

The Pain Management Bias in Patients Experiencing Sickle Cell Pain Crises

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Introduction

Genetic mutations altering the shape of the red blood cell (HbS gene) leading to vaso occlusion \rightarrow ischemia \rightarrow pain and hemolysis.

Shape of the RBC alters the body's metabolism of drug clearance leading to shorter duration of action of drugs in the body.

Patients experience lifelong episodes of unpredictable acute and chronic pain.

Gold Standard guidelines for acute pain management of SCD is the "patient's or family's report of the pain severity and similarity to prior episodes". Due to pain, opioids are needed (Up-To-Date).

The subjectivity of the pain often leads to clinicians dismissing their needs for pain medication and being labeled as drug-seekers. "No combination of clinical and lab findings exist to determine, or confirm, whether an individual is in pain" (Up-To-Date).

63% of nurses believed addiction was prevalent and 30% were hesitant to give high-dose opioids (Pack-Mabien, et.al. 2001).

In the US, 98% of SCD patients are Black Americans. (Nelson & Hackman, 2012)

Ethical Principles

Beneficence:

- Patients should not be dismissed or stigmatized for seeking relief for their pain.
- Special consideration of the patient's presentation and history is necessary to attain a safe environment for individuals with sickle cell disease.

Non-Maleficence:

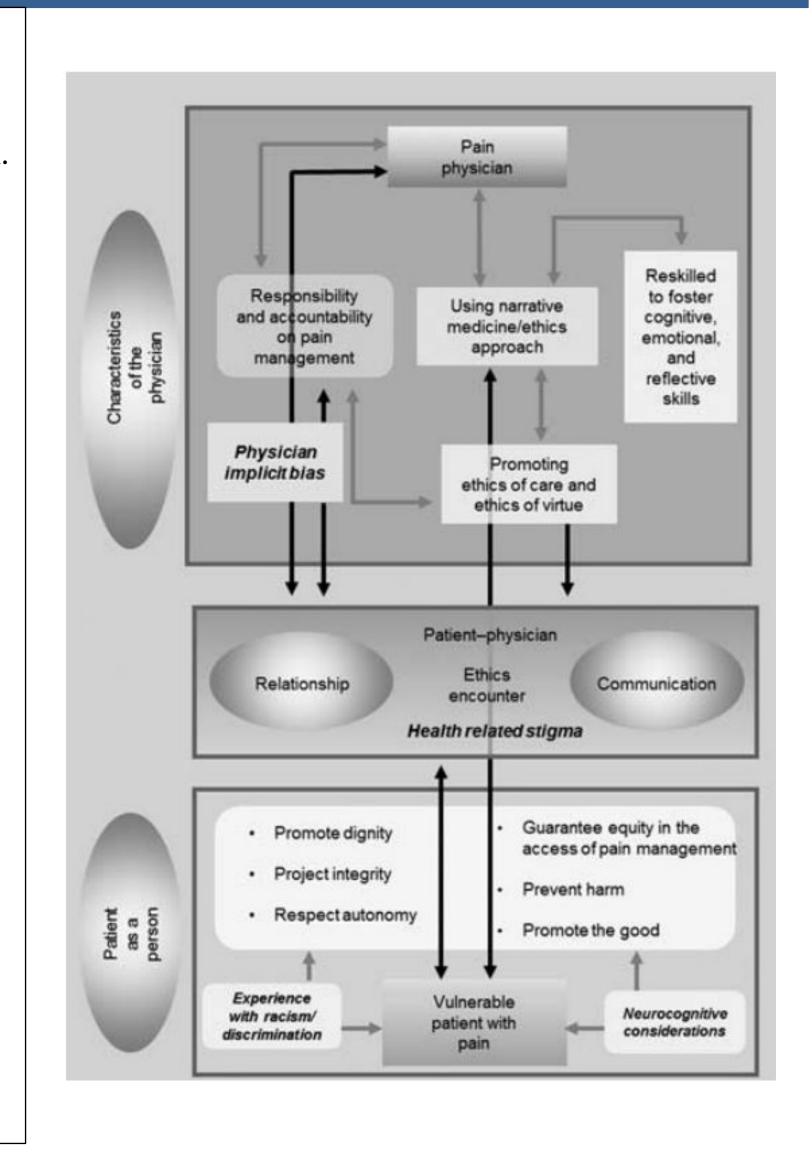
- Providers must weigh the benefit of prescribing a patient the pain medication they need with the risk of overprescribing opioids to vulnerable patient populations.

Justice:

- Healthcare professionals should provide lawful and equitable care to sickle cell patients in all settings.

Autonomy:

- "Untreated pain may reduce patients' autonomy and increase vulnerability" (Mulchan, et. al., 2022).



Case Studies

- R. Edwards "Acute, she says, is a crisis. It feels sharp, stings, and burns. She likens it to the feeling you might have if an elephant sat on your chest or you had your hand slammed in a car door repeatedly."
- F. Yusuf "...during their first trip to the emergency room as an adult, Fouza and her daughter experienced a three-hour wait for care."
- T. Wolford "She began to experience crises "avascular necrosis" and surgeries for her joints, hip replacements, and multiple blood transfusions, one of which caused a reaction that led to liver failure. In high school she experienced multiple silent strokes."

Vera - "I test every Black woman for sickle cell, and I test every White woman for hemophilia.' That was what Vera's doctor told her during an appointment when she was pregnant with her son, Joshua."

A. Hinkinson - "Sickle cell anemia causes episodes of severe pain for Mr. Hinckson, and it has affected his vision. He takes powerful painkillers to manage his pain, but his body has adapted to these medications, and they are no longer as effective as they once were. Because of this, Mr. Hinckson is unable to work. When he does have a severe episode of pain, he has to go to the hospital for narcotics or a blood transfusion. Because he is so frequently in the hospital, he says that staff members sometimes view him as a "drug-seeker." He finds it frustrating that hospitals cannot find a quick way to identify him as a sickle cell patient."

