Update: UAMS Adult Sickle Cell Program

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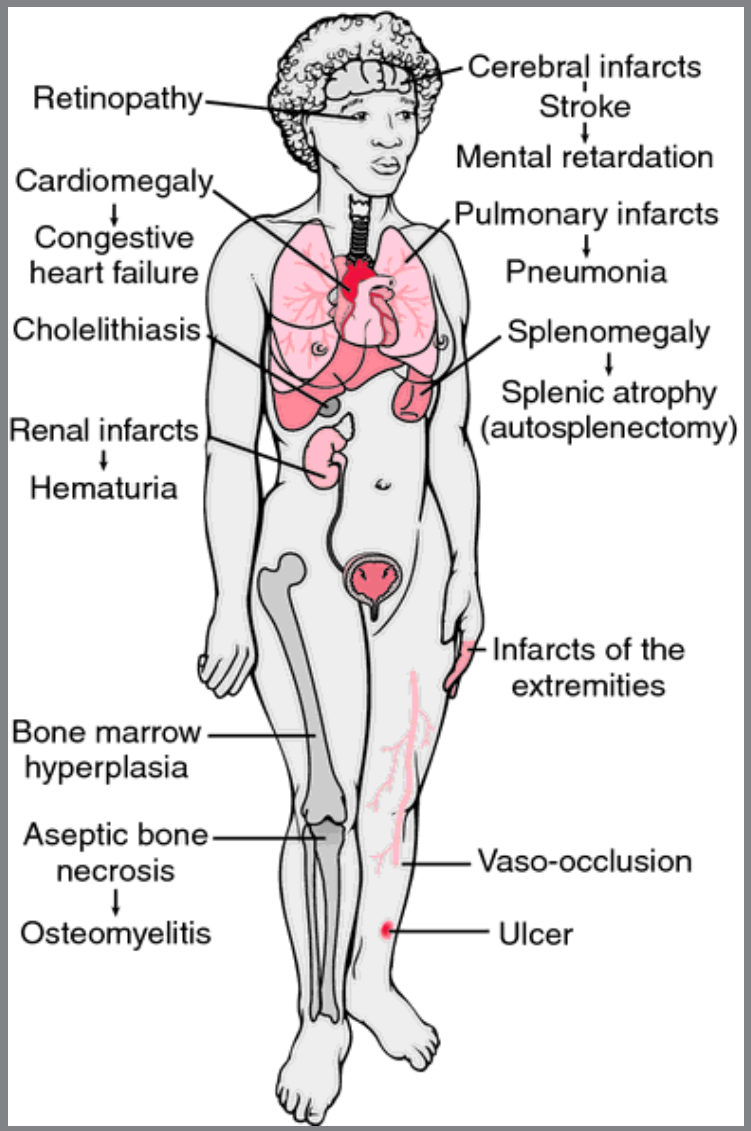
What is Sickle Cell (SC)?

- A group of inherited red blood cell disorders in which the red blood cells become hard, rigid, and sticky and take on the appearance of a crescent shape

SC Is More than Just Pain



Barriers to care for SC patients

- Limited providers with clinical expertise:
  - The vast majority of adult patients receive outpatient disease management from primary care physicians, not a sickle cell disease (SCD) specialist, leading to less comprehensive care (Grosse et al., 2009).

- Opioid Addiction Stigma:
  - Despite having addiction rates comparable to the average, SC patients are often viewed as “drug” seeking and manipulative.

Why the UAMS Adult Sickle Cell Program Matters?

1) Provides specialized care to adult SC patients

2) Facilitates successful transition from pediatric to adult care

3) Disseminates SC education to providers, patients, families, and members of the community

Specialized care to adult SC patients

- SCD was formerly known as a disease of childhood
- Nearly 300 patients have received care from the Adult Sickle Cell Program
- Patients receive coordinated care from the following specialties:
  - Hematology
  - Pharmacy
  - Palliative Medicine
  - Anesthesia Pain
  - Social Work
  - Nursing

Transition Care Importance

- Transition period is the time in which pediatric patients began to transfer care to the adult setting, usually age 18 to 21

- Transition Care Significance:
  - Potentially a high-risk period for youth with SC due to the worsening of disease complications that developed in childhood
  - Complications may be worsened during this period due health care system failures in the transition of care, causing increases in ED and inpatient visits
  - Morbidity and mortality drastically increased for patients with SCD after age 18 due to the above listed factors

Transition from pediatric to adult care

-45 patients have been successfully transitioned from Arkansas Children's Hospital to UAMS Adult Sickle Cell Program

-UAMS facilitates successful transition by:

- Meeting with ACH SC Clinic biannually
- Tracking patients starting at age 16 to ensure readiness to transition and timely appointment scheduling in advance of last visit with ACH
- Providing ACH patients with disease related education to ensure transition readiness
- Ensuring patients receive holistic care which is aimed at caring for their mind, body, and soul
- Demonstrates continuity of care by allowing social worker to initiate relationship with patients during pediatric care and continue this care into the adult setting

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Knowledge Dissemination

- Connecting Across Education talks delivered quarterly by members of the Adult SC Clinic Team
- Received internal grant funding to develop an algorithm to appropriately manage pain in the adult sickle cell population
  - Delivered a presentation at PainWEEK in Las Vegas, Nevada on the development of the SC management algorithm
- Providing education to family medicine residents on proper disease management across the life span
- Ongoing community outreach efforts
- Annual SC Symposium that provides education on hot topics in SCD

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Algorithm Development

- Goal:
  - UAMS Adult Sickle Cell Clinical Program and an expert panel collaborate to develop a clinical tool to assist with the management of opioids in the adult SC population

- Patient Benefits:
  - Safe opioid prescribing that is consistent with CDC recommendations
  - Increased quality of life
  - Decreased mortality by decreasing healthcare utilization

The Future of the UAMS Sickle Cell Program

- Internal education on stigma and bias among the SC population
- Further development and dissemination of algorithm to providers in AR
- Expansion of Regional Program educational sites
- Telemedicine
- Initiate dialogue on improving healthcare navigation for sickle cell patients with AR Medicaid

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