Fostering Trust and Justice

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The following scenario serves as an example of an emerging literature on injustice in health care.1,2 A 19-year-old man with sickle cell disease presents to the emergency department with progressive leg and back pain. His hooded sweatshirt is pulled over his eyes, he is wearing headphones, and is singing along to an unheard tune. His attempts to manage his pain at home have been unsuccessful and he tells the nurse that his pain is a 9 on a 10-point scale. The nurse responds with apparent disbelief and says “Really?” then sends the patient to the waiting room where he sits for several hours before seeing a physician. The patient’s request for a specific dose of morphine is met with doubt and disdain.

This patient is stigmatized as a drug seeker or abuser, with little consideration for the complexities of his pain. Justice in this context is characterized by a fair process with a relationship between the clinician and patient highlighted by empathy and a nonjudgmental approach. The lack of justice that typifies the care of some patients with sickle cell disease may put them at risk not only for inadequate care but also for long-term deleterious effects.1,2

A number of studies link injustice, discrimination, and health care disparities with a vast range of psychological and physical abnormalities.1 Injustice for patients with chronic pain leads to more pain, stress, and disability related to their condition.3 Recurrent injustices (ie, microaggressions) experienced over years of interactions with the health care system, when coupled with the helplessness and lack of control experienced by sickle cell patients, may serve to worsen their fragile health.

Evidence of inadequate attention to sickle cell pain abounds in the literature and is most noted in patients as they reach adulthood.3 Patients who present frequently to the emergency department are at the highest risk for inadequate attention; those who treat most of their pain at home are often vulnerable as well. This is at least in part due to a negative attitude toward patients with sickle cell disease and a profound fear of catering to opioid addiction.3 As with the patient described previously, perceived discrepancies between patient behavior (lack of wincing, moaning, or crying) and pain score may lead to mistrust between clinicians and their patients.

A 1997 survey of hematologists and emergency physicians (115 respondents between both specialties) reported that patient self-report, the criterion standard for pain assessment, was not necessarily a reliable indicator of the existence or intensity of pain in patients with sickle cell disease—that patients reported more pain than they actually experienced or fabricated their pain.4 What these clinicians may fail to understand is the report of severe pain in the absence of physiologic or behavioral changes is common not only in sickle cell disease, but also in other recurrent and chronic pain syndromes.

Tanabe et al7 retrospectively studied management of acute pain episodes related to sickle cell disease in 3 emergency departments that followed Emergency Severity Index guidelines recommending that patients with self-reported pain scores greater than 7 be treated emergently. Of 603 visits for sickle cell pain made by 159 unique patients, 163 visits (27%) were assigned a triage priority level 1 or level 2 (using a 5-level triage system in which level 1 is highest priority and reserved for immediate life-threatening situations, and level 5 is lowest priority). Patients assigned a triage level of 3, 4, or 5 waited an average of 48 minutes longer than patients assigned to triage level 1 or 2 to receive their initial analgesic.3 Most patients with sickle cell pain were not seen as requiring emergency attention despite the known severity of their pain. The problem remains that the ultimate treatment decision lies with individual clinicians, a situation that may allow the long-standing bias against patients with sickle cell disease to marginalize their reports of pain.

Concerns about drug abuse, reluctance to prescribe opioids, and disbelief of patients’ report of pain severity are primary barriers to optimal sickle cell pain management reported by clinicians.8 Physicians may feel trapped between conflicting responsibilities, ie, duty to the patient and duty to protect the community from opioid diversion. However, it is problematic that clinicians may consider opioid addiction to be more common in sickle cell disease than in other chronic pain syndromes.

The data regarding opioid addiction in patients with sickle cell disease provides less evidence for addiction...
than popular opinion would suggest. Prevalence estimates for opioid addiction among patients with sickle cell disease range from 0.5% to 8% vs 3% to 16% in patients with other chronic pain syndromes, and in the general population, a 4.8% rate of prescription opioid abuse (excluding heroin)\(^7\,8\) and a 6% to 15% rate of substance abuse.\(^7\,8\) Behaviors often described in patients with sickle cell disease, such as requesting a specific dose of opioid or requesting that the opioid be administered intravenously, may be normative in patients who have experienced a history of undertreatment of pain and are less indicative of abuse than behaviors such as illicit drug use or using opioids for symptoms other than pain.

From the patient standpoint, interactions with the health care system perpetuate the long history of distrust and injustice that defines this relationship. Some patients report insensitivity and preoccupation with concerns of drug addiction by hospital staff, and inadequate analgesic administration and an overall lack of sympathy in their interactions with clinicians.\(^9\) Some patients with sickle cell disease report considerably less satisfaction with their care than other African American patients.\(^10\)

How can trust and justice be integrated into the care of patients with sickle cell disease? For the clinician, the relateness of the patient's pain is likely inversely proportional to the social distance between the clinician and patient. This distance must be reduced to remove the bias and distrust that affect the relationship between clinicians and patients with sickle cell disease.

Strategies to reduce the injustice experienced by patients with sickle cell disease range in complexity, but have at their core the goal of increasing the familiarity of the clinician with the patient as an individual. A day hospital for patients with sickle cell pain, at centers that have the volume to sustain it, would allow patients to interact with designated clinicians who know them well, and has been associated with improved outcomes. A model of care that strengthens communication between the patient's medical home and the emergency department, either in real time or through the use of individualized protocols, should be encouraged. A "pain passport" would allow the patient's pain plan to be given to clinicians in the acute setting and would validate the patient's request for specific treatment. Mandating the use of strengthened protocols and guidelines may be needed to help reduce the bias that has typified the care of this patient group.

An open dialogue between clinicians and the sickle cell community must be facilitated. Local community sickle cell organizations should assemble patient groups to educate clinicians on the issues and put a face on their disease. Educational initiatives to inform the sickle cell community on effective strategies to improve interactions with clinicians should be developed and implemented. Acute care sites should designate specific clinicians, with knowledge and interest in sickle cell disease and patients, as primary contacts for care. Ultimately, the fair and just provision of care relies on an approach that eliminates the chasm between the sickle cell patient and clinician and allows effective collaboration.

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REFERENCES