2022

Improving Nurses' Knowledge of Patient Self-Management of Sickle Cell Disease

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This is to certify that the doctoral study by

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Abstract

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MSN, Lasalle University, 2012

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Project Submitted in Partial Fulfillment

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Abstract

Sickle cell disease (SCD) is a chronic illness affecting over 100,000 Americans annually. SCD causes severe pain, which may require frequent hospital admissions for pain control. A high level of patient self-care knowledge is needed to prevent readmissions. Patients usually receive self-care education at hospital discharge from nurses, who may not know about self-care in SCD. Inadequate patient education on self-management of SCD at hospital discharge can lead to hospital readmissions. There was a gap in knowledge among RNs regarding SCD self-care at the local facility. This doctoral project was intended to educate nurses about SCD self-management to increase their knowledge. The project question asked whether an education program on patient self-management of SCD would increase the knowledge of RNs about the management of SCD. Transformational learning theory served as the foundation for this project. There were 19 participants who completed the pretest and posttest to determine whether there was an improvement in their knowledge after the education intervention. A *t* test was used to analyze the data, which was used to examine differences in the mean of the pre- and post-intervention scores, which was found to be statistically significant. Increasing the knowledge of care team providers and patients may contribute to positive social change by improving patient outcomes.

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Table of Contents

List of Figures

Section 1: Nature of the Project

Sickle cell disease (SCD) is the most prevalent inherited blood disorder in the United States (Brennan-Cook, 2018). SCD is a medically and socially complex, multisystem illness that affects individuals throughout their life span. SCD's primary manifestation is chronic pain. It also causes chronic organ damage, the primary cause of morbidity and mortality (Russo et al., 2019). SCD affects roughly 100,000 individuals in the United States, with 1 out of 365 newborns diagnosed with the disease (Brennan-Cook, 2018). Approximately 80% of the health care costs associated with SCD relate to hospital care (Farooq, 2020). SCD is complex because patients often experience high levels of pain, which are only manageable with opioid therapy (Ballas, 2016). The stigma related to the opioid crisis causes SCD patients to be subject to implicit bias by health care teams, making it difficult to live with the disease (Darbari, 2017). Experts argued that SCD has multiple effects on the patient, warranting a high level of patient self-care to manage the disease at home to avoid repeated hospital admissions (Brennan-Cook, 2018). Patients also require large doses of opioid and narcotic medications to manage pain associated with SCD due to tolerance that develops from constant use of opioid analgesics (Jacob, 2016). Jacob explains further that, inadequate pain control is a primary reason for patient emergency department visits and hospital admissions for SCD. It is sometimes challenging for patients to optimally manage their pain at home because of the stigma associated with opioid use and the fear of developing opioid dependency

(Darbari, 2017). Studies conducted in pediatric patients with SCD suggested that poor SCD self-management may precipitate health crises, including vaso-occlusive pain episodes and pneumococcal infections, which necessitate urgent and costly health care interventions (Psihogios et al., 2018). In the current project, the successful implementation of an education intervention undoubtedly may have positive implications for patient outcomes. The education intervention was created to empower and educate a consortium of nurses who can help patients manage SCD at home, resulting in a better quality of life and fewer socioeconomic burdens.

Problem Statement

Patients living with SCD being sent home without proper education are set up for an unsuccessful transition. The current project was focused on the nursing knowledge gap regarding patients' self-management of SCD. Nurses were not effectively educating patients on SCD management at discharge from the hospital. Instead, patients were being sent home with inadequate knowledge regarding minimizing disease symptoms, preventing recurrence, and improving health outcomes. This project was relevant because the life span of the global population, including SCD patients, has increased. Therefore, education on the self-management of SCD was necessary to reduce patient suffering, improve their quality of life, and increase their productivity. Brennan-Cook (2018) argued that the health outcomes of SCD patients tend to be better when patients receive care in SCD centers of excellence with specially trained caregivers and care pathways. Brennan-Cook further argued that addressing a knowledge deficit among RNs caring for patients

with SCD has significantly impacted patient health outcomes. In another study, Adam, Flahiff, Kamble, Telen, Reed & DeCastro (2017), discovered that 35.2% of adult SCD patients experience depression primarily because of physical and mental suffering associated with the disease. SCD patients make numerous visits to the emergency department, which could be avoided with proper knowledge on the self-management of SCD (Glassberg, 2017). For example, self-recognition of worsening pain early in the crisis period and initiating an escalating self-medication regimen to address the pain before it gets to an uncontrollable level may enable patients to self-manage pain (Costa, 2016). SCD, like many other chronic illnesses, involves highly individualized self-care and an ability to recognize and interpret evolving problems unique to the individual. An awareness of self is not a competency that many patients have innately. Instead, they must learn it for better disease outcomes when at home. The doctoral project addressed the knowledge gap that nurses have about the self-management of SCD. Findings may empower nurses to engage SCD patients in the management of their disease. Patient engagement may lead to a shared purpose and a common goal between patients and the health care team members.

Purpose Statement

The discharge process can provoke anxiety in patients and may be stressful for nurses involved with the discharge, primarily when they must educate patients on managing themselves at home. Leaving the hospital as a discharge is a high-risk transition of care with the potential for miscommunication of critical information (Hsu et

al., 2016). The gap in practice in the current project was the lack of nursing knowledge on patient self-care in the management of SCD (see Nagshabandi, & Abdallah, 2019). This gap impacts patients' health outcomes. Therefore, nurses need to be knowledgeable about SCD self-management so they are equipped to educate patients across all spectrums of social and cultural influences (Matthie, 2019). The lack of knowledge of SCD care among nurses is not unique to the United States. In a study conducted in Nigeria, one of 3 countries in Africa containing 90% of the world population of patients with SCD, there was a substantial knowledge deficit among community health workers on essential SCD management, early detection, and crisis prevention (Adegoke et al., 2018).

The guiding practice-focused question for the current project asked whether a nursing education intervention on self-care for patients with SCD would increase nurses' knowledge of self-management of SCD. The focus of SCD management is not to eliminate crisis attacks but to teach patients how to predict the onset of a crisis and minimize its impact and duration (Adegoke et al., 2018). This project involved the creation of an educational program to educate nurses on SCD self-care to address the identified gap in practice. The project was intended to improve nurses' knowledge regarding the self-management of SCD by patients. This endeavor would enable nurses to educate SCD patients and improve their care after hospital discharge, be more independent at home, and have positive social change. RNs not familiar with the intricacies of the disease may lack the knowledge to understand the barriers that patients experience in managing SCD when at home. The individualization of care plans and

adequate self-awareness are vital for a seamless transition of disease management between the care team and the patient. Evidence also suggested that patients with SCD can attain a successful transition from a hospital to a home setting by establishing consistency and easy referral systems for outpatient care management services (Rushton, 2019). This essential transition component was included in the comprehensive education designed to lead to a more informed group of health care professionals and patients.

Nature of the Doctoral Project

Evidence-based practice has become a standard for delivering safe, quality care and the achievement of optimal patient outcomes (Tucker & Gallagher, 2019). Data are only as good as their ability to be operationalized in practice by health workers in a way that impacts patients positively. In the current project, evidence from the literature was used to create a comprehensive educational program to educate RNs on the best practices of SCD self-management for patients when at home. This project included the Living Well with Sickle Cell Toolkit for educational content (Centers for Disease Control and Prevention [CDC], 2020; see Appendix A). The approach used to answer the project question was a pre- and pos-intervention knowledge assessment. The assessment tool was developed from the content within the Living Well with Sickle Cell Toolkit (see CDC, 2020). I developed the pre- and post-intervention knowledge assessment test from information in the toolkit, and the assessment was evaluated by the stakeholder group (see Appendix B).

The pre- and posttest assessed the baseline knowledge of RNs working in a unit caring for patients living with SCD. Five experts validated this tool to determine a CV-I calculation and the scale level content validity index CV-S. There is limited research on assessing the knowledge of RNs in SCD management (Nagshabandi & Abdallah, 2019). The education program in the current project provided comprehensive knowledge on SCD self-care at hospital discharge. The program included instructions on symptom management, self-awareness of symptom onset, symptoms for SCD, medication, pain management, and escalation protocols. Data obtained from the pre- and posttest were assessed to determine whether an increase in knowledge of the project participants occurred after the educational intervention.

The purpose of this doctoral project was to increase the knowledge of RNs on self-care in the management of SCD among patients. Self-care refers to a person's perceived ability to participate in general therapeutic activities to improve their quality of life, health status, and performance of activities (Russo et al.,.2019). With a focus on closing the knowledge gap among RNs who work most often with patients living with SCD, there was a potential for a more prepared and self-directed community of patients with SCD. Researchers suggested that creating a standardized psychosocial assessment process with an established plan to individualize care plans and mitigate barriers to self-management is essential to optimize outcomes in patients with SCD (Schulz et al., 2018). In the current project, the focus was on identifying barriers to self-management for pediatric patients living with SCD. This project was intended to provide RNs with

knowledge that could be transferred to patients to bridge the existing gap in the management of SCD.

Significance

Teamwork and collaboration are fundamental components for educating patients on establishing a care plan that helps them transition from hospital care to home-based self-care. Effective patient care requires collaboration from every health care team member across all disciplines. Stakeholders essential for the current project's educational program included health care providers who specialize in caring for patients with SCD, nurses, patients, and family members of patients living with SCD. External stakeholders such as insurance companies and third-party payer representatives were also primary stakeholders impacted by the local problem. This project's impact on general nursing practice may include a more collaborative effort in managing patients living with SCD. There was a fundamental lack of trust among the sickle cell community members, primary care providers, and nurses who care for SCD patients (Gardner et al., 2016). Mistrust and lack of knowledge stem from negative patient experiences causing ineffective treatment plans (Sinha, 2019). The current project may positively impact patients and improve the therapeutic partnership between health care providers and patients for improved health outcomes. The positive impact may be accomplished by establishing trusting relationships between nurses and patients.

The most significant contribution of this doctoral project to the nursing profession was the potential impact on improving nurses' knowledge of the importance of self-care

in the management of SCD. SCD is one of many chronic illnesses that require patients to engage in self-care. This project may also impact the profession in its ability to duplicate the survey for other diseases. The project may influence the way nurses instruct patients on being active and self-directed in managing their SCD. These partnerships could lead to fewer unnecessary inpatient hospitalizations resulting in positive social change and a decreased burden of SCD, which strains existing health care systems.

Summary

The doctoral project was designed to provide adequate education to RNs responsible for providing patients with knowledge and skills for managing SCD at home. Section 2 provides evidence of the knowledge gap and the potential positive social impacts this project may effect. This doctoral project focused on the current challenges in the nursing of patients with SCD, particularly the self-management of the disease after hospital discharge. The project could provide insight into overcoming these challenges by empowering nurses and patients with SCD. Self-managed and self-regulated pain control is the most critical component of self-care in this population (Masese et al., 2019). Ineffective pain control is why most patients with SCD return to the emergency department. Section 2 shows that theorists who transform thoughts to inspire positive behaviors anchored this project and its focus. With a keen eye on the gap in practice, I created the education program which was comprehensive yet specific to meet the needs of the target group.

