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Implementation of an Emergency Department Screening and Care Management Referral Process for Patients With Sickle Cell Disease

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ABSTRACT

Purpose of Study: The purpose of the project was to describe the implementation and evaluation of a care management referral program from emergency departments (EDs) to care management services for patients with sickle cell disease (SCD).

Primary Practice Setting: Patients were referred to Community Care of North Carolina (CCNC), which is a private–public collaboration providing care management services and served as a referral hub for the program. Patients received follow-up from either CCNC or the North Carolina Sickle Cell Syndrome Program.

Methodology and Sample: A multidisciplinary, multiorganizational group streamlined the referral process for patients with SCD who have ongoing care needs by linking patients from the ED to care management services. The article presents a review of program implementation and evaluation over a 3½-year period. The target population were patients who had a diagnosis of SCD and presented to the ED for treatment. Emergency department staff used a modified version of the Emergency Department Sickle Cell Needs Assessment of Needs and Strengths tool to screen for social behavioral health needs in areas such as emotional, financial, pain management, and resources. All forms were faxed to a central number at CCNC for follow-up care management services. Community Care of North Carolina then linked the patient with the appropriate agency and staff for follow-up.

Results: More than 900 referrals were received in 3½ years. Pain was the most common reason for referral. An increase in care management intensity was observed over time. All levels of care management intensity saw an increase in the number of patients.

Implications for Case Management: Care management occurred across organizations after careful planning among stakeholders. The interagency cooperation permitted the development of a streamlined process. In particular, the creation of a single point for referral was an important component to allow for population-level monitoring and ease of making referrals. Patients with ongoing care needs were identified and there was an increase in the intensity of outpatient care management services delivered.

Key words: *care management, case management, emergency department utilization, sickle cell disease, transitions of care*

Patients with sickle cell disease (SCD) face many challenges with disease management. Sickle cell disease is the result of a genetic disease leading to the production of altered hemoglobin and anemia (Hebbell & Vercellotti, 2018; Steinberg, 2016; Ware, de Montalembert, Tshilolo, & Abboud, 2017). In 2010, there were an estimated 72,000–98,000 patients with SCD when adjusted for early mortality

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(Hassell, 2010). In the United States in 2004, patients with SCD experienced 83,149 hospitalizations at a cost of $488 million (Steiner & Miller, 2006). Sickle cell disease has also been associated with an estimated 232,381 emergency department (ED) visits with $356 million in charges in 2006 as well as total acute care charges of $2.4 billion (Lanzkron, Carroll, & Haywood, 2010). In North Carolina, patients with SCD exceed 4,500 people (North Carolina Sickle Cell Program, 2018) and with those in the 18- to 35-year-old range having an average of six ED visits per year (North Carolina Sickle Cell Syndrome Program, n.d.).

Patients with SCD are at risk for many complications including physiological and psychosocial. Physical complications include infection (Steinberg, 2016; Ware et al., 2017) pain, anemia, pulmonary disease, organ damage, and vaso-occlusive crisis as well as others (Hebbell & Vercellotti, 2018; Steinberg, 2016; Ware et al., 2017). Psychosocial challenges consist of anxiety, depression, transportation, inability to obtain/attend appointments, and difficulty obtaining/paying for prescriptions (Smith, Johnston, Rutherford, Hollowell, & Tanabe, 2017).

Case management (CM) is a multiple-step process that can facilitate addressing the needs of individuals with chronic conditions such as those faced by patients with SCD. The first step is screening patients for CM services (Case Management Society of America, 2016; Commission for Case Management Certification, 2018). Screening identifiers such as frequent utilization, cost, lack of support, age, diagnosis, socioeconomic indicators, and funding concerns can be triggers for referral (Clark, 2014; Powell & Tahan, 2010). Specifically, high health care utilizers can benefit from CM through patient assignment to proper level of intensity and coordination (Hudon et al., 2017). Case management also utilizes a holistic approach to address determinants of health, navigate the health care system, facilitate communication, link patients with SCD with various resources (Case Management Society of America, 2016; Clark, 2014), and overcome the barriers they face through various approaches (Brennan-Cook, Bonnabeau, Aponte, Augustin, & Tanabe, 2018). Overall, CM can improve a variety of clinical and utilization outcomes (Joo & Huber, 2014; Kumar & Klein, 2013).

