EDITORIAL

Understanding and Meeting the Hospitalist's Challenge: Caring for Adults With Sickle Cell Disease

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In November 2010, the National Heart, Lung, and Blood Institute celebrated the 100th year anniversary of the discovery of sickle cell disease (SCD) in the United States by hosting the Herrick Symposium. Despite progress in the past 100 years, there is just one treatment available (hydroxyurea) and, while SCD is no longer considered only a disease of children, patients' life spans remain severely shortened (42 and 48 years, respectively, for males and females).[1] With restrictions in residency hours and hospitals efforts to contain costs, hospitalists are increasingly being called upon to manage inpatient care for adults with SCD during their hospitalization. With the Centers for Medicare and Medicaid Services' recent plans to penalize hospitals with 30-day readmission rates in excess of expected, hospitalists should address the challenges they face in providing care to adults with SCD and identify strategies to successfully meet them.

In this issue of the *Journal of Hospital Medicine*, Carroll and colleagues examined data from the California State Inpatient Database provided by the Healthcare Cost and Utilization Project (HCUP) for persons with International Classification of Diseases, Ninth Revision (ICD-9) codes for SCD.[2] They characterized patterns of hospital use during a 4-year study period. Records for all patients, age 13 and older, with an admission for an SCD ICD-9–related cause were included. Patients with 4 or more hospitalizations in a 12-month period were classified as having high hospital utilization, and 25% of the 1879 different patients evaluated fell into this category. A general perception exists that most persons with SCD have high hospital utilization, but data from Carroll et al. challenge this perception.[2]

While 1 in 4 patients in the cohort had high hospital utilization, why were not even more able to stay out of the hospital? Characteristics of these high utilizers shed light on contributing factors. Many patients died in the hospital (6.6%), consistent with research by others who also demonstrated the high risk of death associated with rehospitalization among patients with SCD.[3,4] In a prospective cohort study of 71 adults with either $\geq$70 hospital days or $\geq$6 admissions in a 12-month period, 15% of the cohort died within a 24-month study period.[3] Patients with the highest number of hospital days, and those suffering from depression, were at highest risk of death. A separate prospective, longitudinal, 4-year cohort study of adults with sickle cell anemia found an overall mortality of 14%.[4] Mortality for those readmitted within 1 week of a painful crisis was 20%, compared to 11% for others in the cohort. High hospitalization use and hospital readmissions should be seen as worrisome markers of high risk for death, and patients should be carefully evaluated for life-threatening complications, and not assumed to be purely drug seeking.

Why do some patients with SCD experience high readmission rates and mortality? Such patients with frequent hospitalizations have been found, in fact, to be "sicker," and Carroll's research confirms that high utilizers were more likely to have comorbidities (acute chest syndrome, aseptic necrosis, renal disease) and complications (sepsis, pneumonia, pulmonary embolus, diabetes, mood disorders, and cocaine and alcohol use).[2] Fortunately, high utilization appears to moderate over time for most patients, but those with persistent high utilization were more likely to have sepsis and mood disorders. Aisiku and colleagues studied a cohort of adults with SCD, in Virginia, in which emergency department (ED) utilization provided additional evidence for the association of high utilization with worse outcomes.[5] Patients with 3 or more ED visits in 1 year were found to have lower hematocrits and higher white blood cell counts, to require more blood transfusions, and to report more pain, more pain days, more pain crises, and a worse quality of life. It is clear that patients with high hospital utilization are sicker and at an increased risk of death. While enlightening, this data does not tell the entire story.