Section 2: Background and Context

RNs who specialize in the care of patients with SCD are well versed in the overall progression of the disease and how to get patients through acute crises. However, these nurses have limited knowledge about patients' self-care. This doctoral project addressed whether a focused educational intervention for RNs regarding patients' self-care in the management of SCD increases nurses' overall knowledge about the care of patients with SCD. At the time of this project, there was a perceived knowledge deficit among RNs caring for patients with SCD, which translated to a patient population that had insufficient knowledge about their disease (see Matthie & Jenerette, 2017). The education program was intended to be a comprehensive education curriculum for RNs to increase their knowledge regarding SCD self-care. This education program also provided RNs with strategies for educating patients with SCD on caring for themselves. This project was designed to prepare RNs to deliver SCD self-care education before hospital discharge.

Certain terms are included in Sections 1, 2, and 3 regarding the meaning and application of transformational learning theory. The terms include critical reflection, critique, perspective transformation, and connectedness. According to DiSapio (2017), connectedness is a person's sense of relatability to some external entity (such as an idea, philosophy, person, group, or organization) that gives some measure of meaning to their identity.

Other terms include 30-day readmission, which refers to a patient readmitted into the hospital within 30 days of being discharged from any other hospital (CDC, 2020). Inpatient admission refers to a patient admitted and cared for in a hospital facility for a stay longer than 24 hours. Sickle cell crisis is a physiological state characterized by severe and excruciating pain requiring opioids or narcotics treatment. Sickle cell crisis is the most common reason for hospital admissions for patients with SCD.

Operational terms include self-care, comanagement, self-directed, and engagement. Self-care and co-management refer to behaviors taught in the educational intervention. The intervention provided information on the ways to individualize a plan of care to consider body cues, allowing patients to take a proactive approach in managing symptoms such as pain and crisis. Self-directed engagement refers to the attributes of a well-informed and educated patient on the components of self-care that they are responsible for (Crosby et al., 2020). Self-directed engagement contributes to a patient's ability to self-manage their disease while at home. The rest of Section 2 informs the reader of the concepts and theories to create this educational program. Additionally, Section 2 includes the connection and relevance of this topic to overall health outcomes for patients living with SCD.

Concepts, Models, and Theories

Mezirow's transformational learning theory was crucial in providing a framework for this project (Hodge, 2018). Hodge explains, the theory is used to explore the interactive effects of personal and environmental determinants on fundamental health-

related behaviors. Transformational learning includes the introduction of skills to develop essential insights and critical reflections on human behavior and how it motivates a person to take charge of their health. (Tsimane & Downing, 2020). The success of the patient's transition to their home environments depends on the patient's willingness and ability to participate actively in their care. The transformational learning theory is used to identify barriers to engagement and provides patients with the tools necessary to overcome such barriers (Tsimane & Downing, 2020). The theory suggests that personal, interpersonal, and environmental factors positively or negatively influence the beliefs and the practice of health-promoting behaviors. This theory helped me create a framework that provided instruction to nurses on how to effectively teach patients how to engage in self-care (see Matthie & Jenerette, 2017).

Transformational learning, which can occur gradually from a sudden and powerful experience, changes how people see themselves and their surroundings. The primary reason for selecting this theory was that it provided clarity on engaging and motivating patients to manage their health. Such endeavors would include competencies such as negotiating and acting on feelings of purpose and meaning learned from others. Education created through the fundamentals of the transformational learning theory provided staff with the tools necessary to motivate and engage patients in their care plan after hospitalization. When patients received hospital discharge, they would be fully knowledgeable about creating and implementing a care plan for their illness. Transformative learning stimulates the development of competence and self-confidence

in new roles and relationships that bring about change in the learning and working environment (Tsimane & Downing, 2020). Applying Mezirow's theory in the educational program's development helped me inform the educators on how to improve their teaching styles to ensure maximum effectiveness.

Relevance to Nursing

The most effective intervention that the health care team can provide to impact the overall outcomes of patients with SCD is providing them with the necessary knowledge and skills to care for themselves at home. Available literature suggested that adherence to the complex set of recommended self-care practices among people with SCD positively impacts health outcomes (Issom et al., 2020). Self-care practices among individuals living with chronic diseases are essential in promoting better disease outcomes and improving the quality of life (Sinha, 2019). Sinha (2019) further argued that self-care activities are more critical in vulnerable populations, such as individuals with SCD.

In the case of SCD, medical interventions have severe financial and psychological implications. The current experience for patients living with SCD is that they need to access the health care system frequently throughout their lifetime as a result of their disease (CDC, 2020). However, a general reluctance to seek health services exists due to health-related stigmatization, hindering care seeking for acute pain exaggeration (Brennan-Cook, 2018). Although pain is not the only symptom that patients living with SCD must manage at home, it is typically the symptom that most often provokes a trip to the emergency department for patients (Sinha, 2019). Around 80% of adults with SCD

manage episodes of acute pain at home, avoiding the health care system most of the time (Brandow et al., 2020).

Lack of knowledge about the effective use of opioids to control pain may predispose the patient to severe pain, resulting in decompensation. Hospital readmissions impact the quality of life for patients living with sickle cell anemia. There is also a heavy financial burden on the health care system due to the inefficient use of health care resources (CDC, 2020). As care and treatment for SCD progress, providers may offer options for patients experiencing acute pain crises other than accessing emergency departments. These options include outpatient office settings for intravenous pain medication therapy or telemedicine visits in which health care providers coach patients through pain medication escalation to prevent a crisis requiring hospitalization. Although these measures do not always prevent emergency department visits, the increased frequency of engagement with patients can lead to fewer inpatient admissions (Matthie et al., 2016). Usually, the mitigating factor contributing to a patient's decision to visit an emergency department is their ability to manage their pain at home.

The apparent lack of agreement between observed and presumed patient behavioral cues can lead to provider skepticism about the veracity of the SCD patient's report of pain (Pur et al., 2018). Providing the RN at the bedside with this information may help them understand the anxiety that comes with the anticipation of pain.

This project was intended to educate RNs on the proper way for patients to manage SCD at home. Learning how patients living with SCD cope with the challenges

of SCD may provide nurses with adequate knowledge on how patients can address these challenges while incorporating appropriate self-care strategies into their plan of care. Patients with SCD need to learn how to manage the symptoms of the disease and maintain control from the time of diagnosis (Matthie et al., 2016). Furthermore, patients should aim to minimize the crisis events throughout their lives. Evidence has shown that patients and their caregivers are unprepared for patients' role in self-management and do not understand essential steps in managing patients' condition (Puri, Nottage & Hankins, 2018). The current project addressed the knowledge gap that RNs have on SCD self-management. The RNs may use this knowledge to educate patients and improve their knowledge levels on managing SCD in the comforts of their homes.

Local Background and Context

The lack of knowledge and understanding of patients' role in the care and management of chronic illness can contribute to an unengaged population of patients. The lack of knowledge by patients is related to the lack of understanding of their care providers regarding how to educate them on self-management skills. Many chronic illnesses require active self-management in a home setting. Such conditions include congestive heart failure, diabetes, and chronic obstructive pulmonary disease (Matthie et al., 2016). The education and knowledge transfer that must happen during the patient discharge process has become crucial. Improved knowledge of self-care can help health care providers equip patients with the knowledge needed to participate in their disease management (Matthie et al., 2016).

However, many patients with SCD are not knowledgeable about managing the condition in a home setting. There is a lack of knowledge of preventing sickle cell crises or managing the pain that is characteristic of the illness (Adegoke et al., 2018). When at home, patients are not aware of the knowledge necessary to improve their health outcomes. However, this pattern can change if patients receive adequate training (Brennan-Cook, 2018). Yacoub et al. (2019) found that education programs about the management of SCD improved the RN's capacity to manage patients with the disease. More research was needed to determine the most relevant topics nurses need to learn about SCD care. The education should include information pertinent to the prevailing issues.

SCD can cause patients to experience increased financial, psychological, or physical stress. Many patient visits to the emergency department are because of severe pain (Simmons et al., 2019). RNs and patients need to learn new knowledge and skills for managing SCD. This doctoral project targeted nurses' knowledge of patients' self-management of SCD. The RNs may use this knowledge to educate patients on managing SCD when at home.

The setting for this doctor or nursing practice (DNP) project was a community-based hospital in the heart of a metropolitan city, which is part of a five-hospital university-based health care system. The organization's mission is to provide patient-centered and world-class care to all patients. The hospital's vision is to provide comprehensive, culturally specific, and relationship-based care. The hospital has been

designated as the site location for the sickle cell anemia program and serves at least 220 patients living with SCD per year. The project site uses a third-party vendor, to solicit feedback from patients with SCD who receive care there to facilitate continuous process improvements in SCD care.

Patients living with SCD represent a large, underserved community laden with health care disparities, which impact their ability to live productively and function within the confines of this chronic illness (Shih & Cohen, 2020). In the United States, Black and Hispanic populations are disproportionately impacted by this disease (Matthie & Jenerette, 2017). Opportunities to coordinate care and support patients while in their homes living with SCD have been identified through the increasing numbers of preventable hospital readmissions. Health care organizations do not receive any reimbursement for caring for patients with SCD who are readmitted within 30 days of discharge from an acute care facility. SCD accounts for 22% of 30-day hospital readmissions at the project site. Additionally, the patients who feel the need to seek additional health care through the emergency department within 30 days of being discharged may not have been educated on how to care for themselves at home. This lack of preparation may have contributed to a higher rate of dissatisfied patients after being discharged from the facility. Successful implementation of this project may enable nurses to educate patients living with SCD about self-care, thereby reducing the frequency of hospital readmissions.

Role of the DNP Student

I am a clinical director of nursing in a small community hospital close to the project site. I have experience with oversight of the emergency department and am very familiar with the care of patients living with SCD. I have experienced how patients with SCD overutilize the emergency department for pain management. Data from the department showed that 16% of all visits to the emergency department were from patients exhibiting complications of SCD. The need for intentional and purposeful focus on transitions of care and proper discharge preparation has been shown through high SCD readmission rates (CDC, 2020).

My primary role in this doctoral project was to lead the development of this educational program. An interdisciplinary team of experts reviewed the educational content and assessed the pre- and posttest for content validity. Some of my family members have SCD. I have spent much of my professional career caring for family members and patients with SCD in my place of employment. In addition, my youngest son was born with the sickle cell trait. SCD was not discussed or explained throughout my pregnancy, and my child was not screened.

Given that SCD is a prominent disease among African Americans, more focus should be on providing testing opportunities for pregnant African American females. Sickle cell disease is more common among people of African descent, including African Americans, among whom 1 in 12 carry the sickle cell gene (Goldstein et al., 2020). The current project addressed patient self-care, the lack of preventive education about SCD,

and the pathophysiology associated with how children come to be born with the disease. No education or information was provided regarding asking my partner before conceiving a child whether he knew was a carrier of the sickle cell trait. The sickle cell trait is inherited from one or both parents; two parents who carry the trait produce children with active disease (Goldstein et al., 2020). SCD manifestation can be predicted and avoided if prospective parents are educated on how the disease is passed on to their children. My experience with the health care system during one of the most vulnerable times in my life has driven my passion for advocating for change that would better prepare women for all possible outcomes.

