his pain is controlled and the adverse effects noted with the analgesia prescribed daily. A three-step ladder for analgesia use and a plan for managing common side effects of opioids and other analgesics was explained to Ben. The RN provided and explained the use of a NRS for rating pain and a daily diary to measure mood, pain level, medication taken and response, and affect on ADL (self-care, rest/sleep, attending class, extracurricular activity, etc.). The RN taught Ben that although developing opioid addiction was a concern, only 3% of patients with SCD were reported as developing addiction (Dorman, 2005). She





explained that taking opioids as directed for moderate-to-severe pain in conjunction with monitoring pain levels and response would decrease the duration and severity of the pain that he experienced. She provided information on adverse effects of nonopioid, NSAIDS, and opioid medications, and how to best manage and prevent complications. She recommended switching to nonopioids or NSAIDS when the pain was lowered to a mild level and to accurately document all medications and pain responses in his diary. She described other nonmedication interventions available for managing pain (e.g., distraction and self-motivation) and told Ben that the PT would demonstrate the application of heat and use of massage (Ballas et al., 2000). Lastly, the RN explained that complete pain relief may not be possible and that a realistic goal is to achieve an acceptable level of pain that allows engagement in his usual daily activities so that he might remain active in school (Willens, 2010). The PT modified the exercise program established in the inpatient setting so that Ben could carry it out safely at home. The program was designed to correct Ben's gait and strengthen his core, thus decreasing pain in his left hip. The PT also instructed Ben's girlfriend in the use of massage and application of heat to decrease the pain in his joints. A spiritual care provider from the home health agency completed an assessment of Ben's spiritual and personal beliefs, perceived quality of life, and coping skills. He provided ongoing support and helped Ben make connections with the college minister at a neighborhood church. He provided some helpful strategies for improving his spiritual awareness and using meditation/prayer to manage disease symptoms and medication side effects. He made arrangements to meet with Ben monthly to foster his developing self-efficacy and provide ongoing spiritual guidance and support.

After 4 weeks, Ben was discharged to self-care, with instructions to contact the agency should he experience another VOC. His physician, in collaboration with the ED and the home care agency, was willing to attempt management of a subsequent VOC in the home if the crisis was identified in its early stages.

Call to Action: Summary

Many patients with SCD consider the ED as the safety net for the provision of acute care, completely unaware that home care may be a significant viable option. Sickle cell pain is complex, highly individual, and influenced by their past and present experience. These patients are often undertreated, or ineffectively treated and suffer recurring pain crisis or complications needlessly. Home healthcare allows for an effective web of interdisciplinary support that is available for transitioning the patient with SCD from acute care to home self-care. Home care includes preventative health maintenance; early assessment and intervention with complications; continuous assessment of psychological, spiritual, and social support; and continuing education. The home care interdisciplinary approach offers patients with SCD a healthier, happier quality of life. ⌂

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