Most admissions for patients with SCD begin with a vaso-occlusive crisis, and frequently other complications may develop. Smith et al. provided the first prospectively collected data documenting that these patients reported pain on more than 54% of days, and many experience pain daily, yet infrequently access healthcare services.[6] Hospitalists should appreciate that chronic pain is common for many adults with SCD. Pain management in this patient population is complex and often challenging, requiring high doses of opioids. In this current issue of the Journal, Smith and colleagues have contributed an excellent overview of how to manage pain in adults with SCD.[7] The review specifically addresses some of the most challenging aspects of

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pain management in the hospital setting. Unfortunately, healthcare providers too frequently perceive patients as addicted to narcotics and abusing them, despite clear evidence that patients with SCD suffer from chronic pain. The consequent crisis of trust between the patient and provider commonly leads to inadequate treatment of pain and subsequent self-discharge. Haywood and colleagues compared trust levels in adults with SCD and a history of sudden self-discharge (ie, leaving against medical advice [AMA]) to those without such a history.[8] Patients with a history of self-discharge reported lower levels of trust of the medical staff and more negative interpersonal experiences. In a separate investigation, researchers compared scores on the Picker Patient Experience Questionnaire between a cohort of adults with SCD and national norms.[9] Patients with SCD scored lower on 9 of 12 items. More specifically, 86% of respondents reported having insufficient involvement in decisions about care and treatment, and 50% reported staff did not do enough to control pain. Sadly, it appears the health system overall has undertreated and mismanaged patients with SCD suffering from pain crises.

Hospitalists face many challenges when managing care for adults with such a complex disease associated with high mortality, severe pain, and often a high readmission rate. The complexity of SCD calls for a comprehensive approach, and the need for each patient to have a clearly identified medical home.[10] The hospital, emergency department, and hospitalist cannot and should not serve this role. Recently, Lindquist and Baker proposed a framework to understand and prevent hospital readmissions.[11] They recommend optimizing the interfaces of transitional care among the patient, hospitalist, and primary care physician (PCP). By applying this framework of care, hospitalists must identify a PCP and provider with SCD expertise for follow-up. Clear communication between the PCP, sickle cell expert, and hospitalist can be used to facilitate inpatient and emergency department care, and avoid inconsistent care that fosters mistrust. Individualized and consistent analgesic protocols established by outpatient providers, in collaboration with the patient, are more likely to deliver effective care, compared to variable attempts by whatever hospitalist happens to admit the patient.

Working with physicians expert in the care of patients with SCD, hospitalists might also identify patients who may benefit from hydroxyurea (HU) therapy. Despite clear evidence of HU's multiple salutary effects (decreased number of painful crises and need for hospital admissions, reduced number of blood transfusions and frequency of acute chest syndrome, and an overall benefit in mortality),[12,13] it remains underprescribed.[14] In an analysis of a Medicaid managed care organization database in Maryland, 85% of patients never refilled a HU prescription. Moreover, patients with the highest rate of refills had the lowest number of hospital admissions and cost of care. Based on the evidence, hospitalists should screen all patients to determine whether or not HU has been prescribed, and if not, patients should be carefully assessed to determine if they are candidates for this effective therapy with communication to the patient's PCP and SCD expert.

Carroll's analysis confirms that patients with sickle cell disease frequently admitted to hospital (high utilizers) suffer a heavier burden of their illness and are at remarkably high risk of further morbidity and mortality.[2] Though admissions are usually for acute pain crises, these high utilizers also suffer greater risk of hematologic, cardiovascular, infectious, orthopedic, and psychiatric complications. The common psychiatric issues, including both mood disorders and substance abuse, emphasize the need for a multidisciplinary team of care providers to provide a comprehensive bio-psycho-social assessment of all patients with SCD who experience high hospital utilization. These patients will also benefit from system improvements that integrate and coordinate care across inpatient, outpatient, emergency department, and patient homes. Hospitalists are well positioned to engage in this model of care, as well as develop and improve processes to ensure seamless transitions across the various settings of care delivery. It is also crucial that hospitalists are engaged in research needed to better identify and understand risk factors that lead to high utilization. Only through collaborative efforts can we hope to solve the conundrum of frequently hospitalized patients with sickle cell pain crises.

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