There are many barriers for patients and their families to access the services needed to manage SCD. These challenges include chronic pain, perception of addiction, implicit bias, frequent hospitalizations, and several emergency departments' visits (Goldstein et al., 2020). There is also a knowledge deficit for clinicians or patients and stigma associated with SCD. Evidence suggests a preconceived notion about narcotic addiction and sickle cell patients that caused many healthcare professionals to be very reluctant to administer appropriate doses of opioids (Bulgin et al., 2019). In that same study, other findings included that the nurses verbalized feelings of frustration, anger, and a sense of being manipulated by patients with sickle cell disease due to the lack of knowledge about the disease (Bulgin, et al., 2019). These feelings of frustration and anger from nurses collectively hinder the delivery of evidence-based care to patients living with SCD.

Emergency Department providers performed a cross-sectional study to assess their self-reported adherence to national pain recommendations regarding opioid use in managing SCD. The study determined that 93% of providers self-reported adherence to recommendations; however, they also reported that they tend to deviate from recommendations on patients where there is a general lack of compliance with disease management outside of the hospital. (Rushton, 2019). This evidence shows that negative healthcare provider attitudes are the care that some patients living with SCD experience.

African American patients living with chronic illness, especially those living with SCD, encounter numerous health care disparities daily. The differences hinder them from achieving quality healthcare. I have an affinity toward this patient population and am committed to providing patients with SCD with culturally sensitive and comprehensive care.

The self-management of chronic illness improves health outcomes for patients living with SCD and improves their quality of life by empowering their health. Optimal management of this population must include an evidence-based standardized plan of care (Yacoub et al., 2019). Being a healthcare executive, I am always looking for ways to deliver quality care efficiently and in the most cost-effective manner. More importantly, I am also responsible for ensuring that the care being provided to patients in this vulnerable group is effective and meaningful. Our greatest need is to provide information and education to care providers (mainly nurses) who influence how well patients transition back into their home environments after discharge from the hospital. The education

program that I emanated from this doctoral project was intended to empower nurses with knowledge about the self-management of SCD. The nurses, in turn, educated the patients before their discharge, an endeavor that ensures patients are well equipped to manage themselves even after they leave the hospital.

Role of the Project Team

In addition to myself, the doctoral student, project team members included the social worker for the sickle cell program, the SCD program director, and the clinical nurse education specialist for the SCD unit. Each project team member was responsible for providing their expertise and guidance to create the content for a health education program. There was also a panel of experts in the management of SCD who validated the knowledge assessment tool and determined the content validity (CVI) of the tool. The expert panel consisted of 3 attending physicians who provide care for patients with SCD at the project site, one nurse practitioner who works with patients living with SCD, and a clinical education specialist from the Emergency Department who has a significant amount of experience in the management of SCD. The project team expects to use this project to educate nurses about the self-care of SCD. A series of classes spread out over one week was offered to make it convenient for those attending the program. There was a purposeful effort to identify and address any barriers to participation to ensure the targeted RNs could participate without reservation from the participants.

Summary

Section 2 was intended to help justify creating an education program targeting caring for patients with SCD. This project was explicitly designed to make a difference for patients with SCD. However, this program can easily be replicated to address other chronic illnesses where self-management has proven to impact overall outcomes for patients. Section 3 provides the reader with details on determining the most valuable data, collection methodology and processes, and data collation for this proposed education project. It was designed to understand that data integrity and validity must be controlled in the design phase. The effectiveness of the project was based on our ability to compare two sets of data to determine if an educational project for RNs leads to increased knowledge of patient self-care in the management of SCD. Section 3 also provides information on how the data was collected, managed, and analyzed to answer the practice question.

Section 3: Collection and Analysis of Evidence

SCD presents significant medical challenges to patients, relatives, and society. Symptoms of the disease may worsen in adolescence. When symptoms worsen, health care providers should transfer the responsibility of care to patients. The current project was designed to determine whether an educational intervention targeting RNs increased their knowledge of the impact of self-care in SCD management. Providing RNs with education to teach and provide self-management support to patients living with SCD may improve transition outcomes in this vulnerable population (Melita et al., 2019). The gap in practice was addressed by developing and delivering an education program for RNs focused on defining the role of self-care for patients in the overall care and management of SCD. The gap in practice addressed by this project was nurses' lack of knowledge of patient self-care in the management of SCD.

The process used for data collection and data analysis used is discussed in this section. Patient feedback via patient satisfaction survey scores indicated the lack of preparation patients have, which warranted the need for this DNP project. The pre- and posttest tool to assess the nurses' knowledge in this project was the Living Well with Sickle Cell Self-care Toolkit (see Appendix A). The CDC (2020) created the toolkit as a resource to help patients living with SCD maximize their quality of life through mastering self-care and knowledge of the SCD process. An overarching goal in developing this tool was to change the approach patients have taken with SCD to be more comprehensive and inclusive of patients as partners. The CDC created the toolkit as a

step-by-step guide for patients and their families for understanding the disease and its impact on their bodies and for managing the disease in everyday situations. The toolkit also contains a knowledge assessment for patients, which was used to create the knowledge assessment tool for this project (see Appendix B). Expert clinicians validated the tool, especially in SCD, using the content validity index scores. Providing this additional education to nurses may lead to improved nursing knowledge and could positively impact the quality of patient education on self-care management at hospital discharge. The education program focused on recognizing individual body cues and self-management of disease symptoms at home for patients living with SCD. The target audience for this doctoral educational program was RNs working in a hematology unit that primarily cares for patients living with SCD.

The evidence sources that provided context for the identified practice problem included prevalence data from the Sickle Cell Disease Association of America. Literature from peer-reviewed sources was also included from the *Journal of Advanced Nursing* and the *American Journal of Hematology* on the role of self-care in chronic disease management (see Brandow et al., 2020). Experts specializing in caring for patients living with SCD were also engaged to include best practices regarding pain and symptom management. Information gathered from these experts was used to create a comprehensive educational program for RNs.

A pre-intervention and post-intervention knowledge assessment were administered to the participants to determine whether there was an increase in knowledge

after implementing the education program. SCD presents significant medical challenges, including but not limited to severe pain, difficulty breathing, anemia, and chronic fatigue for patients who have this diagnosis. These symptoms are most extreme during adolescence when health care workers prepare to hand off the disease care to patients (Crosby et al,, 2020). This DNP project was designed with this challenge in mind for nurses to understand the impact of adequate self-care on overall health outcomes in this patient population.

The local problem was a lack of knowledge of patient self-care among RNs who care for patients with SCD. This lack of education contributes to the more significant problem of patients being sent home unaware of managing their disease on their own. This could lead to unnecessary hospitalizations and poor health outcomes. The practice-focused question addressed in this project was whether RNs can increase their knowledge of the self-care of SCD after receiving an educational intervention. The project was a comprehensive and focused educational program that offered an extensive discussion of SCD self-care and its impact on the management of SCD.

Sources of Evidence

The evidence for this project was obtained from databases and search engines including CINAHL, Med Scape, Science Direct, Academic Search Premier, PubMed, and the Cochrane Library. Outcomes from previous studies with a close relationship to the practice problem were provided by the Sickle Cell Disease Coalition, an organization formed to amplify the voice of the SCD stakeholder community to improve outcomes for

individuals with SCD. Key search terms used to search included *self-care in sickle cell management*, *discharge planning and self-care in pain management, self-efficacy*, and *discharge planning*.

Evidence Generated for the Doctoral Project

Evidence for this project was generated in two ways. The first was through a systematic review of literature. The purpose of this doctoral project was to create knowledge that educates RNs on how patients with SCD can manage their disease at home. The primary source used to construct this education project was a self-care toolkit created by the CDC to instruct patients on the practical ways that they can improve their health and how to manage the symptoms of SCD at home. The toolkit provides a comprehensive overview of SCD and offers an easy-to-follow guide containing all of the considerations that patients living with this illness should know. The toolkit provides the top six steps to manage SCD, including finding good medical care, getting regular checkups, preventing infections, learning healthy habits, engaging in research studies if possible, and participating in support groups (CDC, 2020).

Evidence was generated to answer the project question via the administration of a pre- and post-test to program participants. The method was essential in evaluating the impact of this program to improve knowledge. At the program's start, the participants completed a pre-intervention knowledge assessment to evaluate what they knew about SCD self-care. Then the education program was given to the participants. Upon its conclusion, the participants completed a post-intervention knowledge assessment with the

same content as the pre-intervention knowledge assessment. Results from the two tests were compared to determine the level of learning. The outcome provided crucial evidence on the knowledge gap among nurses regarding the management of SCD. The outcome also highlighted the areas where nurses had knowledge deficits.

Participants

Participant selection was an integral component of the implementation of this project. The individuals identified and targeted for participation in this education program included RNs assigned to an 18-bed hematology unit whose primary patient population includes patients diagnosed with SCD admitted with a diagnosis of complications associated with SCD. Knowledge gaps, prejudices, negative attitudes, and suboptimal pain management plans can perpetuate a cycle of SCD patient–provider mistrust and dissatisfaction (Puri et al., 2018). The nurses on the project unit are responsible for educating SCD patients and preparing patients for hospital discharges. The unit has 22 nurses whose participation in this doctoral project was voluntary. These prospective participants were relevant to this project because they regularly contact patients from admission through discharge. Nurses who had worked on the nursing unit for fewer than 6 months at the program's implementation were excluded from participation. The experience gained from working in this unit has enabled these nurses to learn specialized care of patients with SCD and work closely with attending physicians who oversee care for these patients on an inpatient and outpatient basis. The selection of participants was intentional due to their established therapeutic relationships with many of the patients in

the sickle cell community. Informed consent was obtained from participants before the initiation of the program.

Analysis and Synthesis

The data collected for this project included the scores from the knowledge assessment tests for each participant pre- and post-intervention. The knowledge assessment test contained 15 questions with associated multiple-choice responses. The participants were asked to circle the best answer corresponding to the question. Each participant's pre- and post-intervention knowledge assessment was labeled with the same code to allow me to compare pre- and post-intervention assessment scores. Participant names were not collected to maintain anonymity. Walden University Institutional Review Board (IRB) approval was obtained, per program rules. However, the program site's IRB was not engaged due to the project design of an education program and no request to use any patient or participant information in the program. The project site deferred to Walden University's IRB review process.

The knowledge assessment included items that measured RNs' knowledge of SCD self-care: pain assessment, control of acute pain, identification of individual cues of crisis onset, and education on discharge. The content aligned with the CDC's Living well with Sickle Cell Self-Care Toolkit. The toolkit was designed to provide valuable information to help patients understand and monitor their health care and manage their disease (CDC, 2020). To ensure the validity of the scoring process, I was responsible for scoring the knowledge assessment tests using an answer key that was created using the

Living Well with Sickle Cell Toolkit used to develop the educational program. The questions were answered based on the information in the program, and each participant's knowledge assessment was scored using the answer key. After scoring the tests, I entered the results into the Excel spreadsheet for analysis. The same process was carried out for the pre- and posttests. Microsoft Excel was used to organize the two sets of data, which were contained in two separate datasheets. One sheet included scores for the pre-intervention test, and the second sheet was used to record post-intervention scores. The data were analyzed using Statistical Package for the Social Sciences software to provide inferential statistics via paired *t* tests to determine the statistical significance of the difference of the scores before and after the intervention.

