PKR activators are investigational. Safety and efficacy are not established. There is no guarantee that investigational PKR activators will become commercially available for the use(s) under investigation.

Navigating your transition into living with sickle cell disease as an adult

Transitioning into adulthood is a period of change that can come with potential health risks

The transition to adulthood for individuals with sickle cell disease involves a pivotal shift toward greater self-management, with each journey shaped by unique timelines, experiences, and needs. When important aspects of the transition are not carefully planned, it can result in disrupted access to treatment, gaps in care, and emotional distress. These challenges contribute to adverse health outcomes commonly observed during this critical period.

Young adults (aged 18-25) with sickle cell disease experience:

Increased organ complications

18.7% having two or more dysfunctional organs compared to just 6.1% of adolescents.[1]

Higher frequency of acute pain crises

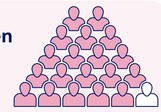
8.8% report hospital visits for acute pain crises compared to 3.3% of adolescents.[1]

Lower quality of life

Poorer sleep, more fatigue, lower social support, and decreased emotional well-being compared to adolescents, using standardized measures of quality of life.[1]

Overall, these disparities contribute to a well documented rise in hospitalizations and mortality following the transition from pediatric to adult care.[2,3]

Today, over 95% of children with sickle cell disease are surviving into adulthood.[4]



Each year, a significant number of individuals undergo this critical transition period and *need support to navigate it successfully.*

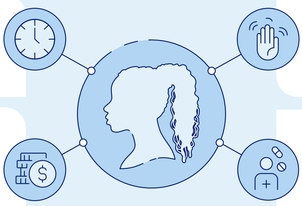
What healthcare system barriers might you face in achieving optimal care during this transition?

There are many healthcare system barriers that patients may face when leaving pediatric care that can impact one's ability to achieve optimal care as a young adult.

Some of the barriers are:

1. **Limited Access to Specialized Care**
   Many patients struggle to find adult sickle cell disease specialists, and as a result may face long wait times.

2. **Bias and Stigma**
   People with sickle cell disease often face discrimination or feel unfairly treated by healthcare providers due to unconscious bias or prejudice.



3. **Financial and Insurance Hurdles**
   Challenges like insurance disruptions, job changes, and limited funding for comprehensive sickle cell disease care can make treatment harder to afford or access.

4. **Burden of Self-Management**
   Patients often carry the full weight of managing medications, appointments, records, and coordinating between providers, which can be overwhelming.

What are the key milestones of a successful transition?

Each individual's path and timeline in transitioning from pediatric to adult care is unique. Despite this, there are essential milestones that can help towards a successful transition.

Milestones of transitioning into adult care[7]:

1. **Establishing care with an adult sickle cell disease specialist**
2. **Forming connections with adult care support services**, including engagement with specialized care teams, dedicated nursing staff, and advanced practice providers
3. **Developing and implementing a personalized pain management plan**
4. **Securing a plan for ongoing transfusion support**
5. **Transitioning from your parents' insurance to your own**

A great resource to utilize is the Center for Transition to Adult Health Care for Youth

Proactively planning your transition and securing strong support can significantly reduce the risk of serious health setbacks, empowering you to take charge of your care and confidently navigate your healthcare journey.

What you need to know when planning for your transition

It is important to begin planning at least a year before you start the transition to give yourself enough time to get organized.

Key actions during your transition include[8]:

- Obtaining and organizing past medical records in a secure and easily accessible place
- Becoming aware of your condition and how it affects you
- Accessing resources on how to find an adult provider in-network
- Navigating insurance changes (ex. Moving from your parents' insurance to your own)
- Finding available emotional support and advocacy groups

To get you started on planning for your transition into adulthood, some national sickle cell disease patient resources and organizations include:

Resources

- Transition Toolkit – Sickle Cell Disease Coalition
- Patients - Hematology.org
- National Sickle Cell Advocacy Network

Be sure to also ask your healthcare providers about programs available in your community to aid in your transition.

Key Takeaways

- During the transition period from pediatric to adult care, patients experience a rise in healthcare utilization, emergency room visits and even mortality.
- The transition is often hindered by a shortage of specialized providers, persistent bias and stigma, financial and insurance barriers, and the overwhelming burden of self-management, all of which contribute to the elevated risk of adverse health outcomes during this vulnerable period.

While transitioning to adult care may be difficult, becoming aware of your unique patient needs, utilizing community support programs or resources, and taking proactive steps to mitigate the risk of adverse outcomes will empower you to navigate your healthcare journey with confidence.

ER, Emergency Room; SCD, sickle cell disease

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