

Improving the Quality of Whole-Person Healthcare Delivery

Critical Components of a Sickle Cell Disease Nurse Navigator Role

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ABSTRACT

Purpose/Objectives: Sickle cell disease (SCD) is a complex genetic hemoglobinopathy which is associated with a severely shortened lifespan; the median age of death remains in the low 50's. Individuals living with SCD have complex medical, psychological, and social needs. The complexity results in difficulty navigating the healthcare system, and often being unaware of existing resources that may assist with addressing unmet social needs. Navigating fragmented healthcare and other support systems, as well as ensuring access to care, is challenging for persons with complex chronic diseases such as those living with SCD. Most healthcare institutions do not use SCD-specific nurse navigation models. The purpose is to describe an evidence-based SCD practice model for nurse navigation to improve the quality of whole-person healthcare delivery.

Primary Practice Settings: Care for individuals with SCD.

Findings/Conclusions: This disease-focused, nurse navigation model was adapted from effective models and theories. The authors identify and describe nurse navigator competencies, including care coordination, patient education and support, communication, and expertise in SCD care delivery. Each of these competencies is operationalized into core and adaptable intervention components in this model to improve the quality of life and longevity of individuals living with SCD.

Implications for Case Management Practice: Nurse navigators are required to understand and manage the care of individuals with complex healthcare needs. The authors identified a comprehensive model that clearly delineates the most effective components of nurse navigation for SCD that can be adopted to a variety of healthcare and community settings to achieve the highest likelihood of meeting whole person healthcare delivery needs. Partnering with community-based organizations, healthcare systems, and government resources is critical.

Key words: case management, disease management, patient navigation, sickle cell disease

Sickle cell disease (SCD) affects approximately 100,000, predominantly Black, African American, and/or Hispanic individuals living in the United States. It is a genetic disorder that alters the shape and function of hemoglobin and results in a severely shortened lifespan (life expectancy of 52.6 compared to 76.4 years for the general population) (Jiang et al., 2014; Xu et al., 2022). Individuals frequently experience severe acute and chronic pain, in addition to a range of complications such as stroke, sepsis, pulmonary and renal dysfunction. The complexity of SCD requires engagement from multiple specialties, including hematology, emergency and hospital medicine, among others (Crego et al., 2020). Goal-directed care for specialties includes preventative strategies, treatment monitoring, and changes in disease and symptom-modifying therapies

when needed. In a 12-month sample of 2,045 individuals living with SCD in North Carolina, there were 8,827 out-patient visits to non-hematology specialty care (e.g., pulmonology, nephrology, ophthalmology), 2,792 hematology visits, and 6,251 primary care visits (Crego et al., 2020). In addition to out-patient care, SCD is associated with a very high rates of emergency department (ED) visits, hospitalizations, and readmissions within 30 days, ultimately resulting in high medical costs (Attell et al., 2023;

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Cline et al., 2018; Crego et al., 2020; Jiang et al., 2014; Kidwell et al., 2021; Paulukonis et al., 2017; Peterson et al., 2020). Navigating healthcare systems to meet these needs is incredibly complex and missed appointments are common. Preventative care, while complex to navigate, can contribute to achieving optimal patient outcomes and quality of life (QoL).

In addition to the frequent medical complications of SCD, social determinants of health (SDOH) play a critical role in patients' overall health and well-being. SDOH factors prominent among individuals living with SCD include difficulty accessing healthcare, economic instability, low educational attainment (often due to disease severity experienced as a child or adult), stigma, and discrimination (Khan et al., 2023). A recent report representing 66% of mothers of newborns with SCD within 11 U.S. states were living in counties classified as moderate or high levels of social vulnerability (Kayle et al., 2024). Approximately 39% of patients in a national implementation study lived in what is considered a distressed or at-risk community using the distressed community index (Mendez et al., 2024). Furthermore, access to SCD specialty care is limited as many individuals live far distances from an SCD center and have inadequate access to transportation making it difficult to keep medical appointments (S. K. Smith et al., 2017). Often they will wait for family or friends to take them to the ED when experiencing a vaso-occlusive episode, or other emergent complaint requiring ED treatment versus emergency medical services evaluation and transport to the nearest acute healthcare facility. Other barriers include being uninsured or underinsured, unable to obtain prescriptions due to a high co-pay, as well as other barriers related to pharmacy including transportation or inability to obtain consistent prescriptions for opiates and other essential medications (S. K. Smith et al., 2017). In addition to the multitude of SDOH factors that are barriers to obtaining healthcare and the large number of medical complications, the prevalence of anxiety

