Understanding the health-care experiences of people with sickle cell disorder transitioning from paediatric to adult services: This Sickle Cell Life, a longitudinal qualitative study

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Plain English summary

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Plain English summary

What happens during transitions from childhood to adulthood can affect young people's future lives. Children with long-term health conditions must learn to manage their own health as they get older and eventually start using adult health-care services. These transitions to adult care do not always go well. Sickle cell disorder is one long-term condition for which transitions are particularly challenging and people's health can suffer.

We investigated the experiences of young people with sickle cell disorder as they transitioned to adult services. We explored what else might affect their health-care transitions outside the hospital. We interviewed young people with sickle cell disorder and sickle cell disease specialist health-care providers in two cities in England.

Key obstacles young people face during transition include not being listened to by others (e.g. teachers, friends, non-specialist hospital staff) and not being recognised as experts in their own condition. Health-care providers and other adults want young people to learn about their condition and act responsibly to stay healthy. However, when young people try to take responsibility (e.g. making requests about the care they receive) they are often ignored. As a result, young people stop trusting places where they have not experienced good care, such as in accident and emergency departments and on general wards, and avoid going, although they know that avoiding hospital is risky.

Such young people also struggle to develop adult identities (i.e. ideas about how they should behave as adults). They want to work hard and do well in school, but this is incompatible with their need to take responsibility for their condition, for instance needing to rest to avoid pain. These conflicting demands are hard to balance.

We need to support others in young people's social and health-care environments to learn about sickle cell disorder and to treat young people as experts in their own condition.

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