Children's Hospital of Philadelphia
PolicyLab

Identifying Best Practices for Transitioning Youth with Sickle Cell from Pediatric to Adult Care

Statement of Problem

Youth with special health care needs face many challenges when transitioning from pediatric to adult care, including high risk for lapses in health care coverage, a shortage of adult health care providers and poor care coordination between health care systems. The 100,000 Americans living with sickle cell disease — a group of genetic red blood cell disorders that causes severe pain and anemia — are no exception to this rule. Entrance into adulthood is an especially risky period for youth with sickle cell disease as these patients experience a seven-fold increase in mortality rates during this time.

In addition to poor health outcomes, these youth often have not learned how to manage their care and advocate for their interests. While their caregivers and providers would previously be in charge of coordinating multiple doctors' visits and picking up medications, youth with special health care needs are often required to take over responsibility for these tasks as they enter adulthood. Small missteps along the way as a result of poor care coordination can have lasting impact on the health of these young people.

Description

Drs. David Rubin, Kim Smith-Whitley and Sophia Jan are leading a collaborative team of researchers at Children's Hospital of Philadelphia's Comprehensive Sickle Cell Center and PolicyLab and Northwell Health's Cohen Children's Medical Center to identify best practices for helping youth with sickle cell disease transition from pediatric to adult health care. Over five years, the study will examine the efficacy of two support interventions – a six-month community health worker program and a mobile health application – in providing self-management tools to youth 17 years and older with sickle cell disease who are in the process of transitioning from pediatric to adult care. The research team will compare these six-month interventions to usual care to see if these tools improve patients' ability to care for themselves, stay connected with their doctors, avoid visits to the emergency room, improve overall quality of life, and, ultimately, transition into healthy, productive adults.

This is the first-ever randomized controlled trial (RCT) that will compare two different transition-related interventions using the same patient populations.

Next Steps

Understanding if either of these interventions are effective at improving health outcomes and care management for youth could inform the ways in which hospitals and health systems allocate resources and prepare patients earlier in the transition process. Ultimately, this research could inform how providers and policies support all youth with special health care needs as they bridge the divide between adolescence and adulthood.

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Related Tools & Publications

- Training Young Adults as Community Health Workers Specializing in Pediatric to Adult Health Care Transition to Support Emerging Adults with Sickle Cell Disease
  Article
  Feb 2024

- Development of the iManage SCD Mobile Health Application for Transition
  Article
  Oct 2024

- Community Health Workers Supporting Emerging Adults with Sickle Cell Disease
  Article
  Feb 2025

- Community Health Worker and Mobile Health Interventions for Quality of Life Among Young Adults With Sickle Cell Disease
  Article
  Nov 2025