Summary

This section provided information on the methodology of this doctoral project. This section highlighted the design used in the project. Secondly, I explained the study process, including the pre- and post-assessment of the participants' knowledge levels and the development of the educational program. Additionally, Section 3 provided information about the participants of this project. Because this project addressed the knowledge deficit among nurses concerning the care of patients with SCD, I recruited nurses working in a SCD unit. This approach helped the project team gather relevant information on patients' self-care issues. I also discussed how the data from the pretest and posttest assessments were analyzed. The evaluation results were used to help the

project team assess whether the doctoral project was successful. Section 4 provides the results of statistical analyses and an assessment of the education program's effectiveness.

Section 4: Findings and Recommendations

Evidence-based practice is centered on the ability of clinicians to review the findings of a study or quality project and translate the findings into actionable interventions. The local problem that influenced this project was an investigation of a perceived nursing knowledge gap regarding the self-management of SCD for patients living with the disease. This results in ineffective patient education on this crucial information on SCD management at the time of discharge from the hospital. As a result, an educational program was created targeting RNs who primarily care for patients living with SCD to improve RNs' baseline knowledge of self-management in the SCD population. The primary source of evidence used to determine whether there was an increase in knowledge was the analysis of the preintervention knowledge assessment scores and the post-intervention knowledge assessment scores. Inferential statistical analysis was performed using a comparative *t* test to analyze the difference in pre- and post-intervention scores. In Section 4, findings of the project and recommendations for action are presented.

Findings and Implications

Participant selection was crucial to the overall impact of the project. Participant selection was intentional as I targeted a specialized group of nurses who cared for patients living with SCD. Nineteen nurse participants were selected via convenience sampling on a 21-bed hematology/oncology inpatient unit for SCD exaggerated patients. These 19 nurses represented 56% of the nurses on the unit. This sample included nurses

from the day and night shifts. All nurses who participated in the project had worked on the unit for over 3 years and included two male nurses and 17 female nurses. The collection of other demographic information was intentionally scarce to preserve the anonymity of those who volunteered to participate. This DNP project addressed the knowledge of nurses caring for patients with SCD regarding the components of self-care and self-management necessary for patients to manage their SCD at home after discharge from the hospital.

After providing informed consent, participants completed a knowledge assessment test on patient self-care in the management of SCD. This was done to establish baseline knowledge levels before the educational program was given. After the preintervention knowledge assessment test was completed, the educational intervention was conducted in a lecture-style format using a PowerPoint presentation (see Appendix C). Immediately following the intervention, participants received an identical post education knowledge assessment test to complete. The sources of evidence used to determine the project's success were the pre- and post-intervention knowledge assessment test scores. The tool consisted of 15 questions that were created from the content found in the toolkit for patients with SCD (see Appendix B). The tool also had specific questions about acute and chronic pain management and identification of body cues for patients to guide the patient's choice of pain management. The evidence used to create the knowledge assessment test was the self-care toolkit for patients with SCD created by the CDC (2018) to systematically instruct patients on how to engage in their

plan of care as partners with the medical team to manage their disease successfully at home. The data from the pre- and post-intervention scores were recorded, and the differences, mean difference, and sum of the squared difference were determined (see Appendix D). Data were analyzed using a *t* test. Results showed a *t* value of 10.54 for the differences in pre- and post-education intervention scores, as shown in Figure 1. The statistical significance had a 95% confidence interval with a *p* value of < 0.00178 (see Appendix D). The difference of means of the preintervention and postintervention scores was -33.32, the degree of freedom was 18, and the standard error of difference was 0.725.

Figure 1

Statistical Analysis of Pre- and Posteducation Intervention Scores

Difference score calculations

t-value calculation

The results showed that the participants displayed a higher level of knowledge after the educational intervention. Therefore, it increased nurses' knowledge of caring for patients living with SCD, and the results met the identified goal. This project had all of the foundational qualities that helped guide its success, including a clear and shared focus

among all stakeholders and high levels of collaboration and communication during project implementation. The DNP project addressed the knowledge of nurses caring for and preparing patients living with SCD to care for themselves and manage their care upon discharge.

One of the unexpected findings from this project was how high the baseline knowledge was regarding the topic of self-care in the management of SCD. Factors such as professional experience, personal experience, and education level can impact a nurse's baseline knowledge of the importance of self-care in the management of SCD. Due to the variability of factors that impact an RN's baseline knowledge of patient self-management in SCD management, all nurses working with SCD patients should be provided with this information when caring for SCD patients consistently because this information has a profound impact on the overall management of the disease process. Ensuring that all nurses working with SCD are provided SCD education may help ensure that all patients receive information in self-care in the management of this disease.

Although this project targeted nurses working with patients with SCD, this program can also be used to educate other nurses not as knowledgeable about SCD or the challenges of patients living with this disease. This education may increase patients' overall success in managing SCD at home. Another implication is the lack of standardization in the information being taught on the inpatient units and what is taught in the office setting. The education program ensures the availability of evidence-based knowledge and consistency between what is taught to patients in inpatient and outpatient

settings. The alignment of discharge instructions and teaching between the inpatient and outpatient setting will provide redundancy for patients, which may increase patient knowledge of self-care.

Recommendations

This project's findings may increase nurses' knowledge regarding patient self-care in SCD management. The primary recommendation was to add educational content defining and describing the importance of patient self-care and the potential impact on the overall management of SCD to the RN onboarding program and to the annual competencies for all RNs. The recommendations are for all RNs who directly or indirectly care for patients living with SCD. This project demonstrated that nursing education on the components of self-care for patients living with SCD increased nurses' knowledge. Increasing the number of RNs educated on this subject may improve patients' preparation to manage their disease on their own after discharge, and may reduce the number of unnecessary hospital admissions. Patients who are able to become familiar with their body cues have a better chance of intervening to manage their symptoms before they get so bad they need to go to an emergency department. Fewer emergency department visits may lead to a better quality of life as patients can spend time doing the things they enjoy instead of lying in a hospital bed.

Standardizing the education program is essential for all RNs caring for patients living with SCD to close the knowledge gap currently seen in practice. The self-care toolkit for patients with SCD is a single source for education. Unit leaders can add a

section into the current curriculum for newly hired staff. I categorize this intervention as a low-energy high-impact intervention that improves the knowledge of the bedside nurses caring for patients with SCD, which better prepares patients to manage their disease at home.

Contribution of the Doctoral Project Team

Individual commitment to a group effort constitutes effective teamwork. The doctoral project team for this project included clinicians working with the SCD population. This team served as expert consultants to validate the knowledge assessment and contributed to developing the educational content designed as the intervention. The project team members included the nurse educator for the hematology/oncology unit. The role she played in this project was in the capacity of a content expert. She was able to aid in developing the educational PowerPoint. She was also instrumental in developing an implementation plan post project because she is heavily involved in designing the nursing onboarding curriculum. The social worker for the SCD program was also a project team member. She served as an expert advisor and provided validation and information on the social aspects of life with SCD, which contributed to the development of the curriculum. I was fortunate to work with this group of talented individuals who contributed so much to the project's success. The key to this team's success was that we were all aligned and focused on a common goal. Every team member was vested in making a difference for the patients living with SCD, which allowed for a successful project. This project team

had all of the necessary elements to be successful. Those elements included commitment, contribution, good communication, and cooperation.

Strengths and Limitations of the Project

The strengths of this doctoral project were numerous. This project involved the creation of an educational program targeted at a small population of nurses. This was a strength because it made for concise and standardized objectives covering a particular scope. Another strength of this project was that the outcome of this project could impact the direct care of patients. An educated RN produces an informed patient who has the knowledge and skills to make better health choices (Kim et al., 2021). Engaging patients as partners in their care may decrease the number of unnecessary emergency department encounters, which often leads to unnecessary admissions to the hospital (CDC, 2020). When a detailed care plan is not available, patients are likely to return to the emergency department after discharge for problematic issues such as nutrition concerns or drug prescriptions (Kim et al., 2021). RNs who have received the education from this project may provide patients with information on what to do should they have prescription or nutrition questions, eliminating the need to visit the emergency department. The project's strength was determined by applying the intervention on a system or population level. This project may impact a group of patients who receive their SCD care within one organization. A project of similar design could be implemented at a larger organization with a more robust sample of participants. The project could be easily replicated at other organizations with potentially the same impact on the SCD patient population.

Additionally, a strength of this project was that the adoption of the recommendations derived from this project could be easily adaptable to current processes in place for educating nurses. The nursing education curriculum is designed with the flexibility to add or remove content as necessary. Based on the project team's feedback, the educational content derived from this project could easily be added to the current onboarding curriculum for newly hired nurses to the hematology/oncology unit.

Although this project produced the desired result, which was to increase the knowledge of RNs caring for patients living with SCD, some limitations were identified. The most obvious limitation was that based on the project's design, there was no clear way to determine whether the intervention performed in the project impacted overall health outcomes for patients. This project was designed to measure only whether the nurses' knowledge had increased because of an educational intervention. Patients may be impacted when RNs translate what they know in their nursing practice when caring for patients living with SCD, but this project could not provide any validating data to this effect. The other limitation to this study was that the sample size for this project was very small, which affected the statistical significance in the pre- and postintervention scores. The unit was selected as a small 18-bed unit with limited staff. Participation was sought on a volunteer basis, which led to a smaller than desired sample size. The unit employs approximately 45 RNs. The current sample size represented 56% of the total number of available staff nurses. Recommendations for future projects would be to offer this educational program to a larger group of RNs to measure results in pre- and post-

knowledge assessment scores. Additionally, this project could be replicated to educate nurses on any chronic illness that requires a great deal of patient autonomy and self-care in the long-term management of the condition due to disease complexity.

Section 5: Dissemination Plan

The overall success of a quality improvement project is impacted by disseminating the results and translating the findings into actionable items in practice. The dissemination plan created for this project involved an internal and external dissemination approach. First, the project scope and results were shared with the entire team of clinical staff who work on and support this 18-bed hematology unit that houses the SCD program. This dissemination was done via team staff meetings by the nursing unit leaders, many of whom were on the project team. The staff meetings on this unit reach approximately 80% of the staff monthly, so this was an effective mode of communication to the larger group.

The internal dissemination plan included sharing the results with the quality director and performance improvement specialists. Unnecessary hospital readmissions of the SCD population have focused on quality leaders at the selected project site. Sharing this project and making a formal proposal for enculturation of the education project on the unit was very important for helping the quality experts understand the potential impact this project could have on the organization's readmission data. Additionally, the organization has a quarterly forum in which quality projects are shared to individuals across three different sites within the same health system. This formal meeting will also serve to complement the internal dissemination plan and is a good forum to spark interest in replication at other sites within the health system. The external dissemination plan involved sharing the project with other practitioners who care for this unique patient

population in other health systems. The education project will also be shared with the outpatient office staff who are the primary care providers for patients living with SCD who receive care at the hospital site. Due to the limited sample size and the data outcomes, sharing this project on a broader platform such as a professional conference is not likely. However, I have a strong familial history with this disease, which brought this topic to the forefront of challenges to be addressed. I plan to share informally with my family and circle of friends whom SCD might also touch to offer insight and education to them.