Care management and CM follow similar processes but differ in setting and duration of interventions (Ahmed, 2016). Care management generally occurs in the community and with a longer duration than CM (Ahmed, 2016). Community Care of North Carolina (CCNC) uses care management to improve outcomes for chronic care patients (McCarthy & Mueller, 2009) along with Case Management Society of America Guidelines and the Chronic Care Model guide care management for CCNC's populations (Community Care of North Carolina, n.d.).

With the recognition that many patients treated in EDs with SCD experience a wide range of physiological, social, and behavioral health needs, the team developed a program to screen SCD patients in the ED for specific needs and refer them for care management services. This article reports our program development and implementation process, as well as results of the screening and referral program including the number of referrals made, patient characteristics, reasons for referral, ED participation, and change in outpatient care management status (CCNC referrals only) over a 3½-year period.

METHODS

Setting/Sample

The primary setting, CCNC, is a collaboration between the state of North Carolina and a private organization with a provider network throughout North Carolina (McCarthy & Mueller, 2009). Community Care of North Carolina provides care coordination and population health management (Community Care of North Carolina, n.d.). It serves as a medical home for patients with North Carolina Medicaid and State Children Health Insurance Program. Its mission is to improve the health of North Carolinians through strengthening community-based services (Community Care of North Carolina, 2018). In addition, three EDs participated in the program. The first hospital began making referrals at the start of the project. Two additional hospitals began referrals within the following 7 months. Several other hospitals sent referrals in subsequent months, although they were never formally recruited to participate in the project. All patients with SCD presenting to a participating EDs were eligible for screening.

Program Development and Implementation Process

The Duke University Institutional Review Board determined that the project was exempt. A multistakeholder group convened in 2013 with a mission to create a system of communication and collaboration to aid in the improvement of care for patients with SCD across the life span. The team worked with two referral agencies and three EDs.

Community Care North Carolina

The CCNC group included the following members: leadership, pharmacy, care management members, primary care providers, hematologists from academic centers, pediatricians, and behavioral health specialists. Community Care of North Carolina provides referral for all persons with Medicaid in North Carolina. Community Care of North Carolina care managers collaborate with the SCD team (CCNC health coaches, North Carolina Sickle Cell Syndrome Program [NCSCSP] educator counselors, providers, pharmacists, registered dieticians, and licensed social workers) to provide education and genetic counseling to patients and families about SCD types, evidence-based treatment options, SCD triggers, red flags, and pain management. Care managers coordinate care and advocate for patient/family needs with providers regarding medications, provide education, evaluate social determinants, and address barriers that impact care. In addition, facilitating the transition of pediatric patients to adult care and providing other support or tools for patients and providers are additional goals of the care managers and educator counselors.

The North Carolina Sickle Cell Syndrome Program

The NCSCSP was also a critical part of the project. In 1973, the NCSCSP, under the Division of Public Health within the North Carolina Department of Health and Human Services, was established with a goal of improving the health of individuals with SCD. The program targets all North Carolinians with SCD with the goal of improving their health using multiple, systematic approaches. The NCSCSP employs sickle cell educator counselors and funds community-based agencies, who also employ direct service sickle cell staff including educator counselors. The educator counselors conduct follow-up with parents of newborns screened and other patients with SCD throughout the life span, regardless of the presence or type of insurance. The NCSCSP educator counselors are also provided with access to the CCNC care management information system, which creates opportunities for improved collaboration. Both care managers and educator counselors work to ensure that patients have contact information for their local CCNC network, the NCSCSP, and local support groups as well as the Comprehensive Sickle Cell Medical Center for their area. The NCSCSP utilizes a network of educators and counselors to provide quality health care to patients with SCD (North Carolina Department of Health and Human Services, 2018). For the general public, the program provides education and genetic counseling for the general public.