and depression is as high as 30% (S. K. Smith et al., 2017). The need for ongoing nursing engagement and an expert care navigator is clear. Nurses can screen for and identify specific barriers making it difficult to keep monthly appointments for transfusions or prescription refills, navigating multiple specialty appointments, difficulty adhering to or filling medications, presence of anxiety or depression, and a number of other challenges. Nurses are broadly trained to perform the role of a nurse navigator.

While the role of an SCD nurse navigator has not been well described, Table 1 summarizes exemplary nurse navigation services in other diseases or medical conditions and the impact on associated health outcomes. Implementation of the nurse navigator role in cancer is widespread and been associated with increased patient satisfaction with care, social functioning, QoL, and reducing barriers to care (Loiselle et al., 2020). The nurse navigator role became prominent when care coordination was featured as a key strategy for health care reform in the Affordable Care Act and has also been used for the following specialties: cardiovascular, orthopedics, inflammatory bowel disease, prisoner health, trauma, and orofacial cleft patients (Institute of Medicine, 2014, Aug 27). Yet, the description of nurse navigator roles in SCD is somewhat limited and any implementation is likely highly variable. In a single SCD center implementation of a navigator role, non-disease-specific hospital case managers, bedside nurses, and other SCD champions provided disease-specific discharge education and scheduled follow-up appointments after a hospital admission (Edge, 2022). These interventions were associated with a reduction in hospital re-admissions and future ED visits and known to be core components supporting favorable health outcomes for other patient populations. Due to the complexity of medical, social and behavioral health needs among individuals with SCD, the authors describe a practice model for nurse navigation to improve the quality of whole-person healthcare delivery aimed to improve the lives of individuals living with SCD.

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Brief review of an SCD-specific navigation model

Overview and evaluation of existing models

The model leverages the strengths of existing healthcare and community nurse navigation models and the importance of identifying and coordinating all resources needed by the patient to optimize their health and wellbeing; resources at an individual system will vary. While each model may vary contextually and/or culturally, organizations implementing the nurse navigator role should evaluate all available

