

IMPACT PROFILE

Defining the Role of Palliative Care in Sickle Cell Disease

Palliative care (PC) has the potential to alleviate the suffering faced by people with sickle cell disease (SCD) and enhance their quality of life.

The Challenge

Sickle cell disease is a debilitating inherited condition that affects nearly all organs, leading to organ failure, premature death, and significant suffering. Palliative care provides symptom management, improves quality of life and communication for patients and families facing serious illnesses. However, PC is not consistently integrated into the care of individuals with SCD.

The Approach

We will gather the perspectives of multiple key partners to identify the barriers to PC integration in SCD and consequently develop interventions to address these barriers.

- Form a national working group composed of SCD and PC clinicians and researchers to foster collaboration.
- Engage in research to establish clinical guidelines for PC in SCD.
- Integrate patients and caregivers in the design of PC interventions in SCD.

The Impact

Our project will increase the use of PC among individuals with SCD by identifying effective models of integration. This population would benefit from the holistic approach of PC, leading to improvements in symptom management, psychosocial and spiritual support, and decision-making assistance and ultimately improvement in quality of life.

RESEARCH HIGHLIGHTS

- Limited use of PC in SCD: **less than 0.5%** of SCD-related hospitalizations used PC services
- SCD Clinicians state that their patients would benefit from PC but **lack clarity on which patients to refer**

Key Benefits

The *Defining the Role of Palliative Care in Sickle Cell Disease* project aims to deliver **Clinical** and **Community** benefits.



Clinical

Shared-decision making: Establish PC referral guidelines for SCD. (*Potential*)



Clinical

Patient-guided research: Identify culturally and disease-appropriate models for integrating PC into SCD management. (*Potential*)



Community

Life expectancy and quality of life: Improve quality of life in SCD with PC interventions. (*Potential*)

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