Can Technology Help Teens Transition to Adult Care?

Adolescent Health & Well-Being

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Image

Growing up, sickle cell disease was not a term that I knew much about. When I was 12 years old, my mom finally granted my wish of becoming an older sister and we were lucky enough to be blessed with twins. Though I wasn't too thrilled that they were both girls, it was an exciting time. I can recall being in South Carolina, spending the summer with my grandma, when my mom called to tell me that the twins' newborn screenings had come back. They had sickle cell disease, which they inherited from both parents. She sounded distraught and I didn't quite understand what all of that meant.

Sickle cell disease (SCD) is a group of genetic red blood cell disorders that causes severe pain and anemia, increases the risk for infections and damages organs throughout the body. The disease usually starts in childhood and approximately 100,000 Americans are living with the disease today.

The first few years were rough for my sisters, with many overnight stays at Children’s Hospital of Philadelphia (CHOP), but now they are both living healthy lives at the age of 22. Once I got into research and decided to pursue my doctorate, I knew I wanted to focus on sickle cell research.

Tanisha (middle) and her sisters Ashli (left) and Asya (right)

The Challenges of Transitioning to Adult Care

Due to the increase in the life expectancy of teens and young adults with chronic diseases in the past 50 years, now more than 90% of them will survive into adulthood. This increase calls for a focus on how we support patients in transitioning from the pediatric health care system to adult care.

Young adults with SCD have limited knowledge of the adult SCD health care system, along with limited decision-making experience, which pose challenges when faced with transition. Due to these challenges, like loss of insurance coverage, young adults (16-25 years of age) with SCD experience a seven-fold increase in mortality rates during the years that they transition to adult care.

Additionally, young adults with SCD also have the highest rates of hospitalizations, emergency room visits and hospital readmissions compared to all other age groups. Some of this increase is a result of cumulative disease effects and increasing comorbidities due to age, such as stroke and silent infarcts. We know that adherence to chronic transfusion therapy and hydroxyurea therapy can significantly decrease the risk of neurologic complications for SCD patients. But poor care coordination during this transition period from pediatric to adult care, compounded with poor patient engagement and disease self-management skills, can significantly increase the risk of neurologic complications. These complications can have devastating and long-term impacts on physical function, educational attainment, employment, income and quality of life.

Providing Support Through Technology and Community Health Workers

I am part of a team of researchers at CHOP and Northwell Health’s Cohen Children’s Medical Center leading a multi-site randomized controlled trial to identify best practices for helping youth with SCD transition from pediatric to adult health care. When I first heard about this project, supported by the Patient-Centered Outcomes Research Institute, my sisters were turning 19 and they were becoming worried about leaving the care team they have been with since birth. All they knew was CHOP. The thought of leaving their doctor scared them. I remember one of my sister’s asking *"Can't she just keep me a little longer?"*

It’s stories like my sisters’ that show just how important this research is. 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 SCD who are in the process of transitioning from pediatric to adult care. The research team will compare these six-month interventions to typical care to determine if these tools improve patients' ability to care for themselves, stay connected with their doctors, avoid visits to the emergency room, improve their overall quality of life and, ultimately, transition into healthy, productive adults.

Recruitment for this project resumed earlier this year and we are excited to support young adults at each of our partnering institutions. Watch our new recruitment video and share with anyone you may know who would be interested in participating.

Through our work, we will examine the impact of our mobile health app and community health interventions on these teens as they prepare to enter adult care and create more resources for young adults preparing for this transition. Overall, we hope that teens will improve their self-management skills and feel more control over managing their health before they need to transition to adult care, empowering them as they begin their journey into adulthood. And when the time comes for them to transition, patients like my sisters will be met with supportive and innovative methods to help them along the way.

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