TABLE 1**Exemplars of Nurse Navigator Interventions and Associated Outcomes**

Nurse Navigator Interventions	Method/Intervention	Outcomes
Cancer		
Nurse navigators (NNs) provided support in 4 domains: assessing patient needs, delivering education, offering emotional support, and coordinating care (Loiselle et al., 2020)	Surveys compared outcomes for patients who worked with an NN (n = 2,858) compared to those who did not (n = 855)	Outcomes cancer care experiences were higher in all 6 domains, including emotional support, coordination of care, respect for patient preferences, physical comfort, information, communication and education, and access to care, and for all 4 main nursing functions (assessment, education, support, coordination)
NNs facilitated molecular testing and coordinated treatment planning. NNs ensured timely testing for ovarian cancer patients (Rives et al., 2023)	Pre-post evaluation of NN implementation	Higher rate of molecular tumor testing for ovarian cancer (35% pre-implementation vs. 77% with NN)
	Pre-implementation: n = 34 Post-implementation: n = 44	More timely diagnosis and treatment planning (145 days pre-implementation vs. 43 days with NN)
NNs provided education and support from diagnosis through survivorship, as well as navigation of the healthcare system (McMullen, 2013)	Literature review reporting 13 studies of nurse navigation with various methods	NNs led to increased patient satisfaction, timeliness of diagnostic procedures and treatment, lower patient distress, and improved understanding of treatment plans
NNs coordinated diagnostics and multidisciplinary consultations. They expedited procedures and facilitated weekly tumor boards (Kunos et al., 2015)	Pre-post NN implementation	Reduced time from suspicion of lung cancer to treatment
	Retrospective review of 460 patients with lung cancer	Pre-NN implementation: 64 days Post NN implementation: 45 days
NNs managed intake and coordination and schedule appointments (Goldstein et al., 2014)	Process improvement over 18 months	Time from NN call to appointment with breast service line decreased from 14–21 to 7 days
Diabetes		
The NN provided tailored education sessions, self-care reminders, and ongoing follow-up through telehealth and in-person visits (Foppa et al., 2023)	Intervention pre-post design	Pre-post improvements:
	N = 152 adults with Type 1 DM	Adequate glycemic control (19% pre-intervention vs. 35% with NN intervention)
	NN conducted 812 teleconsultations and 158 face-to-face consults	Improved adherence to self-care practices (34% vs. 87%) Increased diabetes knowledge score (9.5 vs. 12.4)
Orthopedics		
The NN (clinical nurse specialist-patient navigator) provided care coordination, support, and helped patients navigate the healthcare system (Sawhney et al., 2021)	Prospective descriptive study of 226 hip or knee arthroplasty surgery patients	Intervention led to shorter hospital length of stay, majority of patients discharged home, low readmission, and increased patient satisfaction
The NN (clinical nurse specialist-patient navigator) provided physical, emotional, and informational support, and coordinated care through preoperative, inpatient, and postoperative phases (Teng et al., 2021)	Qualitative descriptive design to explore patient experiences	Patients described their experiences with the clinical nurse specialist-patient navigator as positive, feelings of reassurance, comfort, and security and improved care coordination
	Total hip (n = 4) or knee replacement (n = 11) Had a minimum of 1 contact with NN	
NNs provided preoperative education sessions covering surgical procedures, postoperative expectations, and rehabilitation plans (Turcotte et al., 2021)	Retrospective cohort study of 177 patients with lumbar fusion	Reduced length of hospital stay (2.1 days vs. 2.6 days)
	Comparison groups: those that attended the education course (n = 104) with those that did not (n = 73)	Reduction in cost
Inflammatory bowel disease (IBD)		
The NN was involved in coordinating appointments, educating patients, enrollment in clinical trials, and supporting transitions from pediatric to adult care (Maheshwari et al., 2021)	Pre-post design	Decreased clinic no-show rates from 16 to 8/month
	Retrospective chart review, 1 year prior and after hiring of NN to the clinic	97% of patients were satisfied with the NN and 94% were satisfied with the education they provide
	Pre—570 adult patients	Higher enrollment in IBD registry and biorepository (83%–90%)

(Continued)

TABLE 1 (Continued)

Nurse Navigator Interventions	Method/Intervention	Outcomes
Prisoner health		
The NN prisoner implemented a bundle of capacity-building initiatives, focused on care coordination, reducing ED visits, and improving care processes for prisoners (Collett et al., 2022)	Retrospective time series analysis to evaluate presentations to emergency departments (ED) 12 months pre and 12 months post-intervention	33% to 3% reduction in yearly ED presentations
Trauma		
The trauma NN provided care coordination, education on diagnoses and treatment plans, psychosocial support, and discharge planning (Lee, 2023)	Described role development	Increased patient satisfaction
	Reported subjective patient experiences	Help with psychosocial support, and better coordination of care
	Calculated financial impact of 329 avoidable hospital days averted	Potential savings of avoidable hospital days averted = \$1,314,955
Orofacial cleft palate		
The NN assisted with scheduling, feeding counseling, nonalveolar molding, and perioperative concerns (Wagner et al., 2022)	Retrospective chart audit comparing outcomes before and after implementation of a cleft nurse navigator.	Prenatal consults increased from 15% to 31%
		Time to initial appointment decreased from 20 to 16 days
		Presence of feeding difficulties decreased from 50%–35%
	Time frame: 2009–2019	Disparities in feeding difficulties between white and black children decreased from 52% to 36%
	Patients: cleft lip (CL) or palate (CP)	Hospital length of stay: decreased from 31 to 17 days
	Prior to NN: n = 454 Post NN: n = 285	Pre NN cohort: non-white, publicly insured patients experienced delays in first appointment as well as time to surgery. Post NN cohort: no differences in these outcomes

