

Improving Children's Lives: An International Interdisciplinary Conference Queens University Belfast

Abstract

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Facilitators and barriers to successful transition from paediatric to adult healthcare services: Informing the development of healthcare services.

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Background: Due to advances in healthcare, increasing numbers of children with chronic illnesses are entering adulthood and transitioning from paediatric to adult healthcare services. While parents are predominantly responsible for their children's healthcare management in paediatric services, the newly transitioned young person is expected to be wholly responsible for their treatment regimen, make autonomous healthcare decisions, and interact with their health providers independently. Abrupt and poorly managed transitions have been associated with poorer health outcomes and health behaviours.

Aims: To obtain a comprehensive understanding of the needs and experiences of young people and their parents transitioning from paediatric to adult healthcare services in Ireland, and provide recommendations for the development of transitional care services.

Conformity with ICL Values: The research adopted an evidence-informed approach in that it sought to understand the needs and experiences of young people and their families to inform the development of transitional care services. It also conformed to an outcomes-focused approach since it explored facilitators and barriers to good health outcomes and behaviours during the transition process. A rights-based approach to children's participation in research was also employed, given that the perspectives of young people on all aspects of transitional care were sought.

Method: Semi-structured interviews were conducted with young people aged 14-25 years with one of three chronic illnesses (type 1 diabetes, cystic fibrosis, or congenital heart disease) (n=47), their parents (n=36), and healthcare professionals (n=32). Participants were recruited at hospital clinics across six hospital sites. Ethical approval was granted by ethics committees at Trinity College Dublin and the hospital sites. The data were analysed using thematic analysis.

Findings: Transition was experienced on a continuum from smooth to traumatic. Adjusting to environmental and cultural differences in adult healthcare services was overwhelming for some young people and their families, while others welcomed the young person's enhanced responsibility and autonomy. The negotiation of healthcare management roles between young people, parents, and new healthcare professionals was a complex and dynamic process. Where young people were unprepared to assume full responsibility for illness management, deterioration in self-care behaviours and hospital attendance was reported. Conversely, successful transitions were experienced where young people had developed adequate self-care skills and self-efficacy; patients and families had positive attitudes and beliefs; there was effective communication by healthcare professionals; and where staff demonstrated flexibility in their communication with patients and families at various stages of transition readiness.

Conclusions and implications: The transition from paediatric to adult healthcare services is a complex, dynamic process. This study provides evidence on the factors influencing successful healthcare transition and associated outcomes for young people and their families. Implications for the development of healthcare services will be explored.