What Interventions Will Best Help Youth With Sickle Cell Disease Transition to Adult Care?

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Although parents and caregivers spend nearly 18 years preparing their children to become adults, the final launch is a difficult one for everyone. As our research team has documented in blog posts (here and here) and in a policy brief, transitioning to adult health care systems and to adult life can be challenging for any adolescent or young adult, particularly if they have chronic illnesses. For these folks, the difficulty surrounding transition is compounded by seeing multiple doctors, being on medication, and experiencing frequent symptoms of their conditions. All of this is in addition to the already tough decision points that occur during this phase of life, like beginning college or work.

One example of a chronic condition that can make this transition challenging is Sickle Cell Disease (SCD). SCD – an inherited blood disorder that causes red blood cells to change into a crescent shape at low oxygen levels – affects approximately 100,000 Americans. Young adults with SCD have the highest rates of death from their disease, and more hospitalizations, emergency room visits, and hospital readmissions compared to other age groups. Some of the increases in mortality and emergency room or hospital utilization at these ages may be due to difficulty coordinating services and care during the transition to adulthood, and is compounded by adolescents and young adults learning to take responsibility for their condition. Though health outcomes are poorer during this period, few rigorous research studies test interventions that look to set adolescents and young adults with SCD up for success in the adult world.

That's why we are thrilled about a new Patient Centered Outcomes Research Institute (PCORI)-funded project that will allow us to test interventions that address this gap. Specifically, we'll be testing community health workers – individuals who have shared experiences with patients and can help patients navigate difficult settings – and mobile health platforms – specifically smartphone apps, SMS texting and social media platforms – to determine if these increasingly popular methods can make a positive impact on the lives of young people during this formative phase.

Researchers at Children's Hospital of Philadelphia (CHOP) from the Division of Hematology and PolicyLab and Cohen Children's Medical Center of Northwell Health designed this PCORI study. And we have important pediatric and adult collaborators from Cincinnati Children's Medical Center, St. Christopher's Hospital for Children, University of Pennsylvania, Connecticut Children's Hospital, and the New England Sickle Cell Institute. However, we are most proud of the young adults with SCD who are also part of the research team. These individuals, who were instrumental in the proposal design and are now assisting with intervention development, have gone through the transition process themselves, bringing their own experiences to the table. When we asked what they wish they knew before transitioning, they said:

> *When receiving pediatric care from the same group of individuals at CHOP most of my life, everyone (including my parents) knew what occurred and I really didn't have to share or voice my experience to health care professionals. This was also the case when I made emergency visits to CHOP's ER department. They had my information pulled up right away. On the contrary, when transitioning to adult care, I had to state information I didn't really recall, which was at times embarrassing since I now was considered an 'adult.'*

> *I wish I would have known other sickle cell patients that were also going through transitioning. It was tough navigating that time in my life without the support of my peers. Having other patients' encouragement could have made my transition a little more comforting knowing that others were going through the same thing.*

Transitioning care for those with SCD can be an uncertain time. The development of a strong support system and self-management skills are key. Throughout the next five years, we're hoping to learn how best to support youth in their transition to adulthood and what tools are best for empowering them to manage the transition process themselves.

For now, as we launch this project, we're inspired by our young adult partners, who always remind us the importance of our work:

> *Seeing other adult patients with sickle cell disease thrive is inspirational and gives me joy. This study aims to give patients struggling with this painful and debilitating disease tools to succeed and live healthier lives during a process that is usually difficult.*

> *As a young professional living with sickle cell, I've always been hopeful and looked towards accomplishing goals as it pertained to my future. Thus, this study would help young adults living with sickle cell plan for their future without having their condition limit their personal ambitions in life.*

We're excited for this opportunity to work with great collaborators to really advance the evidence base for how to successfully transition youth with complex medical needs to adult care.

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