NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE
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Commissioner

2024 Health Advisory #15: NYC Health Department Recommendations on Destigmatizing and Improving Provider Attitudes Towards Pain in Sickle Cell Disease

Purpose:
In December 2023, the FDA approved two gene therapies for sickle cell disease (SCD), which affects approximately 100,000 people in the U.S. New York State has about 10% of the U.S. SCD population, with most individuals living in the New York City area. On Wednesday, May 1, 2024, Kendric Cromer, a 12-year-old boy from Washington D.C. became the first person in the world with SCD to begin gene therapy. While thousands of people in NYC may benefit from these therapies, due to the complexity of this groundbreaking treatment as well as inequities in access to health care, the initial rollout is likely to be gradual and involve a limited number of patients. The pathway to gene therapy for SCD begins with access to a hematologist and initiation of treatment for acute and chronic complications. The most common acute and chronic complication of SCD is pain. To facilitate continuing engagement with providers on advancing equity and high-quality care, please see the following advisory regarding the management of SCD pain.

- Provider bias, discrimination, and structural racism negatively impact people presenting with vaso-occlusive events.
- Misconceptions and misunderstandings of opioid treatment impact the management of vaso-occlusive pain events.
- Neutral language in documentation can destigmatize people being treated for vaso-occlusive events.
- In sickle cell disease management, collaboration between multiple physician specialties is required.

May 17, 2024

Summary

Primary, specialty, and emergency care providers are critical in the well-being and management of people with sickle cell disease (SCD). Unfortunately, stigma associated with opioid use and structural racism negatively influence the quality of care provided to individuals with SCD, leading to inequities in treatment and outcomes. Stigma refers to negative attitudes, beliefs, and practices towards an individual or group, which can ultimately lead to discrimination and delay diagnosis, treatment, and successful health outcomes. Conversely, de-stigmatization emphasizes changing and disrupting sociocultural constructions of groups to mitigate the harmful consequences of stigma.

The combination of societal influences, institutional structures, and a provider's clinical experiences can reinforce implicit biases that unjustly affect their approach when caring for people with SCD. This contributes to a variety of adverse health outcomes for members of this stigmatized and often inappropriately racialized group, including premature death and dysregulated physiological stress responses, highlighting the importance of structural racism as a

factor leading to health inequities. Destigmatizing provider attitudes toward pain management in SCD care and addressing structural inequities is essential for ensuring equitable and compassionate care for all persons living with SCD.

Background

SCD is an inherited blood disorder that causes anemia, pain, infection, and other harmful health effects. **While it has been associated with African ancestry, it is concentrated in specific areas across the African continent, Middle East, Mediterranean, Southeast Asia, and Latin America.**

One of the hallmarks of SCD is a vaso-occlusion event (VOE) and the associated severe pain. Stigmatization of persons with SCD suffering from a VOE is often due to structural racism, perceived frequent use of emergency care, and chronic use of opioids for pain management, which lead to frustrating outcomes for both patient and provider. Patients suffering from VOE have reported depression, low self-esteem, and feelings of hopelessness, which can be exacerbated during a pain event. Lack of empathy can amplify stigma that manifest in attitudes, behaviors, documentation, and language towards patients.

Sickle Cell Demographics in New York City (NYC)

Sickle cell disease is detected in 150-200 newborns annually in New York State. Of the estimated 8,374 SCD patients in New York State, 80% live in New York City. In NYC hospitals in 2019, there were 6,145 SCD hospitalizations, with residents predominantly from the Bronx and Brooklyn. Of the hospitals in NYC, the following were ranked in order of highest SCD inpatient hospitalizations to the lowest (~190-900 inpatient admissions in 2019): Montefiore Medical Center, New York - Presbyterian Brooklyn Methodist Hospital, New York-Presbyterian Hospital - Columbia Presbyterian Center, Long Island Jewish Medical Center, Mount Sinai Hospital, Brookdale Hospital Medical Center, Kings County Hospital Center, and University Hospital of Brooklyn.

Recommendations for Providers

De-stigmatizing Pain Management: More than half of people living with SCD may experience or develop chronic pain in their lifetime. National guidelines recommend using a multi-modal approach to treat pain in sickle cell and normalizing the use of opioid analgesics along with non-opioid analgesics, and non-pharmacological therapeutics simultaneously. ***Do not assume a person with sickle cell disease is "drug-seeking" and refrain from using this term***. Recognize that different treatment options will be appropriate for patients on an individualized basis, and patient-centered preferences should drive clinical decisions in the context of individualized pain plans.

