



## **The Invisible Crisis: *Understanding Pain Management in Medicare Beneficiaries with Sickle Cell Disease***

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Have you ever experienced a kidney stone or witnessed a family member with a broken bone? These conditions are often associated with excruciating pain that would cause a patient to be rushed to the nearest hospital for care. Now, imagine having a severe health condition that causes even greater pain than breaking a bone, but from all outward appearances, you look as if nothing is wrong with you. This is a common experience for people living with sickle cell disease (SCD).

SCD is the most prevalent genetic blood disorder in the United States, with an estimated 100,000 people living with SCD. This disease, which disproportionately affects Blacks and Latinos, causes the body to produce abnormal blood cells shaped like crescents or sickles rather than discs. These sickle-shaped cells have trouble properly delivering oxygen to body tissues, which causes extraordinarily painful and severe attacks known as a crisis. Even though SCD was discovered over 100 years ago, there has been limited progress in available treatments. Until June 2017, there was only one therapy approved by the Food and Drug Administration for SCD. Opioids are an important treatment option known to be effective against SCD pain.<sup>2,3</sup>

SCD impacts every body system and is characterized by acute and chronic pain episodes. Although acute pain management is central in the care of patients with SCD, it can be poorly managed across all health care settings.<sup>1</sup> Pain episodes are not associated with visible physical signs, which often results in the misperception that SCD patients are drug seeking or addicts. Pain from sickle cell crisis is a frequent cause for emergency department visits and hospitalization among patients with SCD, with an estimated cost of \$2.4 billion per year in the U.S.<sup>4,6,7</sup>

The national opioid epidemic has led to local, state, and federal initiatives to regulate opioid-prescribing practices in an effort to combat prescription opioid misuse and abuse. As these policy options for addressing the crisis are considered, it is important to be aware of the unintended consequences they may have, for example, on SCD patient population with regard to treatment and access to opioids--one of the few effective pain treatments. To better understand opioid prescribing among patients with Medicare coverage who live with SCD, the CMS Office of Minority Health analyzed data from 2016 Medicare Part D prescription drug event records.

### **Characteristics of Medicare Fee-for-Service (FFS) Beneficiaries with and without SCD:**

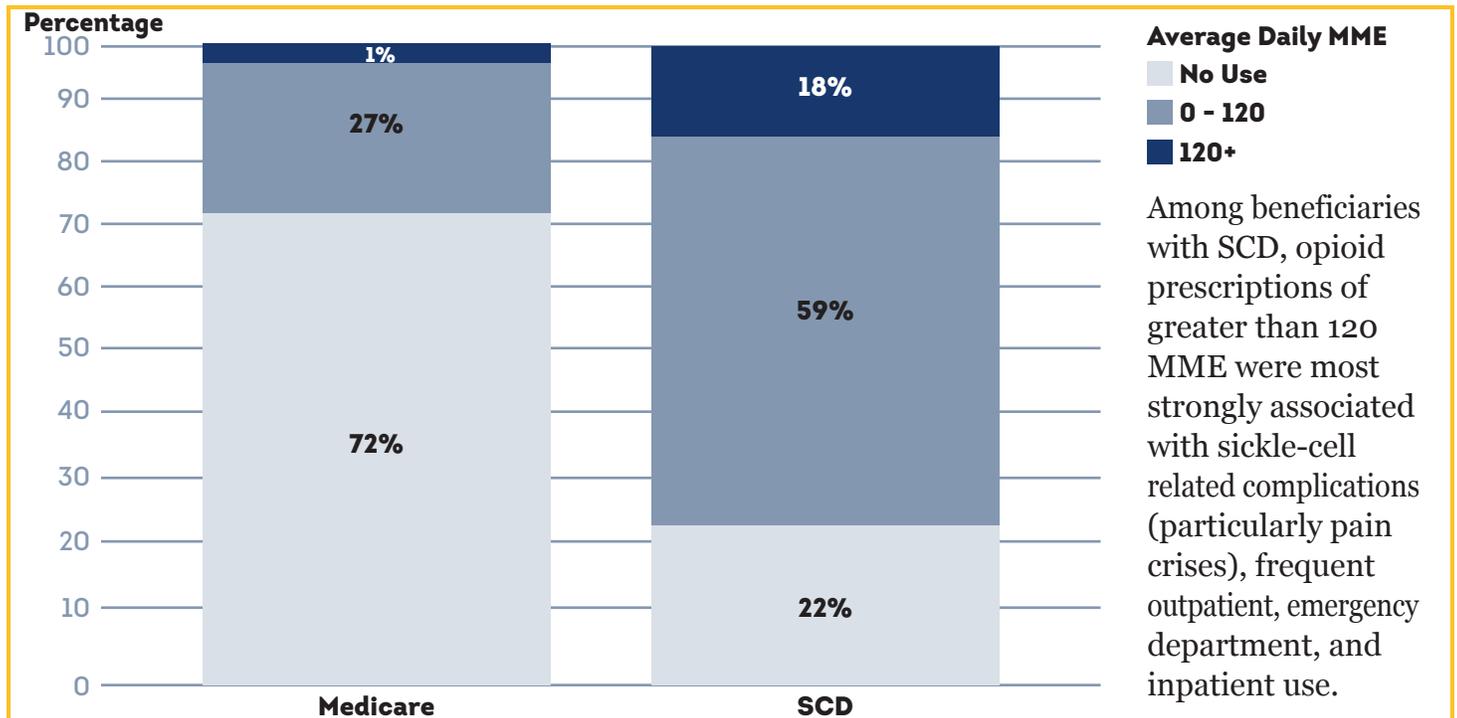
Compared to the overall Medicare FFS population, beneficiaries with SCD tend to be non-elderly (average age 43 years) and mainly live in non-rural communities (87%). Compared to beneficiaries without SCD, beneficiaries with SCD have greater health care utilization across inpatient (55% vs. 12%), emergency departments (74% vs. 25%), and outpatient settings (96% vs. 91%). Among