Nine sickle cell educator counselors are employed with the Division of Public Health and are responsible for providing care coordination, CM, genetic counseling, and education to persons residing in 81 North Carolina counties. Two community-based sickle cell organizations employ sickle cell educator counselors and community health workers, who provide genetic counseling, education, and care coordination services to persons residing in the remaining 19 North Carolina counties. Together, the two sickle cell organizations and Division of Public Health staff cover all 100 North Carolina counties.

Professional Emergency Provider Associations

Representatives from the North Carolina College of Emergency Physicians and the North Carolina Emergency Nurse Association participated in the work group, collaborated with their state boards, and advised the group on how to best implement the screening and referral process in EDs.

Screening Tool

The primary objective of the group was to develop a system to screen persons with SCD during an ED visit for social behavioral health needs at the time of ED discharge to home and refer patients for follow-up. To this end, the group modified a decision support tool for ED providers. The original tool, the Emergency Department Sickle Cell Assessment of Needs and Strength, is a research-based tool with established reliability and validity (Tanabe et al., 2010; Tanabe et al., 2013). The group determined that the tool needed slight modification to include additional social needs. The revised tool (ED SCD Care Management Referral Form) is concise, one-page tool, and identifies a number of unmet social behavioral needs such as emotional, financial including insurance and bills, medical including needing a primary care provider, prescriptions, relational issues/family support system, transportation, pain management, and other. Expert group consensus was used to agree on the final questions for the tool. The tool is available at: https://sickleaware.nursing.duke.edu/section-content/care-management-referral-care-management.

Referral Process

The team streamlined the referral process by providing one fax number for all referrals for patients with SCD treated in a North Carolina ED, regardless of insurance type or lack of insurance. The team trained ED physicians, nurses, social workers, or case managers in the three participating EDs on the use of the screening form and referral process. Once completed, the form was faxed to the CCNC call center, where staff determine whether the patient is referred to their local CCNC Care manager (Medicaid) or to an SCD educator/ counselor with the NCSCSP (all other insurance types or self-pay). The goal of each agency was to contact patients within 3 days.

Outcomes

Selected patient demographic characteristics, the total number of referrals made, number of referrals/patient and per ED, and reasons for the referrals were measured. Initially, a screening question for pain management was not included; this was added later after providers frequently included pain in the "other" category. Information on level of care management service intensity was also collected. Community Care of North Carolina care managers track the patient's use of care management services by categorizing the intensity of patient intervention and degree of patient engagement. The following categories were used to measure care management status:

- high (engage patients weekly or four times per month),
- medium (engagement at least one per month), and
- low (engagement at least once every 90 days).
- A patient could also be categorized as inactive if he or she had never used care management services, or pending if the care manager is attempting to contact the patient to offer services.

The NCSCSP does not track intensity of services provided; thus, this was not included in the analysis.

Analysis

All referral forms received by CCNC between November 1, 2014, and April 30, 2018, were included in the analysis. Descriptive statistics were used to determine the frequency of all variables.

RESULTS

A screening and referral process, which identifies a multitude of care needs of persons with SCD, was successfully implemented in multiple EDs in North Carolina. Between November and April 2018, a total of 952 referrals were made by North Carolina EDs, representing a total of 365 unique patients (mean [SD]) with the age of 30 (10) years. The mean number of referrals/patient was 2.6 (range: 1–21). A small number of patients resided outside North Carolina (*N* = 14); 80% of the referrals were Medicaid recipients. Community Care of North Carolina networks and the NCSCSP followed up with 63% and 37% of the referrals, respectively.

Figure 1 describes the referral pattern from the individuals EDs over time. The majority of referrals came from Hospital 1 (63%). Hospital 3 and Hospital 2 made 14% and 19% of referrals respectively. Of note, six additional EDs also made referrals contributing 3% of the total number of referrals. Five referrals did not indicate the referring hospital. There was a decreasing trend noted for referrals after time period 4.