resources, including health system (inpatient and outpatient), community-based organizations (CBO), and government supported to aim toward ensuring the core components are available and the navigator is prepared to work with all resources (Hsu et al., 2016). Navigation models have employed various structures for leadership and implementation. The navigator role is most often championed by one individual. A variety of disciplines have been used to fulfill a navigator role, depending on the patient population and needs, including nurses, nurse practitioners, clinical nurse specialists, social workers, community

health workers, peer educators, and counselors (W. R. Smith et al., 2022; Sisler et al., 2024). Although the engagement and contributions of other disciplines and interdisciplinary collaboration are required to promote whole person health for optimal SCD care and outcomes, the SCD-informed model leverages the strong training and expertise of nurses. Basic level of training for nurses includes biomedical and psychosocial expertise, including care coordination, community health and wellness, and ethics. Furthermore, the implementation of the American Association of Colleges of Nursing's new competency domains and concepts for prelicensure nursing curriculum (e.g., nursing practice knowledge, person-centered care, population health, quality and safety, interprofessional partnerships, systems-based practice, communication, and SDOH, among others), will prepare nurses to be even more equipped to serve as effective patient navigators (American Association of Colleges of Nursing, 2021).

Framework guiding intervention development. The SCD-informed model for nurse navigation

Figure 1 describes a modified conceptual model to guide development of the SCD Nursing Navigator

The model integrates the core competencies of a nurse navigator—care coordination, education/support, communication, and expertise in SCD care—and how these competencies interact with key domains for behavior change at the patient level to optimize health outcomes.

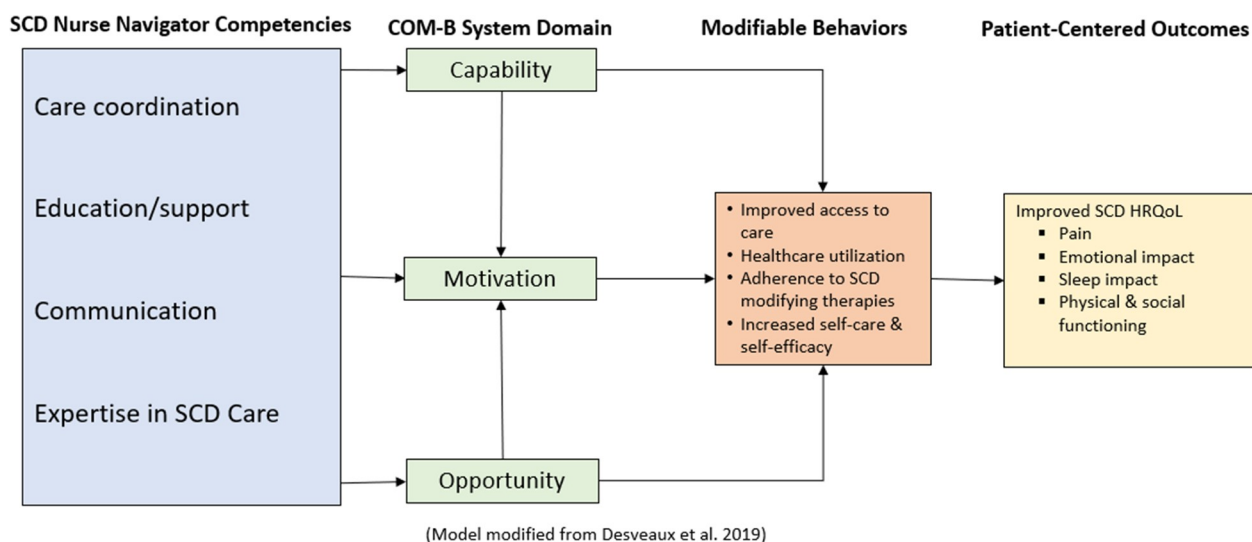


FIGURE 1
SCD-Informed Conceptual Model for Nurse-Led Navigation.