Analysis of Self

As I self-reflect, I played many roles in the management of this project. This was not unusual in my professional career as a nurse leader. Pressing patient care concerns are often presented as an identified need to act to improve patient care. As I began the project by meeting and sharing ideas with stakeholders, all of the stakeholders were engaged in the work. Although the desire to address this problem was apparent, the priorities changed. I found myself stepping up in many different aspects of the project to ensure that it continued moving forward. I did not have a role as a practitioner for the project. The experts in the field provided the clinician's perspective. The roles that I found myself in were project manager and executive sponsor. My primary responsibilities were to lead the team to execute a formal education program for RNs caring for patients with SCD. Other duties that I found myself responsible for were management of the logistics of the project. Those logistics included but were not limited to scheduling the dates to speak to

staff to provide informed consent and elicit interest, booking the room for the education intervention, and ensuring staff were able to spend the time necessary to participate in the program. In my professional life, this type of leadership role was familiar to me and aligned with duties associated with my current leadership role. As a director of nursing, I am well versed in pulling a team together to use data to guide process improvement. This project required a cohesive and collaborative relationship among the health care team members. Open communication and respecting the position of each member on the team were vital in engaging stakeholders toward a common problem.

Summary

Preparing patients for a seamless transition to home self-care is one of the most impactful duties for which RNs are responsible. When the complexity of a chronic illness like SCD is added, the impact of this process becomes more significant. Although SCD is an underfunded illness and has been criticized as a significant contributor to the health care disparities faced by people of color, medical advances and treatments have prolonged the lives of patients living with SCD. My DNP project addressed the impact of a patient's self-management of their disease on their overall heath, and reducing the number of unnecessary hospitalizations resulting from an uninformed group leaving the hospital without the skills or knowledge they need to care for themselves at home. The question posed in this DNP project was whether a focused education program targeting RNs working with patients with SCD on the components of self-care and self-management would improve nurses' knowledge of the topic. The baseline knowledge of

RNs who work with patients living with SCD was measured before and after the education intervention. The findings were that the postintervention knowledge assessment test scores were higher. This difference was statistically significant after a statistical analysis using *t* tests. RNs who were a part of the program had a high level of baseline knowledge of SCD and how patients living with the disease are impacted daily. The project succeeded because the education intervention improved the RNs' overall knowledge. Increased knowledge about patient self-care in managing SCD may lead to better outcomes for patients. Self-care is directly related to health behavior, and it also affects health behaviors indirectly through its impact on goals. Patients living with SCD typically have feelings of fear and loss of control. Providing such patients with the tools to manage their disease at home gives them power and control. Evidence-based practice supports the practice of self-care (Narasimhan et al., 2019). Researchers in the field confirmed self-care existed before formal health systems and is an important contributor to health outcomes (Narasimhan et al., 2019). For many people, self-care within well-established cultural and social norms may be the only portion of the health care system they access. Within the most advanced health care systems, self-care remains a crucial component for maintaining health.

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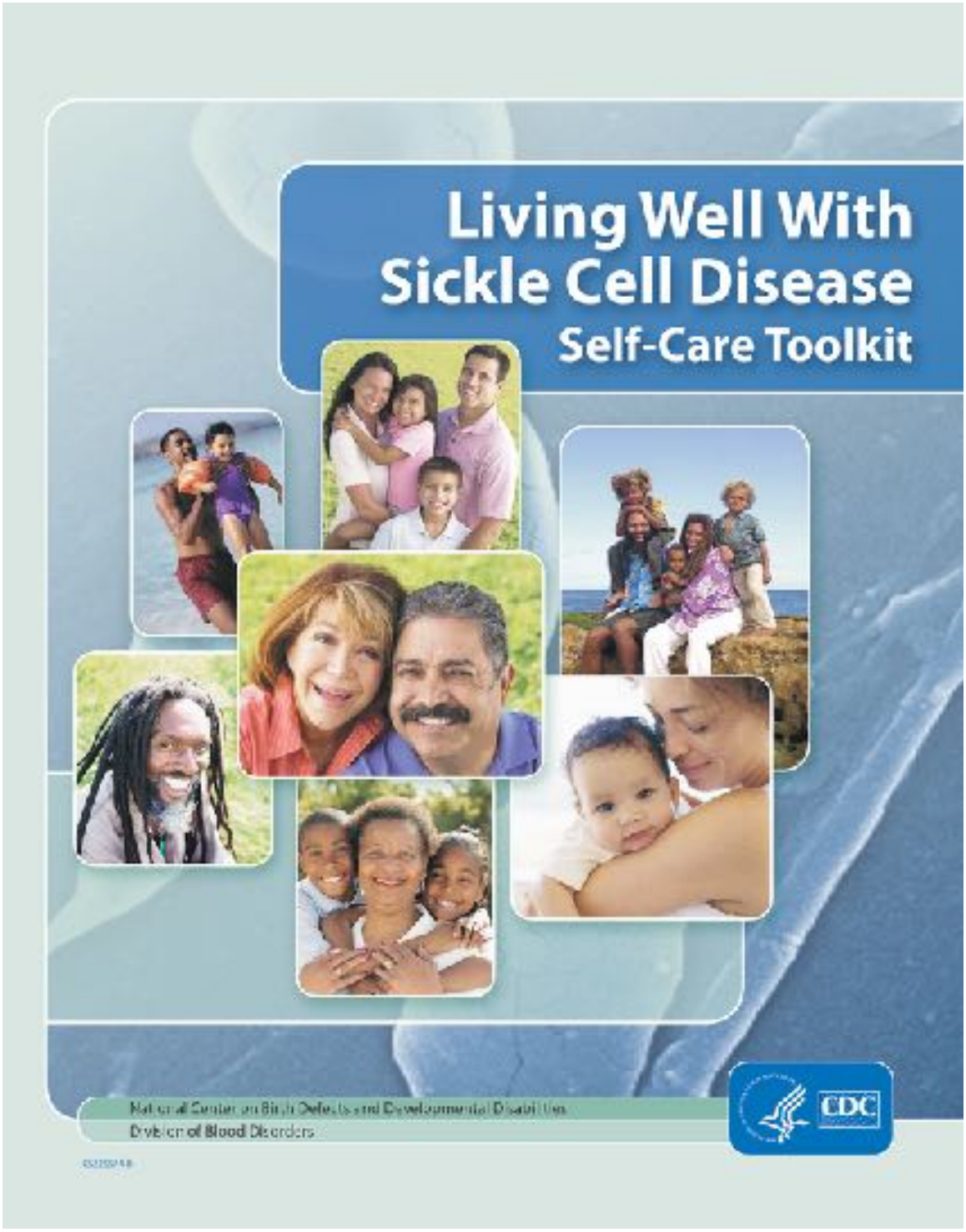
Appendix A: Living Well With Sickle Cell Disease Self-Care Toolkit



Contents

INTRODUCTION

What Is the Living Well With Sickle Cell Disease: Self-Care Toolkit?

A toolkit is a collection of materials that can be used to help you to manage your health and keep track of important information regarding sickle cell disease (SCD). The Living Well With Sickle Cell Disease: Self-Care Toolkit has multiple uses. It is designed to help you and your caregivers with management of your disease, medical care, services, and health providers. The toolkit also will help communication between the many health providers and service providers that are involved with patient care.

Why Should I Use the Living Well With Sickle Cell Disease: Self-Care Toolkit?

Because many doctors are not familiar with SCD, it is very important for you to take an active role in managing your own care. To make important decisions, you need to know about SCD, understand your treatment options, and then make the best possible choices for your health. Using the tools provided in this toolkit will help you to monitor your health care and manage your disease. Putting together a care notebook or binder that you can take with you wherever and whenever (for example doctor's appointments, emergency room visits, vacation, and the workplace) you need it will help you organize all of your SCD-related medical information in one place so that you can keep track of information over time.

You might want to include the following:

- Doctor contact information.
- Medical appointments.
- Changes in medications or treatments.
- Test results.
- Vaccination and immunization (shots) records.
- Community resources.
- Any other information about your condition (facts found on the Internet, in brochures, and from any other sources of information and support).

By organizing all of your SCD-related information in one place, you can:

- Actively take part in, and advocate for, your own care.
- Work together with the doctors on your medical team.
- Remember new and complex information that is hard to process (when the doctor first tells you about a condition, if the condition worsens, or when treatment changes).
- If you are a teenager or young adult with SCD, you can begin to take responsibility for your own health history and information.

Section 1:
Sickle Cell Disease 101

What Is Sickle Cell Disease?

Sickle cell disease (SCD) is a group of inherited red blood cell disorders.

- Healthy red blood cells are round and they move through small blood vessels carrying oxygen to all parts of the body.
- For someone with SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a "sickle".
- Sickle cells die early in comparison to non-sickle cells, which causes a constant shortage of red blood cells.
- Sickle cells can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body. These changes in cells can cause repeated episodes of severe pain, organ damage, serious infections, or even stroke.

What Causes Sickle Cell Disease?

SCD is inherited in the same way that people get the color of their eyes, skin, and hair.

- A person with SCD is born with it.
- People can not "catch" SCD from being around a person who has it.

Who Is Affected by Sickle Cell Disease?

- It is estimated that SCD affects 90,000 to 100,000 people in the United States, mainly Blacks or African Americans.
- The disease occurs among about 1 of every 500 Black or African American births and among about 1 of every 36,000 Hispanic-American births.
- SCD affects millions of people throughout the world and is particularly common among those whose ancestors come from sub-Saharan Africa; regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy.

What Health Problems Does Sickle Cell Disease Cause?

The following are some of the most common complications of SCD:

Pain Episodes or Crises—Sickle cells don't move easily through small blood vessels and can get stuck and stop blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time.

Infection—People with SCD, especially infants and children, are more likely to experience harmful infections such as influenza, meningitis (infection of the brain or spinal cord), and hepatitis (infection of the liver).

Hand–Foot Syndrome—Swelling in the hands and feet, often along with a fever, is caused by the sickle cells getting stuck in the blood vessels and blocking the blood from flowing freely through the hands and feet.

Eye Disease—SCD can affect the blood vessels in the eye and lead to long-term damage.

Acute Chest Syndrome—Blockage of the flow of blood to the lungs can cause acute chest syndrome (ACS). ACS is similar to pneumonia; symptoms include but are not limited to chest pain, coughing, difficulty breathing, and fever. It can be life threatening and should be treated in a hospital.

Stroke—Sickle cells can stop blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.

How Is Sickle Cell Disease Treated?

The goals of treating SCD are to relieve pain and to prevent infections, eye damage, and strokes. There is no single best treatment for all people with SCD. Treatment options are different for each person depending on the symptoms. Treatments can include receiving blood transfusions, receiving intravenous therapy (fluids given into a vein), and medications to help with pain.