Patients could have been referred more than once during the evaluation period. Figure 2 reports

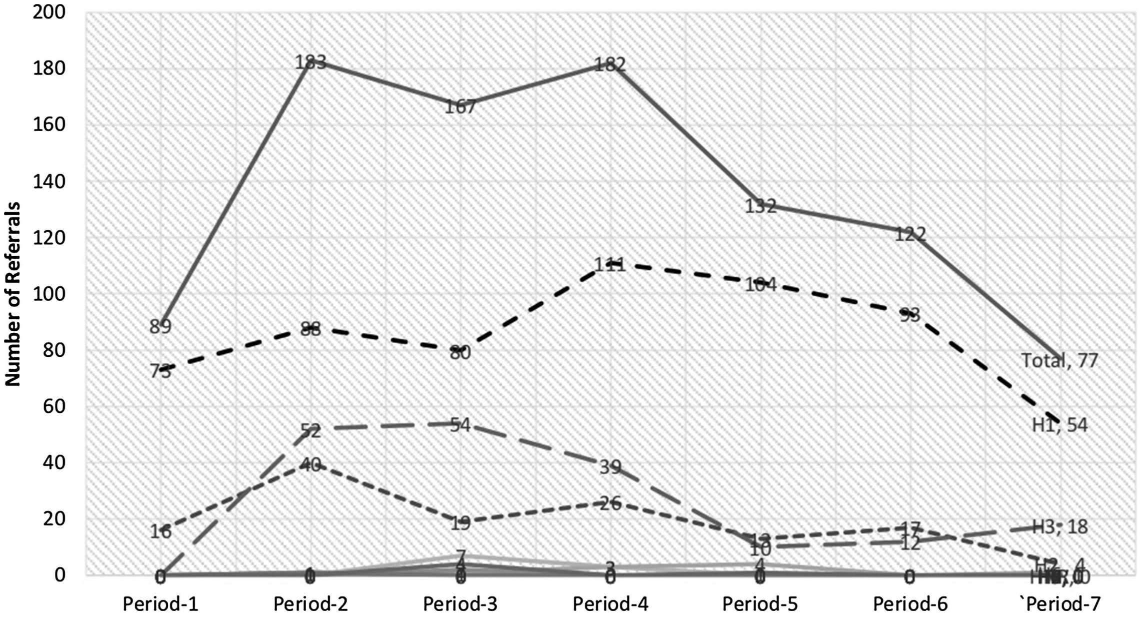

FIGURE 1
Number of referrals per hospital emergency departments per 6-month period. Period 1 began in November 2014. Each period represents a 6-month time interval. Period 7 ended in April 2018. H = Hospital and HNR = Hospital not reported.