Individualized pain plan: Ask if the patient has a pain plan and how to reach their care team. Many plans are in the electronic medical record. For patients without a pain plan, the first dose of pain medication should be given within 30 minutes of triage and could include subcutaneous, IV, or oral opioid/pain medications as appropriate. Additionally, providers may use a stepwise multi-disciplinary approach to offer patients alternative treatment modalities that meet the patient's needs. If the patient has a history of multiple visits without a pain plan, consider creating one in partnership with a sickle cell specialist.

Chronic Opioid Therapy and Opioid Failure: Patients may be prescribed opioid analgesic therapy for daily chronic pain management, also known as chronic opioid therapy (COT). Initiating a COT plan should be done using a shared decision-making process, where goals of care and opiate failure criteria are mutually agreed upon at its onset. Recognize that some patients may become refractory to their treatment regimens and fall under the category of opioid failure, which can be considered after 6-12 months of COT. If a provider suspects possible opioid failure, direct communication with the patient's hematologist (or primary provider) is recommended before modification of the pain management plan is pursued.

Multidisciplinary Care: A Multidisciplinary team of hematologists, pain specialists, PCPs, social workers, and other healthcare professionals may provide the safest, evidence-based care to meet the complex needs of people living with sickle cell. Social work consults should be a routine part of emergency care and community health workers should be embedded into the ED infrastructure to support access to longitudinal care and resources. ***In New York state, all patients living with sickle cell disease and enrolled in Medicaid are eligible for comprehensive care management (Health Homes).***

Ensuring all New Yorkers have access to health care is a top priority of the NYC Health Department. Refer your patients for free assistance to sign up for low- or no-cost health insurance by having them call 311, text CoveredNYC (SeguroNYC for Spanish) to 877877, or visit nyc.gov/getcoverednyc. To connect with a NYC Health Department Certified Application Counselor, visit nyc.gov/health/healthcoverage. This is especially important considering ongoing Medicaid redeterminations.

For more information

NYC-based organizations:

- Candice's Sickle Cell Fund, Inc. (CSCF)
- Falling Angels (Rockland County)
- Medicaid Health Homes- Comprehensive Care Management
- New York State Sickle Cell Advocacy Network, Inc (NYSSCAN)
- Sickle Cell Awareness Foundation Corp International (SCAFCORPINT)
- Sickle Cell Thalassemia Patient Network (SCTPN)
- Westchester Sickle Cell Outreach (WSCO)

National Organizations:

- Sickle Cell Adult Provider Network (SCAPN)
- American Society of Hematology (ASH)
- Sickle Cell Disease Association of America (SCDAA)
- National Alliance of Sickle Cell Centers (NASCC)

References

1. Anderson, D., Lien, K., Agwu, C., Ang, P. S., & Nabil Abou Baker. (2023). The Bias of Medicine in Sickle Cell Disease. *Journal of General Internal Medicine*, *38*(14), 3247–3251. https://doi.org/10.1007/s11606-023-08392-0

2. Hatzenbuehler ML. Structural stigma: Research evidence and implications for psychological science. *Am Psychol*. 2016;71(8):742-751. doi:10.1037/amp0000068

3. *Department of Health* (2023) *New York State Department of Health Recognizes National Sickle Cell Awareness Month*. Available at: https://www.health.ny.gov/press/releases/2023/2023-09-20_sickle_cell.htm#:~:text=In%20the%20U.S.%2C%20most%20people,babies%20in%20New%20York%20State

4. Moulton, T. (2020) *Facts on Sickle Cell Disease - The New York State Senate*, *https://www.nysenate.gov/*. Available at: https://www.nysenate.gov/sites/default/files/29_sickle_cell_thalassemia_patients_-_chair_advisory_board_network_thomas_moulton.pdf (Accessed: 01 March 2024).

5. New York State Department of Health (2019) *Hospital inpatient discharges (SPARCS de-identified): 2019: State of New York*, Available at: https://health.data.ny.gov/Health/Hospital-Inpatient-Discharges-SPARCS-De-Identified/4ny4-j5zv/about_data

6. Brandow, A. M., Carroll, C. P., Creary, S., Edwards-Elliott, R., Glassberg, J., Hurley, R. W., ... & Lang, E. (2020). American Society of Hematology 2020 guidelines for sickle cell disease: management of acute and chronic pain. *Blood advances*, *4*(12), 2656-2701. doi: https://doi.org/10.1182/bloodadvances.2020001851

7. Brandow, A.M. *et al.* (2020) *American Society of Hematology 2020 Guidelines for Sickle Cell Disease: Management of acute and chronic pain*, *American Society of Hematology*. Available at: https://ashpublications.org/bloodadvances/article/4/12/2656/460974/American-Society-of-Hematology-2020-guidelines-for (Accessed: 01 March 2024).

Sincerely,

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