

Coming Home

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Even patients with specialized conditions such as sickle cell disease need primary care physicians.

With the advent of the Sickle Cell Centers of Excellence in the 1970s, patients diagnosed with sickle cell disease began receiving specialized, targeted care that has increased their average life expectancy from 14 years in 1973 to at least the mid-50s in recent years.¹⁻³ This increased life span presents two challenges. First, fewer physicians are specializing in hematology, creating a shortage of doctors to care for the growing number of patients with sickle cell disease. Sec-

ond, as these patients age, they not only suffer from the chronic organ damage that sickle cell disease causes but also are at risk of developing other, more common chronic diseases, such as hypertension, heart disease, stroke, renal disease, and cancer.

The patient-centered medical home (PCMH) model incorporates the concept of caring for patients' basic needs while coordinating the care of their specialized diseases among other providers.⁵⁻⁷ Family medicine physicians serve as the ideal medical home for patients with sickle cell disease because they follow patients throughout a lifetime, providing continuity as these patients transition from the care of pediatric to adult hematologists. Although there are not currently a lot of

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ond, as these patients age, they not only suffer from the chronic organ damage that sickle cell disease causes but also are at risk of developing other, more common chronic diseases, such as hypertension, heart disease, stroke, renal disease, and cancer.

As many of these patients receive their care only from specialized centers, they aren't consistently receiving age-appropriate, routine preventive care and screenings

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resources to show that patients with sickle cell disease do better when followed by primary care physicians, the PCMH model has proven beneficial in improving preventive care.⁸ In theory, by integrating patients with sickle cell disease back into primary care, we can ensure they receive the preventive services and screenings they need as well as coordination of care with specialists as issues arise.

This integration will require more education on the part of the primary care physician. More medications and treatment modalities have been engineered for the

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treatment of sickle cell disease, and specific guidelines are available for improved outcomes. Hospitalizations focus on pain management, infection control, volume retention, and the prevention of tertiary outcomes. Collaboration with other specialties will likely be required for effective treatment and follow-up.

The Southeastern Exploratory Sickle Cell Center of Excellence is making concerted efforts with the specialties of hematology, family medicine, and emergency medicine to engage in research and curriculum development that hopes to aid in the sickle cell disease education of primary care physicians and first-line responders. Physicians and researchers from Georgia Health Sciences University, Morehouse School of Medicine, and the University of Florida are collaborating to assess what barriers both primary care and emergency medicine physicians face in seeing patients with sickle cell disease. They will also address concerns about disparities and socioeconomics of health care that may occur among this population.

The goal is for physicians to start to view sickle cell disease as an outpatient chronic illness that should be managed in the primary care setting with exacerbations that may be managed in the hospital. This will ultimately

result in the integration of these patients back into primary care offices. **FPM**

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