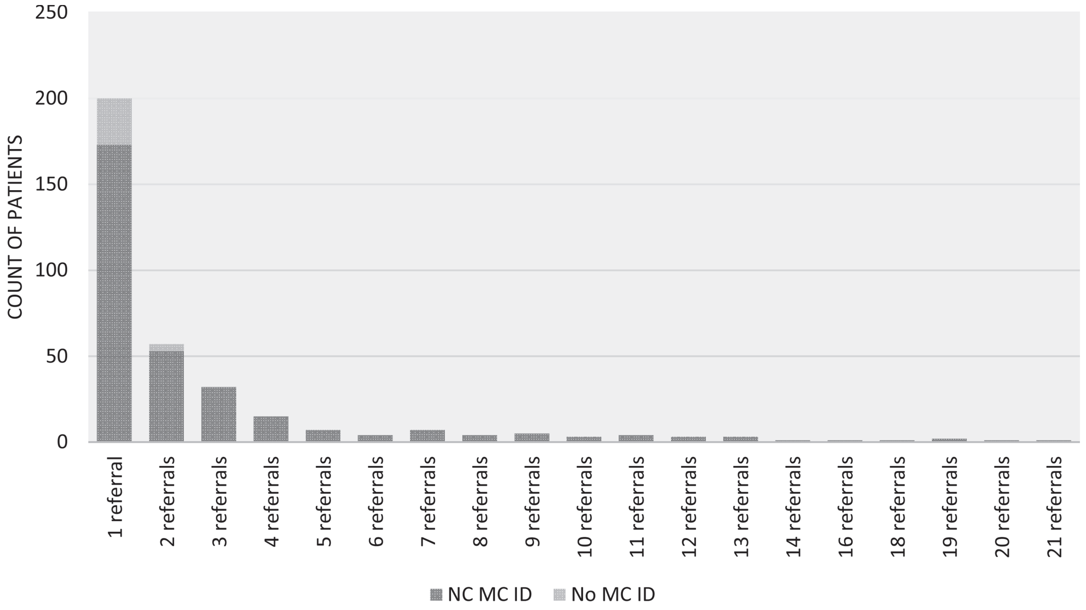

FIGURE 2

Number of referrals per patient. The figure describes the number of referrals each patient from North Carolina had from November 2014 to April 2018. NC MD ID = North Carolina Medicaid Identification Number.

referrals to CCNC for patients with North Carolina Medicaid; the NCSCSP was not able to track the number of referrals per individual patient. The majority of the patients had one referral during program ($N = 173$). Sixty patients had two referrals, followed by 32 patients with three referrals and 15 patients with four referrals. A few patients had a large number of referrals. The number of referrals per patient ranged from one to 21 referrals (see Figure 2).

There was a wide range of needs identified on the referral for care management (see Table 1). A total of 1,518 reasons were identified. The most common reason for a referral was pain management ($n = 543$, 36%).

There was a large shift in care management status from deferred, inactive, and light status to light and heavy status (see Figure 3), indicating an increase in the use of care management services for individual patients after the ED screening and referral intervention. In particular, the heavy care management status increased by 96 patients. There was also a drop in the number of patients in deferred status by 100.

DISCUSSION

Our multiagency team demonstrated the feasibility of developing and implementing a successful screening and referral program in EDs for patients with SCD. First, the team was able to modify a tool to screen for specific needs that identified important psychosocial needs and keep the tool short for use in a busy ED setting. Second, the program required strong collaboration among the agencies to plan and implement an integrated referral system with a single point of contact. Third, ED personnel were able to complete and fax the screening and referral forms. Emergency department providers were able to identify medical, social, and behavioral health needs for the individual patients who required additional follow-up. As a result

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TABLE 1

Reasons for Referrals per 6-Month Period[a]

	Period 1	Period 2	Period 3	Period 4	Period 5	Period 6	Period 7	
Pain management	36	71	83	111	93	97	52	543
Not reported	27	57	48	39	12	12	20	215
Medical (needs primary care provider)	20	31	31	45	31	17	10	185
Emotional	17	35	45	21	25	17	5	165
Financial (insurance, bills)	13	32	28	15	12	8	6	114
Prescription	13	22	29	16	19	9	6	114
Transportation	10	31	30	20	9	7	1	108
Relational issues/family support	8	17	27	9	8	3	2	74
Total	144	296	321	276	209	170	102	1518

[a] Period 1 began in November 2014. Each period represents a 6-month time interval. Period 7 ended in April 2018. The total number of referral types exceeds the 952 referrals as patients may have been referred for more than one category.

of this collaboration, a large number of patients were screened, referred, and received follow-up care using the process outlined previously.

There was variable participation among EDs as the largest number of patients were referred from a single health care system. This is likely related to ED characteristics such as turnover, orientation to the referral process, or sustainability efforts. Three EDs received formal training initially. Two of the original EDs with lower referral rates had attrition of the employees and there was often a delay in training subsequent employees, which contributed to fewer referrals over time. The presence of ongoing orientation to the process at the ED from Hospital 1 could explain their higher rates. There is a trend of increasing referrals until Period 4, followed by a decline at all EDs, which suggests challenges with sustainability. Participating EDs will need to consider plans to investigate ongoing education as well as staffing and sustainability factors. Feedback from the referral agencies to the EDs may be one strategy that could help improve sustainability. Implementing a system-based approach such as including the referral form as part of discharge instructions may also help improve sustainability.

