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Commentary on “Primary Care Providers’ Comfort Levels in Caring for Patients With Sickle Cell Disease”

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Perhaps no other disease entity has generated as much discussion as sickle cell disease (SCD) in terms of multidisciplinary management. During its long, illustrious history in modern medicine, disciplines such as hematology, pain management, palliative care, psychiatry, and addiction have played important roles in its management.¹ The role of primary care is essential, however, because SCD is truly a multisystem disease with many complications requiring both primary and specialty care. Primary care excels in coordinating care, triaging urgent care issues, and promoting health maintenance and longitudinal patient–provider relationships²; however, several key issues of sickle cell care are unique and require special attention, training, and certain levels of competences from primary care physicians. First, most sickle cell patients are young adolescents or young adults and have just been transitioned from pediatric care, and there is evidence to suggest that this transition is crucial because its poor execution can result in inferior outcomes.³ Second, hematological management of the disease—modifying drug hydroxyurea—and the evaluation of bone marrow transplantation eligibility are essential.^{2,4} Finally, given the synonymous nature of pain associated with SCD and the perceived high prevalence of addiction, pain management skills are becoming part of the routine management for sickle cell disease.⁵

Can primary care physicians coordinate and provide all of these elements of SCD care in collaboration with many other specialists? Do they have the necessary skills? In this issue of the *Southern Medical Journal*, Whiteman and colleagues describe a survey study of primary care providers’ comfort levels in caring for patients with SCD and identify several important findings.⁶ The survey comprised 19 questions and measured comfort levels in 4 domains: providing ambulatory care to individuals with SCD, managing SCD comorbidities, managing SCD-specific issues, and managing chronic pain. Although never before validated in a research setting, the survey was developed and used by the Maryland State Department of Health and Mental Hygiene to survey providers for patients with SCD. It is not surprising that they found the majority of respondents lacked confidence in all four aspects of caring for individuals with SCD. Having patients with SCD in the past and using knowledge from residency were both independently associated with increased confidence in their multivariate analysis. Based on these findings, they propose using continuing medical education on SCD to ensure that providers are using state of the art information and knowledge and to identify

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a subset of primary care providers interested in SCD and refer patients to those specific providers, because previous experiences in caring for patients with SCD appear to improve outcomes.

SCD represents a difficult patient population to manage.⁷ Most patients with SCD have many comorbidities, including psychiatric illnesses such as depression, anxiety, addiction, and personality disorders. They also are more likely to have low healthcare literacy and to be underinsured; they truly are an underserved population. Moreover, they have likely spent much of their time in the emergency department, urgent care clinic, and hospital. As such, the transitions of care are crucial.⁸ In this regard, the study by Whiteman et al provides a glimpse into what needs to be done in terms of filling the knowledge gap and improving provider confidence. They should be applauded for their efforts because no such study existed previously in the United States. A similar study of family physicians in Brazil identified limited experience and knowledge deficiency as the primary reasons for lack of comfort in caring for sickle cell patients.⁹

Taking care of patients with SCD cannot be accomplished by one group of providers alone. Despite the time pressure and lack of financial reimbursement, the best SCD care is traditionally provided at specialized sickle cell centers where primary care physicians, hematologists, pain management specialists, case managers, and social workers collaborate to provide integrated and longitudinal care.¹⁰ Without such a specialized center, primary care providers and hematologists are left with much to do, which would require close collaboration, superb communication skills, and clear delegation of responsibilities. Although this seems challenging, the rewards of holistic care, taking care of the whole patient, especially one with difficult SCD, can be enormous for some primary care providers and hematologists. A few practical pearls can be considered. For example, although hydroxyurea is the only proven therapy to reduce hospital admissions, length of stay, and analgesic use, it is still vastly underused.¹¹ Perhaps one important role of primary care providers is to screen patients with SCD for the appropriateness of hydroxyurea, refer them to a hematologist with experience using it, and ensure medication compliance during subsequent follow-up visits. Another example is for primary care physicians to provide SCD-specific health maintenance tasks such as yearly echocardiogram and ophthalmologic examinations.²

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