



Transition from children's to adult services for young adults with life-limiting conditions: A realist review of the literature



Helen Kerr^{a,*}, Jayne Price^b, Honor Nicholl^c, Peter O'Halloran^a

^a School of Nursing and Midwifery, Medical Biology Centre, Queen's University, Belfast, Northern Ireland, United Kingdom

^b Faculty of Health, Social Care and Education, Kingston University and St George's, University London, Kingston Hill Campus, Kingston upon Thames, Surrey, United Kingdom

^c School of Nursing and Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin, Ireland

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ABSTRACT

Background: Improvements in care and treatment have led to more young adults with life-limiting conditions living beyond childhood, which means they must make the transition from children's to adult services. This has proved a challenging process for both young adults and service providers, with complex transition interventions interacting in unpredictable ways with local contexts.

Objectives: To explain how intervention processes interact with contextual factors to help transition from children's to adult services for young adults with life-limiting conditions.

Design: Systematic realist review of the literature.

Data sources: Literature was sourced from four electronic databases: Embase, MEDLINE, Science Direct and Cochrane Library from January 1995 to April 2016. This was supplemented with a search in Google Scholar and articles sourced from reference lists of included papers.

Review methods: Data were extracted using an adapted standardised data extraction tool which included identifying information related to interventions, mechanisms, contextual influences and outcomes. Two reviewers assessed the relevance of papers based on the inclusion criteria. Methodological rigor was assessed using the relevant Critical Appraisal Skills Programme tools.

Results: 78 articles were included in the review. Six interventions were identified related to an effective transition to adult services. Contextual factors include the need for children's service providers to collaborate with adult service providers to prepare an environment with knowledgeable staff and adequate resources. Mechanisms triggered by the interventions include a sense of empowerment and agency amongst all stakeholders.

Conclusions: Early planning, collaboration between children's and adult service providers, and a focus on increasing the young adults' confidence in decision-making and engaging with adult services, are vital to a successful transition. Interventions should be tailored to their context and focused not only on organisational procedures but on equipping young adults, parents/carers and staff to engage with each other effectively.

What is already known about the topic

- There is a growing population of young adults with life-limiting conditions living into adulthood and needing to make the transition from children's to adult services.
- Transition to adult care for young adults is a challenging and complex process.

What this paper adds

- Describes the range of interventions employed to promote an

effective transition to adult services for young adults with life-limiting conditions.

- Identifies key contextual factors influencing the success of interventions.
- Uncovers underlying mechanisms facilitating an effective transition to adult services.

1. Background

Early detection and advances in health care have led to improved survival for children with life-limiting conditions (Schwartz et al.,

* Corresponding author at: School of Nursing and Midwifery, Medical Biology Centre, Queen's University, Lisburn Road, Belfast, BT9 7BL, Northern Ireland, United Kingdom.

E-mail addresses: h.kerr@qub.ac.uk, hkerr09@qub.ac.uk (H. Kerr), j.e.price@sgul.kingston.ac.uk (J. Price), nichollh@tcd.ie (H. Nicholl), p.ohalloran@qub.ac.uk (P. O'Halloran).

2011; Scott, 2011; Department of Health, 2006). This has resulted in a growth in the number of young adults graduating from children's to adult care, making effective transition from children's to adult care (transition) increasingly important (Mellor and Hain, 2010). A commonly used definition for transition is the "purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems" (Blum et al., 1993, p. 570). Transition has been conceptualised as a process and also as an event (Annunziato et al., 2011). Ideally, the transition process should accommodate the gradual transfer of responsibility for healthcare decision-making from the parent to the young adult and the event takes place when the responsibility for providing care transfers to adult care (Gilleland et al., 2012). Although transition is a milestone in the young adult's life (McGill, 2002), leaving the care of children's services is often viewed as a logical step for young adults and their parents (van Staa et al., 2011). However, one of the challenges for young adults in the transition process are the significant differences between children's and adult services (Hait et al., 2006) in that children's services typically provide more family focused care with a high level of parental involvement, while adult services are patient focused and expect the patient to have greater independence (McGill, 2002). This cultural gap (van Staa et al., 2011; Rosen, 1995) between children's and adult services can complicate the transition process for adolescents (Viner, 1999). There is emerging evidence to suggest organised transition protocols and programmes do have measurable benefits for young adults and their parents/carers such as improved clinic attendance, better disease control, reduced hospital admissions and enhanced quality of life for a range of medical conditions (Van Wallegghem et al., 2008; McDonagh et al., 2007; Department of Health, 2006; Holmes-Walker et al., 2006). However, poorly managed transitions are associated with increased risk of non-adherence to medication and other treatment (Annunziato et al., 2007; Department of Health, 2006; Van Wallegghem et al., 2006; Watson, 2000) with attrition/loss to follow up one of the more widely reported markers of effective transition to adult care (Fair et al., 2011; Goossens et al., 2011; Breakey et al., 2010; DoH, 2006; Van Wallegghem et al., 2006). For example, 7.3% of young adults were reported not to be in follow-up care after leaving paediatric cardiology (Goossens et al., 2011) and 19.8% of young adults with the Human Immunodeficiency Virus were reported to be lost to follow up in the year after turning 22 years (Agwu et al., 2015).