This project was initially implemented primarily in three health care systems with some diffusion to other organizations, which was an interesting finding. The exact reason for the diffusion is unknown. The referral form is available on the

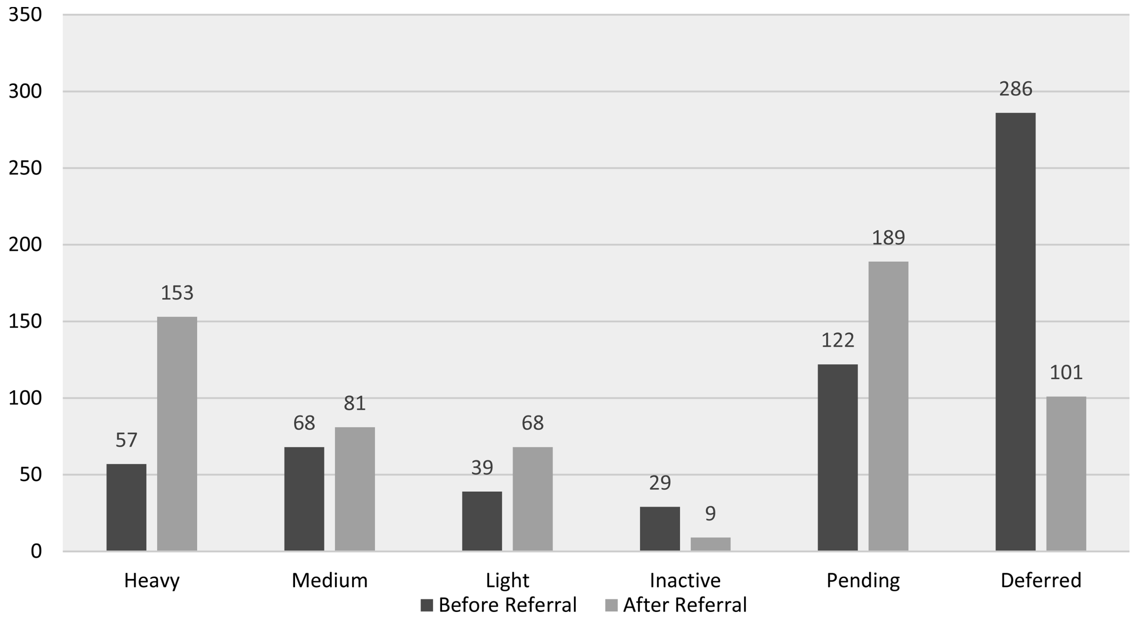

FIGURE 3

Number of patients/care management status before and after referral program. The figure describes case management status category before and after the referral.

The team found that the majority of patients had just a few referrals for CM after an ED visit but also noted that a small number of patients had the highest numbers of referrals. The data support the need for an increase in care management intensity, especially for patients with high ED use.

web (https://sickleemergency.duke.edu/file/sickle-cell-cm-referral-form.pdf). It is likely that other organizations located the form and chose to implement it. The team also speculates that providers or trainees from the original three EDs may have moved to the other EDs and brought the knowledge of the process with them. It is also plausible that patients with SCD asked for assistance based on prior assistance.

As a whole, patients with SCD tend to have high rates of acute care utilization (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Jiang, Barrett, & Sheng, 2006). The team found that the majority of patients had just a few referrals for CM after an ED visit but also noted that a small number of patients had the highest numbers of referrals. The data support the need for an increase in care management intensity, especially for patients with high ED use. Patients with ongoing needs for referral may have multiple care needs secondary to psychosocial circumstances or the impact of comorbidities requiring intervention. Alternatively, the patients with multiple referrals may not be ready for assistance or are unreachable but continue to be referred.

The largest number of referrals were for pain. This was not unexpected as acute and/or chronic pain is common in persons with SCD (Brandow & DeBaun, 2018; Gupta & Jahagirdar, 2018). Treatment for SCD pain can benefit from addressing psychosocial needs in addition to physical (Brandow & DeBaun, 2018). Many patients indicated a lack of resources such as finances and transportation, which may also contribute to pain episodes (inability to afford copays or difficulty picking up prescriptions due to transportation challenges). These needs can be addressed by care management.

