

Treating Patients with Sickle Cell Disease in New Jersey: How Palliative Care Can Help

Submitted by: Hackensack University Medical Center

Overview

Sickle Cell Disease (SCD) impacts Black people at a higher rate than other racial and ethnic groups. Pain is the most common complication of SCD and the biggest reason for emergency room visits. In 2019, the [Hackensack palliative care team](#) identified that a significant proportion of patients in the system with SCD were not being seen by the palliative care service. Chart and care plan reviews revealed that patients with SCD who received palliative care consults had increased services and personalized care compared to patients only seen by the pain service. In response, the palliative care team created a process in which every patient with a sickle cell anemia crisis or related acute admission was seen by the palliative care service; the process also ensured equal access to the outpatient palliative clinic.

Impact/Data Outcomes

Creating a process by which every patient with SCD is referred to the palliative care team has created more equitable access to services. The team reports that they have seen more consistent care in both outpatient and inpatient settings, including more personalized, holistic care plans for these patients.

Feasibility

Patient identification should be relatively easy given that SCD has its own ICD-10 codes. Hackensack's palliative care team worked in the same department as the pain service, making it easy to create a process to streamline referrals. Other palliative care programs interested in replicating this model should start by identifying which providers in their institution are currently supporting patients with SCD.

Scalability

A key consideration for scalability is ensuring that the palliative care team is well-resourced to meet the potential increase in volume and appropriately meet the unique needs of the patient population. This intervention is relatively easy to implement at any organization with a palliative care team. Psychosocial support is particularly critical for people living with SCD so ensuring that there are sufficient social workers on the palliative care team to support the caseload is essential. By educating and collaborating with other providers who care for patients with SCD it can help palliative care, programs see these patients earlier and farther upstream.

Sustainability

To sustain this initiative, true partnership is paramount. While interdisciplinary palliative care teams should generally be well equipped to address most needs for patients with SCD, they should plan for how they will meet increased demand for services—particularly psychosocial support.

Key Advice

- Acknowledge that clinically, patients with sickle cell disease are at a different starting point than many adult palliative care patients with a new diagnosis, having lived with the disease their entire lives. Expect a cycle of trust to mistrust to trust (again).
- In starting to care for sickle cell patients, consider that palliative care training is grounded in being able to adapt to the patient; but continue to learn about the unique experiences of this patient population, and remember to be curious.

Project Team

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