1.1. Complexity of organisational interventions to transition

There are organisational approaches recommended to promote an effective transition to adult care associated with a range of medical conditions (Chambers, 2015; Lidstone, 2013; Department of Health, 2008; While et al., 2004; Forbes et al., 2002; Blum et al., 1993) with an increasing focus in recent years on life-limiting conditions and palliative care (Chambers, 2015; Beresford and Sturtard 2014; Kirk and Fraser, 2014; Noyes et al., 2014; Beresford, 2013; Lidstone, 2013). Interventions include effective communication and information sharing between children's and adult services (While et al., 2004; Forbes et al., 2002), shared responsibility for transition between children's and adult services (Blum et al., 1993), constructing services and care as an extension to children's services or jointly between children's and adult services (While et al., 2004; Forbes et al., 2002), a focus on supporting the young adults development (Forbes et al., 2002; While et al., 2004), the development of a transition plan (Department of Health, 2008), a multi-agency approach (Chambers, 2015) and the appointment of a key worker (Chambers, 2015; While et al., 2004; Forbes et al., 2002). The key worker role is thought to be particularly suitable for young adults with a shorter life expectancy (While et al., 2004; Forbes et al., 2002). Approaches to transition are complex – consisting of multiple inter-related and interdependent components – and their effectiveness

highly context dependent. With this complexity in mind, we conducted a realist review of the literature in order to illuminate the nature and impact of intervention processes and contextual factors on transition outcomes. We have followed the "Realist and meta-narrative evidence syntheses evolving standards" (RAMESES)(Wong et al., 2013) which provide guidance for the publication of realist literature reviews.

2. Review questions

What range of interventions are associated with an effective transition from children's to adult services for young adults with life-limiting conditions?

What are the contextual factors that facilitate an effective transition to adult services?

What mechanisms are triggered by the interventions that support an effective transition to adult services?

3. Design

A realist literature review is a theory driven approach to evaluation which aims to "make explicit the underlying assumptions about how an intervention is supposed to work and then gather evidence in a systematic way to test and refine the theory" (Pawson et al., 2004, p. 3). A realist review offers explanations constructed around three ingredients: context (C), mechanisms (M) and outcomes (O), framed as CMO configurations. The context is crucial to a realist explanation as there will always be contextual variations between programmes. Even if programmes have the same characteristics, the circumstances in which they are played out are always different so they are never really the same (Pawson, 2013). The context consists of intertwined layers which include the individuals involved, interpersonal relationships, institutional settings and infrastructure, characterised as "the prior set of social rules, norms, values and interrelationships gathered in these places which sets limits on the efficacy of program mechanisms" (Pawson and Tilley, 1997, p. 70). These form the social structures into which an intervention is introduced with a view to changing that context. Mechanism is a contested concept, with a range of definitions in the literature (Astbury and Leeuw, 2010). Following Bhaskar (2008), we characterise mechanisms as the unseen ensemble of tendencies, liabilities and powers possessed by objects in the world; and principal amongst these in the arena of healthcare interventions, is human agency (Higgins et al., 2014). Human agency is the power to think, reason, deliberate, imagine, plan and believe, and on the basis of these, to decide to take action (Archer, 2003).

Interventions alone do not bring about a change in behaviour; the intervention introduces reasoning and resources which alter the context, providing individuals with the opportunity and motivation to change their behaviour. Thus mechanism and context combine to produce outcomes, which are the observable responses of groups or individuals to the intervention in a particular context. Programme theories are implicit or explicit underlying assumptions about how an intervention is supposed to work. A realist literature review seeks to provide an account of how complex interventions work along with an understanding of how theory may be developed and improved (Pawson, 2013; Maxwell, 2012; Rycroft-Malone et al., 2010; Pawson et al., 2004; Pawson and Tilley, 2004; Pawson, 2001). The realist approach sets no methodological limitations on the literature eligible for the review (Higgins et al., 2012). Documents are included on the basis that they help to develop and then test provisional theories (Wong et al., 2013) with no preference for quantitative or qualitative research methods as it sees merit in using multiple methods (Pawson et al., 2004).

3.1. Data sources

Inclusion and exclusion criteria. Papers were included if they were relevant to the transition to adult services amongst young adults with

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