Palliative Care: Improving Quality of Life for People Living with Sickle Cell Disease

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What we know about gaps in the current system

➔ Missing or inadequate conversations about what matters to patients and families
➔ Uncontrolled symptoms leading to preventable ED visits and hospital stays
➔ Exhausted parents and caregivers
➔ Disparities in access to high-quality care
The role of palliative care

→ Clinical care focused on quality of life and function for patients living with serious illness

- At the same time as other treatments
- Dosed to intensity of need
- Available for all ages and in all care settings (ideally)
A crucial layer of support for people living with SCD

The interdisciplinary palliative care team works to:

➔ Prevent and relieve pain, other symptoms, stress

➔ Help patients and families understand what to expect and determine patient-family priorities for care

➔ Address bio-psycho-social-spiritual needs of both patient and family
African American patients are more likely than white patients to be suspected of opioid abuse, subjected to more frequent urine screening, and referred to substance abuse services. In the United States, SCD predominantly affects African American individuals, and, thus, patients with SCD may face unique barriers to the management of pain with opioids.

Original Investigation | Hematology

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Management of Chronic Pain in Adults Living With Sickle Cell Disease in the Era of the Opioid Epidemic: A Qualitative Study

Cynthia B. Sinha, PhD; Nitya Bakshi, MD, MBBS, MS; Diana Ross, RN, MS; et al

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Palliative Care: Based on Need

Palliative Care
- Need-based
- Appropriate from time of diagnosis (birth)
- Concurrent with other treatments
- No dedicated funding source

Hospice
- Eligibility = <6 months from end of life
- Medicare benefit
- Comfort care only - no disease treatment
Palliative Care Outcomes

IMPROVES QUALITY OF LIFE AND SYMPTOM BURDEN

Quality of Life

Symptom Burden

Reduces symptom distress by 66% with improvements lasting months after initial consultation

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Side Effects of Higher Quality Care

REDUCES AVOIDABLE SPENDING AND UTILIZATION IN ALL SETTINGS

- **48%** readmissions
- **50%** admissions
- **43%** hospital/ED transfers
- **36%** total costs

INPATIENT²,³

OUTPATIENT⁴

SKILLED NURSING⁵

HOME-BASED⁶
Why doesn’t every patient with sickle cell disease receive palliative care?
Early results:
Office or long-term care sites served by palliative care teams
Value-based payment makes palliative care an imperative.

Today’s health systems can’t afford to ignore quality of life for patients living with sickle cell disease.
An opportunity to improve care

“Better pain management and treatment outcomes may be accomplished by incorporating palliative care and its components tailored specifically towards SCD in the ED service…and by recognizing that for people with SCD palliative care approaches should not be limited to end-of-life treatments and decision making but rather applied throughout the trajectory of the disease.”

References