- For severe SCD, a medicine called **hydroxyurea might** be recommended. Research suggests that hydroxyurea can reduce the number of painful episodes and the recurrence of ACS. It also can reduce hospital stays and the need for blood transfusions among adults who have SCD.

Is There a Cure for Sickle Cell Disease?

To date, the only cure for SCD is a bone marrow or stem cell transplant.

- A bone marrow or stem cell transplant is a procedure that takes healthy stem cells from a donor and puts them into someone whose bone marrow is not working properly. These healthy stem cells cause the bone marrow to make new, healthy cells.
- Bone marrow or stem cell transplants are very risky, and can have serious side effects, including death. For the transplant to work, the bone marrow must be a close match.

Section 2:
Living Well With Sickle Cell Disease

Six Steps to Living Well With Sickle Cell Disease

You can live a full life and enjoy most of the activities that other people do. The following tips will help you stay as healthy as possible:

Find *good medical care*—Sickle cell disease is a complex disease. Good quality medical care from doctors and nurses who know a lot about the disease can help prevent some serious problems. Often the best choice is a hematologist, a doctor who specializes in blood diseases, working with a team of specialists.

Get regular checkups—Regular health checkups with a primary care doctor can help prevent some serious problems.

Prevent infections—Common illnesses, like influenza, quickly can become dangerous for a person with SCD. The best defense is to take simple steps like washing your hands frequently to help prevent infections. See "Five Tips to Help Prevent Infection" for more information.

Learn healthy habits—Drinking 8 to 10 glasses of water every day and eating healthy food will help to maintain hydration and proper nutrition. People with SCD should maintain a balanced body temperature, getting neither too hot nor too cold. Participating in physical activity to help stay healthy is very important. However, it's essential that you don't overdo it. Rest when tired, and drink plenty of water.

Look for clinical studies—New clinical research studies occur frequently and these studies might give you access to new medicines and treatment options.

Get support—Find a patient support group or community-based organization that can provide information, assistance, and support.

Five Tips To Help Prevent Infections

Common illnesses, like influenza quickly can become dangerous for a person with SCD.

The best defense is to take simple steps to help prevent infections.

1. ***Vaccines***—Vaccines are a great way to prevent many serious infections. Adults and children with SCD should have the influenza vaccine every year, as well as the pneumococcal vaccine and any others recommended by their doctor.
2. ***Penicillin***—Penicillin can help prevent infections. Children with SCD should take penicillin (or another antibiotic prescribed by a doctor) every day until they are at least 5 years of age.
3. ***Washing hands***—Washing your hands is one of the best ways to help prevent getting an infection. People with SCD, their families, and other caretakers should wash their hands with soap and clean water many times each day. If you don't have access to soap and water, you can use gel hand cleaners with alcohol in them.

   Wash your hands before:

   - Making food.
   - Eating.

   Wash your hands after:

   - Using the bathroom.
   - Blowing your nose, coughing, or sneezing.
   - Shaking hands.
   - Touching people or things that can carry germs, such as:
     - Diapers or a child who has used the toilet.
     - Food that has not been cooked (raw meat, raw eggs, or unwashed vegetables).
     - Animals or animal waste.
     - Trash.
     - A person who is sick.
4. ***Food Safety***—Salmonella, a type of bacterium in some foods, can be especially harmful to children with SCD. To avoid exposure to this and other bacteria and to stay safe when cooking and eating:
   - Wash your hands, cutting boards, counters, knives, and other utensils after they touch uncooked foods.
   - Wash vegetables and fruit well before eating them.
   - Cook meat until it's well done. The juices should run clear and there should be no pink inside.

- Do not eat raw or undercooked eggs. Raw eggs might be "hiding" in homemade hollandaise sauce, Caesar and other homemade salad dressings, tiramisu, homemade ice cream, homemade mayonnaise, cookie dough and frostings.
- Do not eat raw or unpasteurized milk or other dairy products (cheeses). Make sure these foods have a label that says they are "pasteurized."

5. ***Avoid Reptiles***—Salmonella (mentioned previously) is present in some reptiles and can be especially harmful to people with SCD. Make sure children and adults stay away from turtles, snakes, and lizards.

Emergency Guide: When To See the Doctor

It is very important that every person with SCD have a plan for how to get help immediately—at any hour—if there is a problem. Be sure to find a medical facility that will have access to your medical records or keep a copy that you can bring.

Go to an emergency room or urgent care facility *right away* for:

- Fever above 101°F.
- Difficulty breathing.
- Chest pain.
- Abdominal (belly) swelling.
- Severe headache.
- Sudden weakness or loss of feeling and movement.
- Seizure.
- Painful erection of the penis that lasts more than 4 hours.

Call a doctor *right away* for:

- Pain anywhere in the body that will not go away with treatment at home.
- Any sudden problem with vision.

Coping With Stress

The Basics

Preventing and managing stress can help lower your risk of serious health problems associated with SCD. You can prevent or lessen stress by:

- Planning ahead.
- Preparing for stressful events.

Some stress is hard to avoid. You can find ways to manage stress by:

- Recognizing when you feel stressed.
- Taking time to relax.
- Getting active and eating healthy.
- Sharing your feelings with friends and family.

What Are the Signs of Stress?

When people are under stress, they might feel:

- Worried.
- Irritable.
- Depressed.
- Unable to focus.

Stress also affects the body. Physical signs of stress include:

- Headaches.
- Back pain.
- Problems sleeping.
- Stomach upset.
- Weight gain or loss.
- Tense muscles.
- Frequent or more serious colds.

What Causes Stress?

Stress often is caused by some type of change. Even positive changes, like marriage or a job promotion, can be stressful. Stress can be short term or long term.

Common Causes of Short-Term Stress

- Having too much to do and not much time.
- Having lots of little problems on the same day (like encountering a traffic jam or running late).
- Getting lost.
- Having an argument.

Common Causes of Longer Term Stress

- Relationship issues.
- Death of a loved one.
- Illness.
- Caring for someone who is sick.
- Problems at work.
- Money problems.

What are the benefits of managing stress?

Managing stress can help you:

- Sleep better.
- Control your weight.
- Get sick less often and heal faster.
- Lessen neck and back pain.
- Be in a better mood.
- Get along better with family and friends.

Take Action!

Being prepared and in control of your condition will help you feel less stress. Follow these six tips to prevent and manage stress.

Plan your time—Think ahead about how you are going to use your time. Write a to-do list and decide which tasks are the most important. Be realistic about how long each task will take.

Relax with deep breathing—Take part in deep breathing activities or yoga classes.

Relax your muscles—Try stretching or taking a hot shower to help you relax. Stress causes tension in your muscles.

Get moving—Plan physical activity to help prevent and manage stress. It also can help relax your muscles and improve your mood. Before you start, be sure to discuss any new exercise routine with your doctor.

- Aim for 2 hours and 30 minutes a week of moderate aerobic activity (e.g. walking or biking).
- Be sure to exercise for at least 10 minutes at a time.
- Do strengthening activities (like sit-ups or lifting weights) at least 2 days a week.

Share your feelings with friends and family—Tell your friends and family if you are feeling stressed. They might be able to help.

Get help if you need it—Find help if your stress doesn't go away or keeps getting worse.

Fifteen Reasons Why Exercise Is Good

Being physically active can help with maintaining overall good health. The following are examples of the benefits of exercising:

- ✓ Helps to improve and maintain good overall health.
- ✓ Strengthens the cardiovascular system—heart, lungs and blood vessels.
- ✓ Reduces the risk of persistent illness.
- ✓ Increases muscle strength.
- ✓ Improves flexibility.
- ✓ Increases endurance and stamina.
- ✓ Increases natural pain killers (called endorphins) in the body's nervous system, which help control pain.
- ✓ Helps with weight control.
- ✓ Helps to improve quality of sleep.
- ✓ Helps balance and coordination.
- ✓ Reduces fatigue and increases energy.
- ✓ Reduces muscular tension, stress, and depression.
- ✓ Helps combat depression and anxiety.
- ✓ Helps you maintain a positive outlook.
- ✓ Helps to prevent constipation.

Section 3:
Tools for Managing Your Health

Where Can I Find and Print the Forms for My Self-Care Toolkit?

The Living Well With Sickle Cell Disease: Self-Care Toolkit includes several forms that you can use to keep track of important information, manage your health, and monitor your medical care. You can print copies of these forms, which are available at http://www.cdc.gov/ncbddd/sicklecell/index.html.

How Often Should I Update the Information in My Self-Care Toolkit?

To be most helpful, your Self-Care Toolkit should provide a snapshot of your current health status. Be sure to include new prescriptions and treatment information. Once every few months, you might want to go through your toolkit and remove or file certain sections if they are getting too large or you find you no longer need them.

Who Should Know About My Self-Care Toolkit?

You should make sure that a family member or other caregiver knows that you have a Self-Care Toolkit. You also should make sure that they can find it in an emergency and bring it to the clinic or hospital where you are receiving care.


FORMS

DEVELOPING S.M.A.R.T GOALS

	S specific	M measurable	A attainable	R realistic	T time-frame
	Clearly define desired outcome	Define goals by numbers	Create goals that motivate	Set challenging but realistic goals	Set deadlines for accomplishments
Long-Term ultimate goal	Example: Lose 20 pounds	Example: Progress can be shown by weekly weigh-in	Example: I will increase my exercise to 4 times per week	Example: I will cut back on sugary foods	Example: Lose 2 pounds per week for 10 weeks
Short-Term stepping stones 1					
2					
3					
4					

HEALTHY BEHAVIOR CONTRACT

Use the goals developed on the Developing S.M.A.R.T Goals form to complete your healthy behavior contract. Use this contract to help you to set and attain healthy behaviors that will improve your health and well-being.

Based on an awareness of my health status, I, _____ have decided to set the following behavior related health goal, which will contribute to improvement of my personal well-being.

My health behavior goal is: _____

(Insert your SMART goal)

_____

The benefits of my achieving this goal are: _____

_____

_____

The anticipated problems or barriers to taking positive action are: _____

_____

_____

_____

The behaviors I will adopt to accomplish this personal health goal are: _____

(Restate your SMART goal)

_____

_____

I will reinforce my actions by: _____

and reward achievement of my goal by _____

I _____, have reviewed this contract and agree to be a part of a positive support system throughout this behavior change project.

Signed _____ Date _____

I have reviewed this contract and agree to take action to accomplish my goal and to discuss the results with my provider, family member or friend. Upon completion of this contract, I will identify my next area of opportunity and take further steps to improve my health status.

Signed _____ Date _____

Witness _____ Date _____

Provider/Family Member/Friend

PERSONAL/FAMILY INFORMATION SHEET

Use this form to record personal and family information in case of an emergency.

YOUR NAME:	
DATE OF BIRTH:	
DIAGNOSIS:	
BLOOD TYPE:	
ADDRESS:	
TELEPHONE NUMBER:	

PARENT NAME (IF APPLICABLE):	
ADDRESS:	
TELEPHONE NUMBER:	

ADDITIONAL FAMILY INFORMATION

LANGUAGE SPOKEN AT HOME:		
OTHER LANGUAGE(S):		
INTERPRETER NEEDED (CIRCLE YES OR NO):	Yes	No

MEDICAL EMERGENCY INFORMATION SHEET

Use this form to maintain correct medical information the case of an emergency.

