Health Care Transition for Youth with Sickle Cell Disease

Creating a Pathway to Success by Connecting Clinic and Community

Children's MINNESOTA

Sickle Cell Disease

- The most commonly inherited blood disorder affecting 100,000 Americans
- This disorder is diagnosed via newborn screening through the department of health
- Patients are at risk for complications including; infections, pulmonary issues, pain episodes, splenic sequestration and stroke
- 99% of sickle cell patients survive to adulthood
- Most patients live well into their 40’s-50’s (and older)

What is SCD, part 2

- Signs, Symptoms, Characteristics of the disease
  - Stroke risk
  - Pain
  - End Organ Damage & ACS
- Treatment Options
  - Disease modifying therapy (hydroxyurea, L-glutamine, transfusions)
  - Curative therapies (SCT, gene therapy)

Why this matters - Globally

- Burden of Disease - Globally
- Cultural Context
  - Culture of medicine, chronic disease mgmt, racism/healthcare
- Disparities
  - Health, Research, Access
- Transition
  - Disease of the life span

Why this matters - Locally

- Burden of Disease - Locally
  - Lack of comprehensive adult care
    - Need for additional providers
    - Need for increased resources
    - Increased provider education & support
- Gaps in Care (how/why we received the grant)
  - Data collection
  - Primary Care, Specialty Care
  - Transition

Transition

- Due to the chronic nature of sickle cell disease, patients require a transition to adult care for continued medical care
- Although the focus of transition is the final move to adult care, of equal importance are the phases of transition that occur at different age/developmental levels
- Transition is not a one-time event, it is a continual process!!!!

QI Team

- Patients & Caregivers
- University of Minnesota Health Pediatric Specialty Care, Journey Clinic, Mpls, MN
- Health Partners University Avenue Clinic, St. Paul
- Sickle Cell Foundation of Minnesota
- Children's Minnesota

Children's Sickle Cell Program

- Children's Cancer and Blood Disorders Clinic, Mpls, MN
- Serving 300+ sickle cell patients
- Interdisciplinary team consisting of;
  - Physician, 2 nurse practitioners, 3 nurse case managers, social worker, sickle cell patient and family health advocate
  - 20-25 patients transition to adult care each year

Project Goals

Improve the process of transitioning pediatric sickle cell patients to adult care in Minnesota

Project Goals

- Clinic:
  - Write a transition policy
  - Create a transition plan
    - Checklist & tools
    - Transition Guide (by age)
  - Assess transition readiness for parents/patients with the StarX tool
  - Communicating/relationship building with adult providers

Project Goals

- Community:
  - Host three community events focused on transition education
  - Build relationships with adult hematologists
  - Build trust with the greater sickle cell community

Project Successes - Clinic

- Share data
  - Systematic approach
    - During comp clinic vs. random appts
  - # of completed assessments
  - Tracking new provider/team engagement
    - Did they schedule
    - Did they successfully make it to appt
    - Did they schedule a FU
  - Creation of transition binder(s)
- Relationship building across systems

Project Successes - Clinic

- Relationship building across systems
  - Site visits (UMN, HCMC)
  - Additional providers/programs
    - Children's CBD Hematologist
    - UMN Hematologist
  - Monthly conference calls (CBD & UMN)
  - Care Coordination with primary care
    - Health Partners
    - Broadway Family Clinic

Project Successes - Community

- 2 of 3 events
  - June 2018 – Intro to Transition
  - October 2018 – Navigating adult care
  - April 2019 – Self-advocacy 101
- Use of social media
- Media coverage of event(s)
- Trust building b/t patients & providers

Project Barriers - Clinic

- Data data data!
  - Pulling accurate data
  - No registry
  - # of adults affected
  - LTFU/Outcomes
- Transition where???
  - Limited options for disease-specific care
- Lack of provider support
  - Provider burn-out
  - Clinic scheduling/lack of office time

Project Barriers - Community

- Event attendance
  - Reach
  - Transportation
  - Trust building

Next Steps

- Clinic-based assessments
- Relationship building
  - With other providers/systems
  - Patient and provider trust building
- Education
  - Patient education
    - Management of SCD Symposium
  - Provider education
    - Grand Rounds
    - Project ECHO

Next Steps

- Maintain & grow partnerships
  - MDH
  - HCMC
  - SCFMN
  - Other healthcare systems and providers

Future Opportunities

- Increased funding
  - Statewide data collection
  - Adult Comprehensive Sickle Cell Center
    - Centralized adult care
- Increased research, distribution and participation
  - ASH Clinical Trials Network
  - ASH SCD Care Guidelines
- Additional site visits
  - St. Paul
  - Outstate Minnesota

Quality Improvement Team

- Patient/Caregiver
  - Bathsheba Benson, adult patient, administrative assistant
  - Connie Caston, parent
  - Kenneitha Parson, young adult patient
  - Ruben Kossi Joanem Jr., adolescent patient
  - Rae Blaylark, parent of an adult patient

Quality Improvement Team (con't)

- Providers
  - Stephen Nelson, MD
  - Hannah Lichtsinn, MD
  - Kristin Moquist and Melissa Claar, nurse pracitioners
  - Hannah Batinich and Claire Franke, nurse case managers
  - Keeli Wagner, social worker
  - Rae Blaylark, Sickle cell patient and family health advocate


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