As noted previously, there was a definite increase in intensity of CM services after implementation of the referral program. Care management services address needs; thus, it was anticipated that there would be an increase in CM intensity. What is interesting is that the intensity increased at all levels of active management. Patients with chronic illness may require activation of resources to address care needs such as connection with community and health system resources (Schulman-Green et al., 2012); as noted previously, these are functions of CM. It may also be that the patients have additional comorbidities, which increase their degree of difficulty in maintaining health. Understanding what combinations of referral reasons exist for patients with SCD could also provide additional guidance for future work.

LIMITATIONS/STRENGTHS

This program implementation took place in a single state with a single, statewide strong care management system, which may limit generalizability. The model could be adopted by states using hospital-based case management, community-based care management, and/or managed care organizations with CM resources. The referral form can also be implemented within an individual hospital using hospital-based care management services for follow-up. Finally, we do not know whether the increase in CM was associated with decreased ED visits, hospital visits, or other improvements in health outcomes or quality of life.

CONCLUSION

A multiagency team came together to address the needs of patients with SCD in North Carolina. A CM screening referral process was successfully implemented within three North Carolina EDs. The EDs identified a large number of patients with SCD within this evaluation period, who were referred for and received CM services to meet their health care needs. The centralized referral system provides an opportunity for surveillance of patients with SCD and their care management needs. Tracked over time, this will provide an ongoing opportunity to evaluate care processes and modify as needed to continue to optimize care for SCD patients.

Within the state of North Carolina, the plan is to focus on sustainability and expansion. Given the decreasing number of referrals, reeducation of the staff of the current EDs is the first step to address sustainability. The second component of this plan will be expanding the program across North Carolina with the goal of reaching all patients with SCD, who may require additional resources. Currently, our team is

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funded to disseminate the care management referral form to all EDs across North Carolina. The team will continue to explore other opportunities to improve sustainability and collaboration with the North Carolina EDs to meet patients with SCD needs.

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Debbie Murray, RN, CMAC, CHC, CPN, CNM, is the director of Population Health Outreach and Care Coordination Services at CCNC. Her team of health educators and health coaches works to make sure that all patients have the access to appropriate care and the resources needed to improve self-management of their health concerns.

Charles Talley, BS, is a health educator in Population Health Outreach and Care Coordination Services at CCNC. He maintains the sickle cell referral database and contacts patients following their visit to the ED to ensure that they have access to appropriate care and the resources needed to improve self-management of their health concerns.

Sandra Boyd, MA, is the NC Sickle Cell Syndrome Program supervisor. Her team of educator counselors provides counseling, care coordination, and education to individuals with sickle cell disease and their families throughout the life course. Sandra works with her team to ensure that patients with sickle cell disease who visit an emergency department are contacted within 3 days of receipt of a referral by a CCNC care manager. The program's goal is to ensure that each client has a plan of care, is connected with a primary care provider and hematologist, and is linked to resources necessary that help improve his or her quality of life.

Kern Eason, MBA, is the pediatric program manager at Community Care of North Carolina. He oversees CCNC Pediatric Program activities, particularly in coordination of CCNC's systems, practice, and patient-facing work on behalf of patients with sickle cell disease. Kern has specific skills in pediatric information technology and sees this as a key driver of quality in pediatric health care.

Marian Earls, MD, MTS, FAAP, is the director of Pediatric Programs and deputy chief medical officer for Community Care of North Carolina and has led the CCNC Sickle Cell Project since 2013. She is board-certified in both General and Developmental & Behavioral Pediatrics. She is a clinical professor of pediatrics for the University of North Carolina Medical School.

Paula Tanabe, PhD, MSN, MPH, RN, FAEN, FAAN, is a professor in the Schools of Nursing (SON) and Medicine at Duke University. Dr. Tanabe is the associate dean for Faculty Development and Data Science, SON. Her program of research is focused on improving systems of care, health outcomes, and quality of life for individuals with sickle cell disease.

Instructions:

- Read the article. The test for this CE activity can only be taken online at www.nursingcenter.com/ce/PCM. Tests can no longer be mailed or faxed.
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Disclosure Statement:

The authors and planners have disclosed that they have no financial relationship related to this article.

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