beneficiaries who had inpatient stays, the readmission rate was 2.5 times greater (38% vs. 15%) for those with SCD compared to beneficiaries without SCD. Collectively, the higher prevalence of outpatient visits, emergency department visits, inpatient hospitalizations, and readmissions suggest that there are added challenges in caring for Medicare beneficiaries with SCD.

## Opioid Prescription Use in Medicare FFS Beneficiaries with and without SCD:

As shown in Figure 1, Medicare FFS beneficiaries showed wide variation in dosage of opioid prescriptions. Nearly 8 out of 10 Medicare beneficiaries with SCD had at least one opioid prescription in 2016, and their median average daily morphine milligram equivalent (MME) was over 15 times greater than those without SCD (33 MME vs. 2 MME). Nearly one out of five of beneficiaries with SCD (18.3%) were prescribed opioids at an average daily dose of greater than 120 MME.

**Figure 1. Percent of Beneficiaries by Average Daily Morphine Milligram Equivalent (MME) Dose by Population, 2016**



### What are the morphine milligram equivalents (MME)?

The median average daily morphine milligram equivalents (MME) represents the amount of morphine an opioid dose is equal to when prescribed. MME is often used as a gauge of the abuse and overdose potential of the amount of opioid that is being given at a particular time. Each beneficiary was assigned a median daily MME dose by taking the median of daily MME across the number of days in the observation period (i.e., the number of days a beneficiary was alive during 2016).

CDC Guideline for Prescribing Opioid for Chronic Pain. Available from: <https://www.cdc.gov/drugoverdose/prescribing/guideline.html>

Dowell, D., Haegerich, T.M. & Chou, R. (2016). CDC Guideline for Prescribing Opioids for Chronic Pain - United States, 2016. MMWR. Available from: <https://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm>

## Conclusion

This study highlights variability in opioid prescribing among Medicare beneficiaries with SCD. For the majority of patients with SCD, opioid analgesics were an important treatment option, and a subset utilized doses of greater than 120 MME to manage SCD-related pain. The complex nature of SCD pain management may be exacerbated by ongoing efforts to address the opioid epidemic. Excluding sickle cell patients from efforts to restrict opioid access, similar to exclusions for cancer, hospice patients, and other patients with complex pain syndromes, could help ensure that sickle cell patients have access to appropriate care that improve patient health outcomes. As new pain management options are identified, the needs of patients living with SCD should be considered.

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