(SCD-NN) role. This model was adapted from the Composite Program Theory Underlying Patient Navigator Interventions (Desveaux et al., 2019) and Oncology Nurse Navigator Competencies (Oncology Nursing Society [ONS], 2017). The model integrates the core competencies of a nurse navigator—care coordination, education/support, communication, and expertise in SCD care—and how these competencies interact with key domains for behavior change at the patient level to optimize health outcomes.

Behavior change is an important focus to enable patients to manage their health and the SCD-NN uses the Capability-Motivation-Opportunity-Behavior (COM-B), a model that outlines three essential conditions that influence an individual's behavior (Michie et al., 2011). Patient assessments guided by the domains of the COM-B system will increase the likelihood that a patient would successfully follow through on actions needed.

1. *Capability* is “a person's psychological and physical capacity to engage in the activity concerned, including having the necessary knowledge and skills (Michie et al., 2011).” An example could include the ability to get to appointments or adhere to medications. They may have severe pain and be unable to drive. They may also have neurocognitive deficits from stroke and limited executive functioning to keep appointments or understand a complex medication regimen.
2. *Motivation* is the brain processes that energize and direct behaviors, including goals, decision-making,

habits, and emotional responses. Individuals with depression, for example, may lack the motivation to engage in care.

3. *Opportunity* is the external factors to the person, such as environmental influences, that prompt a certain behavior. Individuals living in areas far from their health care may lack the transportation to get to medical appointments or other resources.

An SCD-NN assessment will help guide selection of interventions that can lead to desired modifiable behaviors. For example, an SCD-NN can collaboratively develop an individualized care plan and goals with an individual with SCD, and can enhance their capability and motivation while identifying and addressing external forces (opportunity [e.g., SDOHs such as transportation, social support]) that can affect the desired patient-centered health outcomes, such as improved SCD health-related quality of life. Examples of individualized plans may include how to manage pain, asthma symptoms, or medication adherence. The SCD-NN would incorporate this assessment when developing the plan with the individual with SCD.

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TABLE 2**SCD Nurse Navigator Competencies With Core and Adaptable Model Components**

SCD Nurse Navigator Competency ^a	Description	Example Core and Adaptable Intervention Components	Associated Outcomes
Care coordination	Serves as a point of contact and facilitates access to healthcare services	Ex: Perform targeted screening and interventions (i.e., referrals) to assist patients with connection to primary care providers, specialists, SCD centers, and other health care resources - Core: Initial screening and referral, reassessments, service logs - Adaptable: Time intervals for reassessment and check in	Increased access to and coordination of care Decrease in the number of missed clinic or specialty provider appointments Decrease in ED visits and/or hospitalizations Increased adherence to disease-modifying therapies (e.g., blood transfusions or hydroxyurea)
Education/support	Provides patient-centered education and self-management support to patients and care partners	Ex: Assist the patient with self-management strategies and identifying barriers by addressing the total individual, inclusive of medical, psychosocial, behavioral, social, and spiritual needs - Core: Initial education and care plan - Adaptable: Intervals for additional education and assessment of care plan (e.g., weekly, bi-weekly, monthly, or quarterly)	Improved self-care Increased self-efficacy Improved SCD HRQoL (e.g., pain, sleep, emotional impact, physical and social functioning)
Communication	Demonstrates effective interpersonal communication to enable exchange of ideas and information with patients, care partners, and healthcare team	Ex: Involve the patient and their support systems (care partner, family, healthcare team, etc.) in the decision-making and goal-setting processes - Core: Initial screening meeting - Adaptable: Intervals for additional communication (e.g., weekly, bi-weekly, monthly, or quarterly)	Increased access to and coordination of care Decrease in the number of missed clinic or specialty visits Decrease in the number of ED visits and/or hospitalizations Increased adherence to disease-modifying therapies such as transfusions or hydroxyurea
Expert in SCD care	Knowledgeable and skilled in SCD care and proficient in the NN role	Use the information in the NHLBI and ASH SCD guidelines when supporting and educating patients & their families - Core: Training and education provided by study team at hire and quarterly updates. - Adaptable: Not applicable	Ability of the SCD-NN to provide SCD-specific education to patients

Abbreviations: ASH, American Society of Hematology; ED, emergency department; HRQoL, health-related quality of life; NHLBI, National Heart, Lung, & Blood Institute; NN, nurse navigator; SCD, sickle cell disease.

