Care for People with Sickle Cell Anemia

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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?

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
  - REMINER: SCD is inherited

- Pain is the most common complication of SCD and the most common reason for emergency room visits

- Sickle Cells (advocacy nonprofit)
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
  - 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?