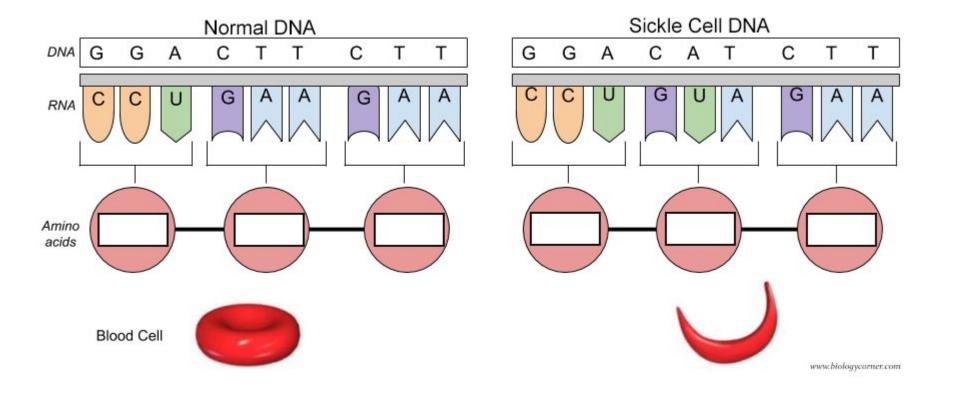
Literature Review

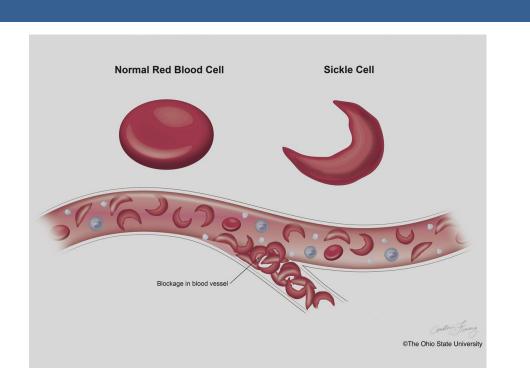
The Sickle Cell Center at Children's Hospitals & Clinics of Minnesota surveyed their pediatric populations ($\geq 12 \text{ y/o}$) and found that a significant amount of patients/families felt that race affects their quality of health care for sickle cell management (Nelson & Hackman, 2012).

A moderate proportion of providers in the acute setting have negative attitudes toward patients with SCD-related pain, especially in their concern that patients may be exaggerating discomfort or manipulate them (Ratanawongsa, et. al., 2009).

Integrated Ethical Framework for Pain Management can be utilized by health care workers to treat SCD. This framework helps the provider treat the patient from a patient-centered approach considering patient characteristics, vulnerabilities and autonomy. Providers can be educated on implicit bias around the SCD stigma (Mulchan, et. al., 2022).

Pregnant patients with sickle cell were found to be 4 times more likely to experience opioid related disorders, namely poor fetal growth, maternal sepsis, and threatened preterm labor. Pregnancy increases the frequency of vaso-occlusive episodes, leading to an increase in opioid use during this time (Darlington et. al., 2020).







Pros

Opioids are readily available in hospitals and effective for relieving acute episodes of pain.

Prescribing opioids leads to reduced length of stay and hospitalizations.

Improved quality of life with management of pain (social, occupational, academic, etc.).

Cons

Long-term opioid use can lead to addiction, dependency, abuse, and potentially fatal overdose.

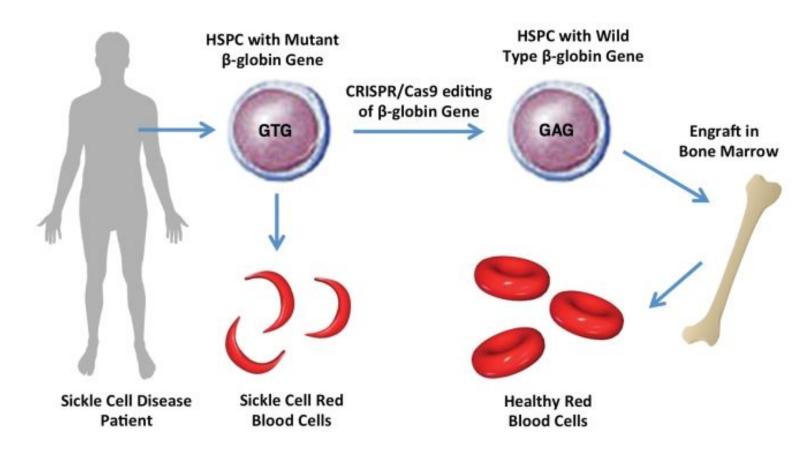
Higher doses of opioids are often less effective for those with chronic sickle cell disease, and prescribing higher doses can lead to hyperalgesia.

Discrimination from medical providers may lead to poorer disease management and compliance with treatment for various conditions including SCD.

Future Implications

In November 2023, the FDA approved the trial use of CRISPR as a potential cure for SCD. CRISPR would aim to genetically modify the DNA (HbS) of SCD patients using their own stem cells. The altered stem cells would then be infused back into the patient (requires only a one-time infusion). This cure could potentially eliminate the need for opioid prescriptions in many sickle cell patients.

As of 2024, CRISPR treatment costs \$3.1 million and \$2.2 million for either LYFGENIA and CASGEVY, respectively. Furthermore, because payments are upfront and the benefit is seen over a lifetime, insurance companies are hesitant to front the bill for a patient who is likely to switch insurances, causing this treatment to be out of reach to the average patient.



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