^aThese competencies were adapted from the Oncology Nurse Navigator Competencies (Oncology Nursing Society [ONS], 2017).

With the aim of addressing behaviors that can improve health outcomes, SCD-NN's should focus their assessments to ensure interventions include care coordination, education/support, and communication specific to the goals, capabilities, motivation, and opportunities for the patient with SCD. For example, an individual patient may be limited in the capacity and opportunity to find transportation to a medical appointment. In collaboration with community, government, or health system resources, the SCD-NN can then identify the transportation

resource and teach the patient how to access and arrange for transportation in order to increase the likelihood of keeping the appointment. Ultimately this will lead to improved patient outcomes. Table 2 describes each SCD-NN competency and provides examples of SCD core and adaptable components of the SCD-NN model. Core model components are the essential interventions that must be included in the role of the SCD-NN. Adaptable model components are based upon the initial assessment and needs of each individual patient.

Core components of this model of care include the intake assessment, comprehensive care plan template, reassessment form, referral pathways, a self-care and education toolkit, and a service tracking log.

- The intake and reassessment forms serve as the basis for assessing and screening for risks and care needs for each individual.
- The comprehensive care plan should be completed by the SCD-NN in partnership with the patient, their care partners, and other members of the healthcare team. The care plan should include mutually developed goals and action steps determined by the needs identified in the intake assessment and reassessments. For example, goals may be related to individual attendance issues to medical appointments, self-management needs including pain, fatigue, stress management, impaired sleep, asthma, adherence to treatments including medications and transfusion therapy, behavioral health needs including anxiety and depression, and/or financial or social needs including the need for insurance and other assistance in obtaining prescriptions.
- Referral pathways should be established, including referrals to resources such as medical care, housing, financial assistance programs, health insurance, food assistance, transportation, childcare/family services, or support groups. Resources may include those from the CBO, state, or health system partners and will vary depending on each institution and state.
- A self-care and education toolkit should be developed with resources to support self-care and educational needs of the participants. Examples of resources in the toolkit include a participant

worksheet to develop a plan for self-managing pain and other self-soothing actions for regulating emotions, as well as information on SCD and associated treatments. Existing resources, such as “Living Well with Sickle Cell Disease Self-Care Toolkit,” and other patient-facing resources developed by the Centers for Disease Control & Prevention should be used (Centers for Disease Control and Prevention, 2020).

The frequency of interactions between the SCD-NN and participant should be adaptable and established based on individual-level needs. Interactions can be via phone, text, videoconferencing, or in person, and can occur on a weekly, monthly, and quarterly basis. Education and support sessions can be individual or small group. At a minimum, the SCD-NN should meet with patients every 90 days, but no more than once a week. Previous work has shown there are varying intensity of interventions based on individual needs and engagement (Rushton et al., 2019). For example, patients with high needs for referral and intervention may need weekly interactions, whereas someone with moderate levels of needs may only require interactions with the SCD-NN once per month. Individuals with low levels of needs may only require interactions once a quarter, or every 90 days. Individuals with a high rate of missed clinic, or a large number of ED visits or hospitalizations will require more frequent visits and increased communication with the SCD healthcare team. Figure 2 provides an overview of the SCD-NN model of care.

