

Care for People with Sickle Cell Anemia



Hackensack
Meridian *Health*

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Why?

- Monthly palliative team meeting
 - Annual review of Hospital Palliative Care Service Scope of Practice
- Discussed experience; gap of care for people who are dx w/ sickle cell disease
- Medicine vs. Hematology vs. Pain vs. Palliative Service?



Adult Palliative Care Inpatient-Acute Service

Scope of Practice

Organizational Culture: Creative, Courageous, Compassionate, Collaborative, Connected

Palliative Care/Medicine definition: A [wholistic specialty highlighting personhood](#), including symptom management and supporting a person's quality of life and family during serious illness.

Team Culture: ***

A. Diagnoses

- Any serious or life-threatening disease(s); e.g.
 - Cancer
 - Chronic cardiac, pulmonary, renal or liver disease
 - HF, VAD program, COPD, ALS, ESRD, ESLD
 - CVA
 - High risk surgical patients
 - Dementia
 - Trauma cases with uncertain or poor outcome
 - Sickle cell

Inconsistent care plans noted

Population Impact

- Sickle Cell Disease (SCD) affects many people; a variety of racial and ethnic groups
 - Black people at a higher rate
 - REMINDER: SCD is inherited
- Pain is the most common complication of SCD and the most common reason for emergency room visits
- Sickle Cells (advocacy nonprofit)
<https://sickcells.org/blog/racism-in-sickle-cell-why-black-lives-in-the-healthcare-system-are-forgotten/>

How?


- Team committed to continue discussion about enhancing continuity of care and wholistic clinical services
 - Team & self reflection
- Reviewed staffing vs. volume of patients
 - Inpatient hospital
 - Pain vs. Palliative Service
 - Ambulatory clinic
- Palliative Care Service committed to trial of seeing all sickle cell patients that were hospitalized
 - AND inviting them to outpatient palliative clinic
 - w/ future consideration for palliative psychotherapy

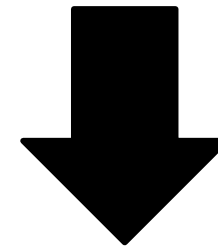
Themes & Experiences

- Acknowledge that clinically, patients with sickle cell disease are at a different starting point than many adult palliative patients with a new diagnosis, having lived with the disease their entire lives
 - Lean into their self knowledge
 - Be consistent with palliative skillset (balance compassion & clinical options)
 - Cycles of trust and mistrust may occur
- 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

Sustainability

- 2020 - present
- 2022 Inter-point of service/department & interprofessional workgroup

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- Patient Experience
 - Cancer Center/Hematology/Infusion Room/SWs
 - Pediatric & Adult Palliative Care
 - Pharmacy
 - Emergency Department
 - Hospital clinical/nursing education
 - Hospital Nurse Manager
 - Pain & Palliative Champions



1. Review of clinical guidelines
2. Learning sessions
3. Clinician processing sessions
4. Optimize patient equity
 - Loop Program
 - Supportive clinical services
5. Patient Support Group

Recommendations

BE REAL
NOT PERFECT

- **REFLECT**
 - Clinical campus/culture/patient population
- **IDENTIFY**
 - Who or what is a gap or vulnerability?
- **TRY**
 - What step can improve care?