PERSONAL INFORMATION			
Last Name		First Name	Middle Initial
Date of Birth	Sex	Weight	Blood Type
Address			
City		State	Zip Code
Primary Insurance		Secondary Insurance	
Primary Insurance Member's & Group		Secondary Insurance Members & Group	

SICKLE CELL DISEASE (TYPE)
☐ SS (sickle cell anemia)
☐ SC (sickle cell hemoglobin C)
☐ S Beta Thalassemia
Other_____

ALLERGIES	CARDIAC	SURGERY
☐ None ☐ Unknown Medical Allergies:	☐ None ☐ Unknown ☐ Angina ☐ Arrhythmia ☐ Congestive Heart Failure ☐ Congenital ☐ MI _____ Other	☐ None ☐ Unknown ☐ Abdominal ☐ Heart ☐ Lung ☐ Neurological Other_____

OTHER CHRONIC CONDITIONS		
☐ None	☐ Gastrointestinal	☐ Psychological
☐ Asthma	☐ Headaches	☐ Seizures
☐ Bleeding Disorder	☐ Hepatitis	☐ Substance Abuse
☐ Cancer	☐ HIV +	☐ TB
☐ Diabetic	☐ Hypertension	☐ Unknown
	☐ Paralysis	Other_____

CURRENT MEDICATIONS
☐ None
☐ Unknown

EMERGENCY CONTACT INFORMATION	
Primary Physician:	Physician Telephone Number:
Primary Contact Name & Relationship:	Primary Contact Telephone Number:
Secondary Contact Name & relationship:	Secondary Contact Telephone Number:

Update information regularly! Use a separate sheet for additional information.

SPECIALITY CARE INFORMATION SHEET

Use this form to keep track of the specialty providers who are part of your medical treatment team.

SPECIALTY CARE PROVIDER:	
DATE OF 1ST VISIT:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	
COMMENTS:	

SPECIALTY CARE PROVIDER:	
DATE OF 1ST VISIT:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	
COMMENTS:	

SPECIALTY CARE PROVIDER:	
DATE OF 1ST VISIT:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	
COMMENTS:	

MEDICAL APPOINTMENT SHEET

5 Steps to an effective medical appointment:

- ✓ Write down problems or questions, or both, before you go.
- ✓ Rank your questions from most important to least important.
- ✓ Share the list with your provider.
- ✓ Talk with your health care provider about options for addressing your problems or concerns.
- ✓ Speak with your provider about next steps or follow-up activities.

APPOINTMENT DATE/TIME	HEALTH PROVIDER	HEALTH PROVIDER CONTACT INFORMATION	REASON FOR APPOINTMENT	WHAT WAS DISCUSSED OR DECIDED	FOLLOW-UP REQUIRED/ NEXT APPOINTMENT

PHARMACY PROVIDER INFORMATION SHEET

Tip: If possible use one pharmacy for all of your prescription needs. This will allow your pharmacist to keep track of all medications being used and the potential for interactions between medications.

Use this form to keep track of all of your pharmacy providers.

PHARMACY NAME:	
NAME OF PHARMACIST:	
MAILING ADDRESS:	
TELEPHONE/FAX NUMBER:	
EMAIL ADDRESS:	

PHARMACY NAME:	
NAME OF PHARMACIST:	
MAILING ADDRESS:	
TELEPHONE/FAX NUMBER:	
EMAIL ADDRESS:	

PHARMACY NAME:	
NAME OF PHARMACIST:	
MAILING ADDRESS:	
TELEPHONE/FAX NUMBER:	
EMAIL ADDRESS:	

PHARMACY NAME:	
NAME OF PHARMACIST:	
MAILING ADDRESS:	
TELEPHONE/FAX NUMBER:	
EMAIL ADDRESS:	

INSURANCE INFORMATION SHEET

Use this form to keep track of insurance policy and identification numbers. Record contact information for all health insurance providers for emergency situations.

PRIMARY INSURANCE:	
COMPANY:	
POLICY NUMBER:	
CONTACT PERSON:	
MAILING ADDRESS:	
TELEPHONE NUMBER:	
FAX NUMBER:	
EMAIL ADDRESS:	

MEDICAID/HMO IDENTIFICATION NUMBER:	
POLICY NUMBER:	
CONTACT PERSON:	
MAILING ADDRESS:	
TELEPHONE NUMBER:	
FAX NUMBER:	
EMAIL ADDRESS:	

SOCIAL SECURITY INCOME IDENTIFICATION NUMBER:	
POLICY NUMBER:	
CONTACT PERSON:	
MAILING ADDRESS:	
TELEPHONE NUMBER:	
FAX NUMBER:	
EMAIL ADDRESS:	

MEDICATION LOG SHEET

Use this form to keep track of your medication usage.

MEDICATION (NAME)	DATE		DOSE/ STRENGTH	FREQUENCY PER DAY	PURPOSE OF MEDICATION	SIDE EFFECTS
	START	STOP				

SPECIAL INSTRUCTIONS
Note: List any allergies or changes to medications listed

DESCRIPTION/ BRAND NAME	CONTACT PERSON/ TELEPHONE NUMBER	DATE OBTAINED	SERVICE SCHEDULE	COMMENTS

Medical Equipment: Use this space to record any information related to your medical equipment (description, brand name, size, etc.)

VACCINATION AND IMMUNIZATION TRACKING SHEET

Use this form to record information about your vaccination and immunization history.

NAME:							
DATE OF BIRTH:				BLOOD TYPE:			
VACCINE	DATE	DATE	DATE	DATE	DATE	DATE	TOTAL DOSES
DTP; DtaT; DT							
Id or Tdap							
Hepatitis B							
OPV							
IPV							
HIB (under age 5)							
PCV (under age 5)							
Measles*							
Mumps*							
Rubella*							
Hepatitis A (born after 1/1/2006)							
Varicella*							
MCV/MPSV							
Rotavirus							
HPV							
Nasal Spray Flu Vaccine*							
Td or Tdap (Booster Dose)							

*Check with doctor about vaccinations you can give.

HOSPITALIZATIONS AND SURGERICAL PROCEDURES TRACKING SHEET

Use this form to record information about your hospitalizations and history of surgical procedures.

NAME:			
DATE OF BIRTH:		BLOOD TYPE:	

HOSPITALIZATIONS

DATE	HOSPITAL	ATTENDING PHYSICIAN	PURPOSE OF STAY	COMMENTS

SURGICAL PROCEDURES

DATE	HOSPITAL	ATTENDING PHYSICIAN	PURPOSE OF PROCEDURE	COMMENTS

TRANSFUSION TRACKING SHEET

Use this sheet to record information about your transfusion history.

NAME:			
DATE OF BIRTH:		BLOOD TYPE:	

TRANSFUSION REQUIREMENTS

PREMEDICATION NEEDS

TRANSFUSION DATE	NUMBER OF DAYS/WEEKS SINCE LAST TRANSFUSION	PRE-TRANSFUSION HEMOGLOBIN	COMMENTS/NOTES

LABORATORY TESTING SHEET

Use this sheet to keep track of your laboratory procedures and results.

NAME:					
DATE OF BIRTH:			BLOOD TYPE:		
	Date	Date	Date	Date	Date
COMPLETE BLOOD COUNT (CBC)	RESULTS	RESULTS	RESULTS	RESULTS	RESULTS
White Blood Cell					
Hemoglobin (Hgb)					
Hematocrit					
Platelets					
Reticulocyte* (Retic) Count					
Absolute Neutrophil Count (ANC)					
Other:					
Other: _____					

LABORATORY TESTING GLOSSARY	
Complete Blood Count	The complete blood count (CBC) is the most common blood test. The CBC is done to find out the number, shape, and size of the blood cells and the hemoglobin level.
White Blood Cell	White blood cells (WBCs) are cells of the immune system involved in defending the body against infectious diseases.
Hemoglobin	Hemoglobin is the protein molecule in red blood cells that carries oxygen from the lungs to the body's tissues and returns carbon dioxide.
Hematocrit	Hematocrit is a blood test that measures the percentage of the volume of whole blood that is made up of red blood cells.
Reticulocyte (Retic) Count	The retic count is the number of young red blood cells produced by bone marrow being released into the blood.
Absolute Neutrophil Count (ANC)	The absolute neutrophil count is the total number of WBCs in a neutrophil or blood stream.

ADDITIONAL TESTING TRACKING SHEET

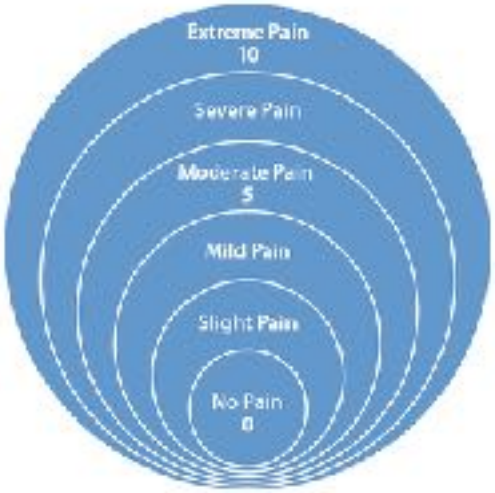
Use this sheet to keep track of your laboratory procedures and results.

NAME:			
DATE OF BIRTH:		BLOOD TYPE:	

	ENDOCRINE LABORATORY TEST			
	DATE	RESULTS	DATE	RESULTS
Fasting Blood Glucose				
Hemoglobin A1C				
T3				
T4				
Thyroid Stimulating Hormone (TSH)				
Free Thyroxin				
Growth Hormone				
Parathyroid Hormone(PTH)				
Follicle Stimulating Hormone (FSH)				
Luteinizing Hormone (LH)				
Estradiol				
Testosterone				
Cortisol				
Glucose Tolerance Test				
Other:_____				
Other:_____				

DAILY PAIN TRACKING SHEET

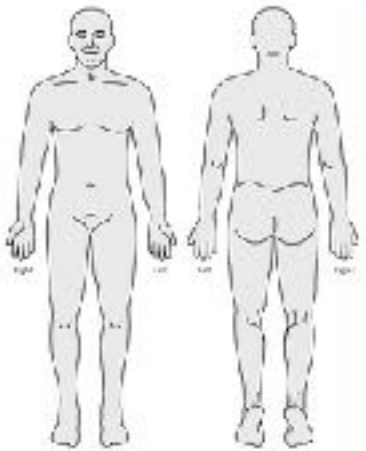
Use this tracking sheet to record your pain and what you did to relieve it. This will help your health provider to better understand your pain. Complete the form daily and share the information with your health provider at your next visit.



Time (pain episodes occurred)	Rate the pain on a scale of 1–10 (or list the word from the scale that describes your pain level)	What were you doing when pain began?	Did you take prescription medicine (check yes or no)		If yes, what was your pain rating after an hour?	If no, what was your pain rating after an hour?
Ex. 6 am	Ex. 5 or Moderate pain	Ex. Walking	Yes	No		

DESCRIBE THE PAIN SHEET

Use this form to illustrate where you experienced pain. This form can also be used with your health provider for routine visits or during emergency situations.