Implementation of the role

The SCD team should assess each individual who is being considered for the SCD-NN role to determine

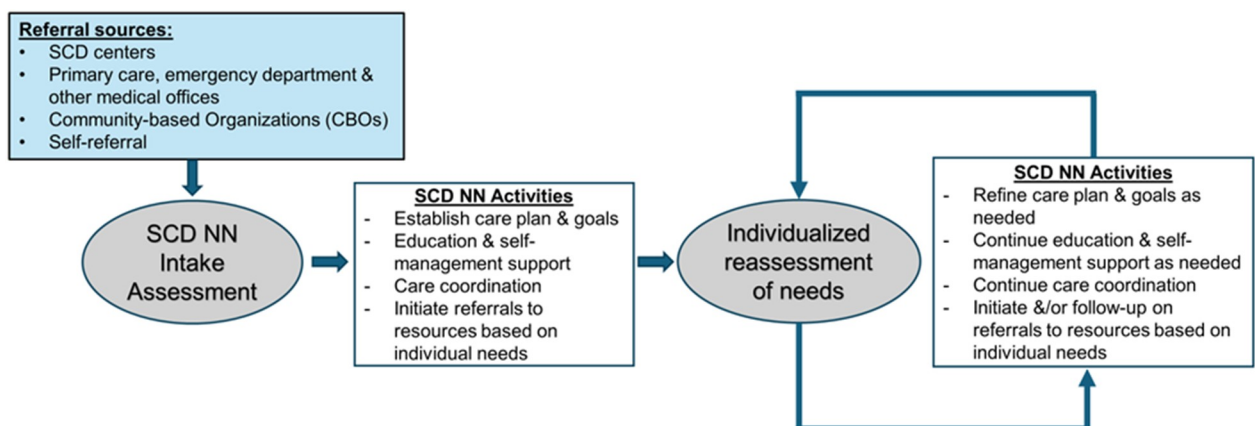


FIGURE 2
Sickle Cell Disease Nurse Navigator Model of Care.

their knowledge of SCD and experience in care coordination, education, and communication skills with healthcare professionals, government agencies, patients, families, and CBO. Depending on the training and background of the nurse, additional training may be needed that should be tailored to the expertise of the individual. At a minimum, the SCD-NN must be a licensed registered nurse or advanced practice nurse and demonstrate proficiency in all SCD-NN competencies (Table 2). To enhance the SCD-NN specialty knowledge, specific training is available through the Sickle Cell Disease Association of Illinois (2024), a weeklong SCD bootcamp is offered for nurses through the International Association of Sickle Cell Nurses and Professional Associates (International Association of Sickle Cell Nurses and Professional Associates [IASCNAPA], 2024) and a several day course to train SCD health navigators (SSCAPE, Sickle Cell Care Coordination for Achieving Patient Empowerment Conference) is offered yearly at Virginia Commonwealth University (VCU Health CE, 2022).

Importance to case management practice—future directions and need for research

Case managers are required to understand and manage the care of individuals with complex healthcare needs. The nurse navigator model complements traditional case management roles and responsibilities and has the potential to advance whole person health in people living with SCD. For example, case managers primarily focus on coordinating care and managing resources to ensure cost-effective treatments and smooth care transitions, depending on the setting (e.g., acute care/hospital, insurance company). While some case managers may take on a navigator-like role, their primary function is often broader and more system-driven, whereas a nurse navigator's role is inherently patient-centered. Additionally, case manager positions can be held by professionals from various disciplines, such as social work or nursing, whereas nurse navigator roles are exclusively filled by licensed registered nurses or advanced practice nurses, ensuring a clinical foundation for patient education and advocacy. These specially trained nurses in the biomedical and psychosocial needs in SCD can serve as a point of contact for the patient, helping patients navigate the complex healthcare system, identify and access resources and services based on the specific needs of the patient, and coordinate care between different healthcare providers, facilities and community and government resources. Nurse navigators can also provide education and support to patients and families to help them understand and better self-manage their condition and treatment. While some SCD clinical programs may employ a nurse in their SCD

program, the implementation and effectiveness of a specially trained SCD nurse navigator to help patients navigate and manage their SCD has not been systematically tested or evaluations have not been published. With the biomedical complexities and psychosocial contributors to SCD, a nurse navigator specially trained in SCD will help assist people to achieve optimal whole person health.

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