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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John O Warner reports acting as a principal investigator and a scientific advisory board member (2005 to present) for trials of infant milk formulae for the prevention of allergy (Danone SA, Paris, France/Nutricia, Zoetermeer, the Netherlands); acting as an investigator and a scientific advisory board member (2008 to present) for trials of an environmental control system for allergic conditions (Airsonett AB, Angelholm, Sweden); bursaries for lectures at conferences for Danone SA/Nutricia, Airsonett AB, UCB Pharma (Brussels, Belgium), Novartis Pharmaceuticals UK Ltd and Allergy Therapeutics plc (Worthing, UK); acting as medical advisor (1993 to present) for the Anaphylaxis Campaign (www.anaphylaxis.org.uk); membership of the scientific advisory board (2017 to present) for a UK government Home Office enquiry into potential toxic health hazards from the Grenfell Tower fire; and acting as academic theme lead (2014–19) for the Collaboration for Leadership in Applied Health Research and Care for Northwest London (until 30 September 2019).

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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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