1. Using a pen or marker identify the area on the body drawing to illustrate where you experienced pain (use different colors to show more or less pain).
2. Does the pain move or travel across your body?_____
3. Did you cancel, avoid, or limit any of your routine activities today due to pain?
4. Have you experienced different types of pain today?
5. What did you do to relieve your pain today? (Check all that apply)

❑ Prescription medicine	❑ Herbal remedies
❑ Exercise	❑ Massage
❑ Psychological Counseling	❑ Relaxation Technique
❑ Nonprescription medicine (e.g., Advil)	❑ Hot packs
❑ Physical Therapy	❑ Rest
❑ Prayer or meditation	❑ Other_____

STRESS DIARY SHEET

Use this form to monitor and track what causes you stress daily or weekly and what you do to prevent or reduce your personal stress level.

STRESSORS	SHORT-TERM STRESS	LONG-TERM STRESS	STRESS-REDUCING ACTIVITIES

DAILY PHYSICAL ACTIVITY TRACKING SHEET

Use this form each week to keep track of your daily physical activity.

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
Type of activity							
What time and how long?							
Who will participate?							
Did you complete the activity?							
Comments							

WATER INTAKE TRACKING SHEET

Health providers recommend that people with sickle cell disease drink six to ten 8-ounce glasses of water per day. Use this form each week to keep track of your water intake.

	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Week 1	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:
Week 2	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:
Week 3	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:
Week 4	# of 8 oz glasses:	# of 8 oz glasses:	# of 8 oz glasses:	# of 8 oz glasses:	# of 8 oz glasses:	# of 8 oz glasses:	# of 8 oz glasses:

Week 1 Total: _____

Week 2 Total: _____

Week 3 Total: _____

Week 4 Total: _____

QUESTIONS TO ASK MY HEALTH PROVIDER

NOTES PAGE

NOTES PAGE

Appendix B: Knowledge Assessment Test Form

T dentifier _____

PLEASE DO NOT WRITE YOUR NAME ON THIS ASSESSMENT TEST ****

KNOWLEDGE ASSESSMENT TEST

1. Approximately 80% of healthcare costs associated with SCD relate to _____
   a. Pain management
   b. Sickle cell support groups
   c. Inpatient hospital care
   d. Mental health services

2. People of _____descent make up % of the population with sickle cell in the United States

   a. Hispanic
   b. Native American
   c. African
   d. South Asian

3. Stress and lack of coping skills can cause patients living with SCD to go into acute crisis attacks.

   True False

4. Which of the following symptoms could be signs of stress in patients living with SCD

   a. Problems Sleeping
   b. Depression
   c. Trouble Concentrating
   d. Weight Gain/loss
   e. All of the above

5. Sickle cell is a chronic progressive disease that can be cured with appropriate medical management.

   True False

T dentifier _____

6. Due to Opioid addiction, patients living with SCD should seek care in the Emergency Department immediately before self- medicating at home.

True False

7. Pain Medication should be taken as ordered and not escalated based on unresolved pain.

True False

8. Patients should be taught to self-administer pain medication when their pain reaches
   a. At least a 9 out of 10
   b. Before they even have pain
   c. As soon as their pain begins

9. Sickle Cell Disease tends to impact young adults, as such the following risky behaviors may contribute to acute exacerbation
   a. Drinking
   b. Smoking
   c. Recreational drug use
   d. All of the above

10. All of the following therapies are associated with Sickle Cell Treatment except
    a. Opioid Medications
    b. Blood Pressure Medication
    c. Hydroxyurea
    d. Blood transfusions

11. All of the following lifestyle choices can increase the chances of patients living with SCD going into an acute crisis attack except
    a. Getting tattoos with unsterilized needles
    b. Extreme temperatures for prolonged periods of time
    c. Illicit drug use
    d. Uncontrolled hypertension
    e.

T dentifier _____

12. The primary reason for readmissions for patients living with SCD is
    a. Uncontrolled hypertension
    b. Suicidal ideation
    c. Uncontrolled pain
    d. None of the above.

13. Sickle Cell Disease affects more men than women
    True False

14. The key factors involved in effective self –management and self- care for patients living with SCD include all of the following except
    a. Knowing your individualized body cues and how to predict an oncoming crisis
    b. Practice shared decision making with the care team
    c. Be consistent in keeping your outpatient office visits
    d. Limit your drinking and risky behaviors to monthly instead of weekly.

15. The following factors can impact the quality life for sickle cell patients
    a. Frequent hospitalizations interrupting school or work opportunities.
    b. Medical bias around pain management
    c. Hospital costs
    d. Isolation from family/friends
    e. All of the above

Thank you very much for your time and attention.

Appendix C: Educational Intervention PowerPoint Presentation

THANK YOU

- I would like to thank you all for your agreement to sitting down with me to learn more about how to better prepare patients living with SCD to manage their disease on their own when discharged home.
- To show my appreciation for the time that you are giving I have provided dinner while you receive this information.
- Before we begin, I would like to ask you to complete this 12 question knowledge assessment to understand your baseline knowledge of self management in SCD care.

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INTRODUCTION

- Sickle Cell Disease(SCD) is a medically and socially complex, multi system illness that affects roughly 100,000 individuals, primarily African Americans in the United States (Brennan-Cook, 2018)
- Approximately 80% of healthcare costs associated with SCD relate to hospital care(Brennan-Cook, 2018). SCD has a multi-system impact which warrants a high level of patient self care to manage the disease at home.
- Registered Nurses(RN) working in the acute care setting with patients with SCD have the primary responsibility of ensuring patients have the information they need to effectively care for themselves at home

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INTRODUCTION

- Sickle cell is a disease that is often stigmatized and marginalized mostly by members of the health care community.
- Despite being the group that accounts for 80% of hospital readmissions, patients living with SCD do not like receiving care in Emergency Departments. Reasons include inconsistent standards of care from institution to institution, medical bias, and inadequate pain control.

The Impact On Society

- It is estimated that SCD affects 80,000 to 100,000 people in the United States mostly African Americans (CDC, 2020).
- The disease occurs among about 1 of every 365 African American Births (CDC,2020). The etiology of the disease is through a hereditary gene passed through genetics.
- SCD has been a global health issue that has not gotten the attention and support through policy makers as it deserves. There have been a few key public health interventions, such as screening of newborns , provision of prophylaxis against bacterial infections, and immunizations against pneumococcal infections to have the greatest impact(Aygun & Odame, 2016).
- Because people with SCD need comprehensive , lifelong care , the cost to cover treatment is expensive. Hospital admissions and ED visits due to unpredictable pain crisis can add to these costs as can complications of the disease.

The Impact of Society

- A study sponsored by bluebird bio,[4] revealed that the estimated cost of healthcare for a person with sickle cell disease[5] was between $2.5 million and $4 million over the course of their lifetime, which is **7 to 11 times higher than costs for the general US population.**
- Research suggests that racial bias in healthcare settings contributes to a barrier to care.

Impact of Education on Outcomes

- Patients living with SCD are unable to prevent crisis and acute pain events no matter how engaged they are in the self management of their disease. However, they do have the ability to control the severity and frequency of such attacks.
- **For this reason, patients with SCD should focus on minimizing the severity of** the attack. Through recognition of patient specific indicators of an impending attack, there are steps patients can take to manage the systems to impact the severity of the attack.

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TOOLS FOR THE TOOLBOX

There are six key steps that have been identified by experts in Sickle Cell Disease Management as best practices to minimize the severity and frequency of SCD crisis attacks (CDC, 2020)

- *Get connected to a SCD physician* who specializes in blood diseases such as a hematologist. These physicians typically work with a team of specialists to provide a comprehensive treatment plan.
- *Pay attention to the body's cues* related to the escalation of pain and follow the prescribed pain contract as agreed between you and the care team.
- *Participate in preventative care measures* for developing any type of infectious disease process. Common illnesses, like influenza, can quickly become life threatening for SCD patients. The best defense is to engage in frequent handwashing, receipt of preventative vaccines and self isolating from others in the community actively fighting an infection.

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TOOLS FOR THE TOOLBOX

- *Learn healthy habits*—Drinking 8 to 10 glasses of water every day and eating healthy food will help to maintain hydration and proper nutrition. People with SCD should maintain a balanced body temperature, getting neither too hot nor too cold. Participating in physical activity to help stay healthy is very important. However, it's essential that you don't overdo it, rest when tired, and drink plenty of water.
- *Look for clinical studies*—New clinical research studies occur frequently and these studies might give you access to new medicines and treatment options.
- *Get support*—Find a patient support group or community-based organization that can provide information, resources, and support.

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Manage your Stress

- Stress in the patient with SCD can have a direct impact on the initiation of an acute sickle cell crisis (Aygun & Odame, 2016).
- Patients living with SCD should be encouraged to seek informal support from a close friend or engage in a support group for patients living with SCD.
- SCD tends to affect the entire life of patients. These patients are often young and tend to lack effective coping skills.
- Nurses caring for these patients should be sure to assess the support system in place for patients and if there is none, they should make a purposeful effort to connect them with a sickle cell support group prior to discharge.

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SIGNS OF STRESS

- **What Are the Signs of Stress?**
- When people are under stress, they might feel:
- ..Worried.
- ..Irritable.
- ..Depressed.
- ..Unable to focus.
- Stress also affects the body. Physical signs of stress include:
- ..Headaches.
- ..Back pain.
- ..Problems sleeping.
- ..Stomach upset.
- ..Weight gain or loss.
- ..Sore muscles.
- ..Frequent or more serious colds.

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LETS TALK PAIN MANAGEMENT

- SCD is a chronic, progressive condition with no visible cure. Disease management involves pain medication, hydroxyurea and red blood cell transfusions.
- Due to the nature of the disease process, many patients experience most of their pain at home. Depending on their ability to manage their pain at home, they typically attempt to manage their pain at home until it is no longer effective.
- Some attending physicians utilize pain management contracts which outline in detail the escalating use of opioids to attempt to control pain and prevent the need for an ED visit.
- Patients should be taught to address pain as soon as it occurs even in the earliest of phases so to prevent the pain from getting out of control. Patients should keep a written journal of what their pain level is, what they take and the time that it was taken.

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Pain Management

- Pain medication should be taken according to the level of pain that the patient is experiencing.
- Patients should also be reminded to always ensure that they have an adequate supply of pain medication in the house. Keeping up with prescriptions plays a large role in effective pain management.
- Nurses should be sure to assess the patient's comfort level with utilizing a pain scale to determine appropriate medication selection during the beginning phases of crisis.
- If pain is not resolving despite escalating the medication regimen, patients should be encouraged to report to the emergency department for evaluation.

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OTHER IMPORTANT TIPS

- Other important tips to share with patients that the key to avoiding unnecessary ED and visits for complications of SCD is to ensure compliance with all outpatient visits. Compliance with these visits will allow attending physicians to assess ongoing progress with the patient's ability to self manage their own care.

- SCD is an illness that primarily impacts young adults, and as such patients should be reminded that common behaviors that young adults tend to engage in such as social drinking and drug use should be eliminated.

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