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Ezenwa's research focuses on health disparities in pain management with the goal of reducing these disparities. Her current research is on pain management related to sickle cell disease. She studies the use technology and other methods to reduce pain among underserved populations.

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**MAYDAY FOR PAIN: THE FIGHT FOR RELIEF FOR
AFRICAN AMERICANS WITH SICKLE CELL DISEASE**

Introduction

What are the barriers related to the management of pain for African Americans with sickle cell disease (SCD)? What can individuals with SCD and their families do to advocate for policy initiatives that would reduce disparities in pain treatment?

SCD is an inherited blood disorder affecting approximately 100,000 Americans, mostly of African descent. The pain associated with SCD is unrelenting, reoccurring and often debilitating and it adversely affects the quality of life of patients and their families. Opioids are one of the best ways to treat pain from SCD, yet doctors are reluctant to prescribe opioids because they believe individuals with SCD abuse drugs. When opioids are used to treat SCD, because of their addictive nature, doctors do not believe patients' reports of pain. In fact, doctors often prescribe dosages of opioids too small to adequately mollify the pain associated with SCD. Furthermore, government policies, such as the Affordable Care Act's (ACA) "30 Day Readmission Rule" disadvantages people with SCD and favors other individuals with inherited disorders, such as those with Cystic Fibrosis (a disease that primarily affects Caucasians). This rule penalizes the hospital where a patient is readmitted through a reduction in payment if patients are readmitted within 30 days. Individuals with Cystic Fibrosis are exempt from the rule, however its implementation could effectively shut down programs specifically designed to help those with SCD control pain as a reduction in payment could handicap services. Non-adherence to SCD treatment guidelines, inadequate research funding, and unfavorable government policies lead to experiences whereby African Americans with SCD are often denied optimal pain relief.

The data for this project was collected through an intervention program called Mayday for Pain Intervention (MPI). African Americans with SCD and their family members participated in multimedia intervention sessions to increase their knowledge about policymaking as an avenue to advocate for better pain treatment.

Findings

- As a result of the intervention, patients and their families know more about how policies can both negatively and positively affect the control of sickle cell pain. Those affected by SCD learned strategies to help their advocacy efforts. Some of the advocacy strategies include sharing their stories, writing letters, contacting elected officials, and participating in advocacy visits to the state and US capitol.
- Participants of the intervention expressed interest in using the video component depicting the pain and suffering of individuals with SCD as a tool to raise public awareness, inform policy, and garner funding to expand the MPI project.

Recommendations

Currently, individuals in the MPI program are petitioning to be exempt from the 30 Day Readmission Rule. They have partnered with Illinois State Representative La Shawn Ford who is urging the Department of Healthcare and Family Services to waive the 30 Day Readmission Rule for patients with SCD. Grass-root advocacy movements like MPI should look to engage the SCD community in advocacy and public policy initiatives to address disparities in the control of sickle cell pain. The focus of these endeavors should be to bring attention to the barriers to pain relief experienced by people with SCD, ways to advocate for their pain relief, and increased research funding and public awareness of SCD.



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