

Adult Care Sickle Cell Disease

Health Disparities

After

Transition to Adult Care

Keith Quirolo, M.D.

Sickle Cell in the United States

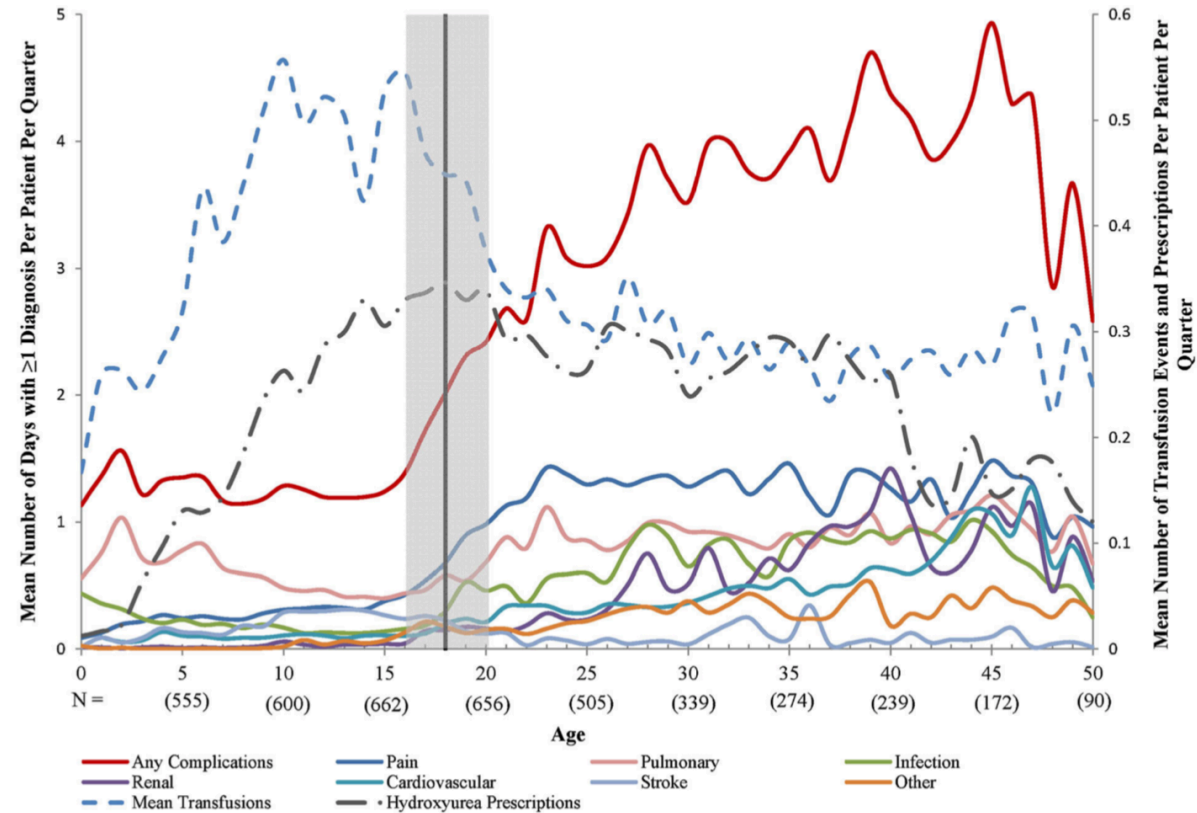
- Sickle Cell Disease: United States
 - 1 in 12 African Americans have sickle cell trait
 - 1 in 500 African American births
 - At least 100,000 people have sickle cell disease
- Sickle Cell Disease in California
 - Possibly 7,000 people with sickle cell disease
 - 50% reside in Southern California
- Prevalence of Other Inherited Disorders
 - Cystic Fibrosis: 30,000
 - Hemophilia: 20,000
 - Thalassemia: 1,000

Importance of Primary Care

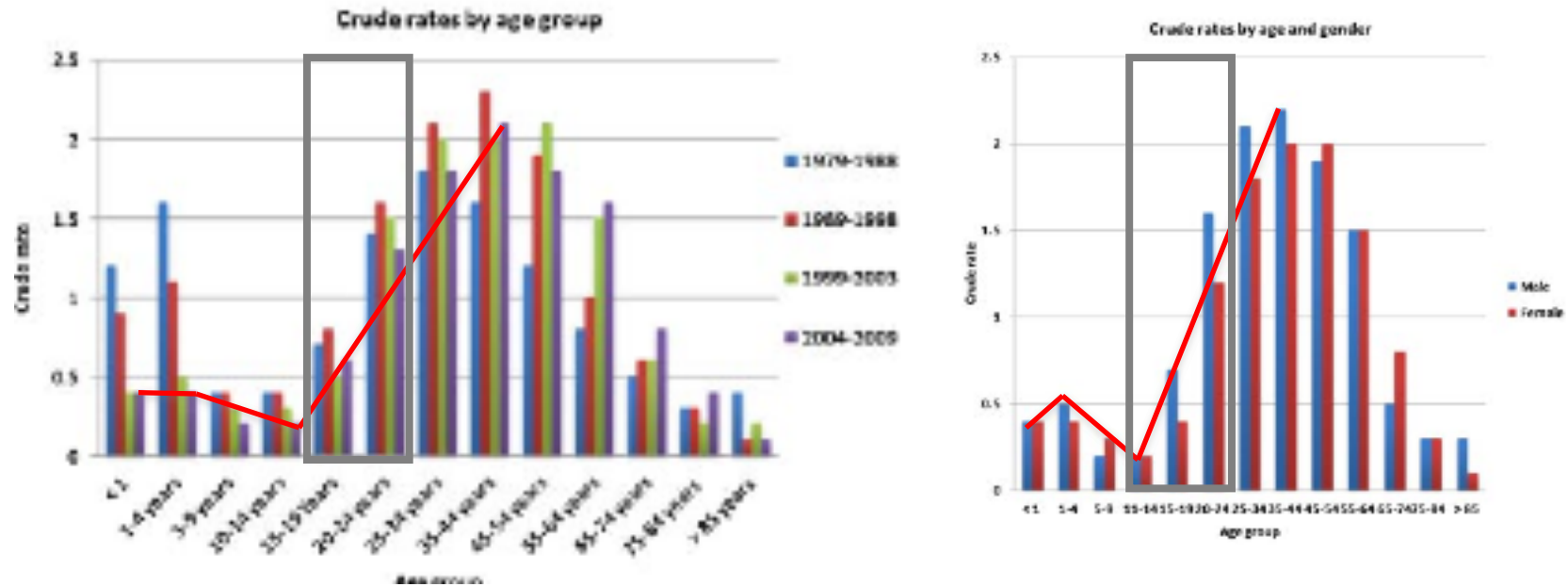
- Primary care for a complex illness such as sickle cell disease is essential.
 - A medical home that can direct care and know a patient's history is imperative
 - In order to access appropriate medical therapy a primary provider is necessary
 - Many therapies need to be monitored during treatment
 -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



Hamideh D, Alvarez O. Sickle Cell Disease Related Mortality in the United States (1999-2009). *Pediatric Blood & Cancer*. 2013.

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