Children's Hospital of Philadelphia PolicyLab

Transitioning Adolescents and Young Adults With Sickle Cell Disease From Pediatric to Adult Health Care: Provider Perspectives

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The transition from pediatric to adult health care is often challenging for adolescents and young adults with sickle cell disease (SCD). Our study aimed to identify (1) measures of success for the transition to adult health care; and (2) barriers and facilitators to this process. We interviewed 13 SCD experts and asked them about their experiences caring for adolescents and young adults with SCD. Our interview guide was developed based on Social-Ecological Model of Adolescent and Young Adult Readiness to Transition framework, and interviews were coded using the constant comparative method. Our results showed that transition success was measured by health care utilization, quality of life, and continuation on a stable disease trajectory. We also found that barriers to transition include negative experiences in the emergency department, sociodemographic factors, and adolescent skills. Facilitators include a positive relationship with the provider, family support, and developmental maturity. Success in SCD transition is primarily determined by the patients' quality of relationships with their parents and providers and their developmental maturity and skills. Understanding these concepts will aid in the development of future evidence-based transition care models.

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