Adult Care Sickle Cell Disease

Health Disparities
After
Transition to Adult Care
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Sickle Cell in the United States

• Sickle Cell Disease: United States
  • 1 in 12 African Americans have sickle cell trait
  • 1 in 500 African American births
  • At least 100,000 people have sickle cell disease

• Sickle Cell Disease in California
  • Possibly 7,000 people with sickle cell disease
  • 50% reside in Southern California

• Prevalence of Other Inherited Disorders
  • Cystic Fibrosis: 30,000
  • Hemophilia: 20,000
  • Thalassemia: 1,000
Importance of Primary Care

- Primary care for a complex illness such as sickle cell disease is essential.
  - A medical home that can direct care and know a patient’s history is imperative
  - In order to access appropriate medical therapy a primary provider is necessary
    - Many therapies need to be monitored during treatment
  - Screening and referral require a primary caretaker
Adult Versus Pediatric Care

Between the ages of 15 and 25 years there is a dramatic increase in Stroke and Pulmonary Complications.
Mortality

Adult Medical Care

• COMPREHENSIVE CARE
  • PREVENTION OF COMPLICATIONS
    • SCREENING
    • EARLY TREATMENT
    • MEDICAL MANAGEMENT
      • PAIN MANAGEMENT

• MEDICAL THERAPIES
  • Hydroxyurea/l-glutamine/voxelotor/crizanlizumab
  • New pharmaceuticals as they become approved
  • Acute and chronic transfusion ordering and monitoring
  • Transplant and Gene Therapy
Quality Care for Sickle Cell Disease

- Comprehensive Sickle Cell Centers
  - Comprehensive Centers Providing Research and Guidance
- Increase Adult Sickle Cell Providers
  - Increased reimbursement for complex medical care
- Institution of NHLBI and ASH Guidelines for Care
  - Requirement for reimbursement