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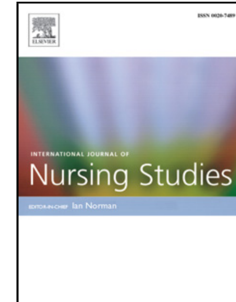

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Article type:

Review article

Article title

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

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Background

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

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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 Walleghem 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 Walleghem 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 Walleghem 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).

Complexity of organisational interventions to transition

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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 Stuttard 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 interrelated 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.

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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?

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

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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

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no preference for quantitative or qualitative research methods as it sees merit in using multiple methods (Pawson et al., 2004).

Data sources

Inclusion and exclusion criteria. Papers were included if they were relevant to the transition to adult services amongst young adults with life-limiting conditions. Life-limiting conditions "are those for which there is no reasonable hope of cure and from which young people will die" (Together for Short Lives, 2013, no page number). Following a scoping review of the literature, which included a substantial body of policy and guidance, it became apparent that much of the transition literature is focused on both life-limiting and chronic medical conditions that are not considered life-limiting. To ensure life-limiting conditions were included in the review, after documents were sourced in the literature search, medical conditions were only included if they were present in the Directory of Life-Limiting conditions in children (Hain et al., 2013).

Resources searched

The search was undertaken in four electronic databases; Embase, MEDLINE, Science Direct, Cochrane Library from January 1995 to April 2016. The selection of key search terms was informed by literature searches undertaken by previous authors in systematic reviews including a review for young people with palliative care needs (Doug et al., 2011) and a Cochrane review protocol focusing on transition from children's to adult services (Campbell et al., 2012). Terms combined in a search strategy for Medline and adapted for other databases are presented in Table One.

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Identifying primary sources

The initial search in the four electronic databases was independently undertaken by two reviewers (HK and PO) which resulted in 2082 papers (Figure one). Grey literature was also sourced in Google and Google Scholar using keyword searches identifying relevant transition information from professional organisations, voluntary bodies and conference papers (n=29). Papers were also sourced from reference lists of included papers (n=25). A total of 2136 papers were identified in the search. 68 duplicates were removed leaving 2068 papers for further screening. Titles and abstracts were reviewed by one reviewer (HK) to assess if the content focused on the process of transition from children's to adult care; with a second reviewer (PO) assessing a sample of titles and abstracts to check decision-making on inclusion and exclusion. 1776 papers were rejected because the medical condition was not included in the Directory of Life-Limiting conditions (Hain et al., 2013) or because the focus was on transition processes related to other areas, such as the transition from curative to palliative care, or the transition from hospital to home. Two members of the review team (HK and PO) read the remaining 292 papers in full with the same criteria for removal of papers. 78 papers were considered relevant and are presented in Table Two: Supplemental File.

Table Two

See Supplemental File

Figure one

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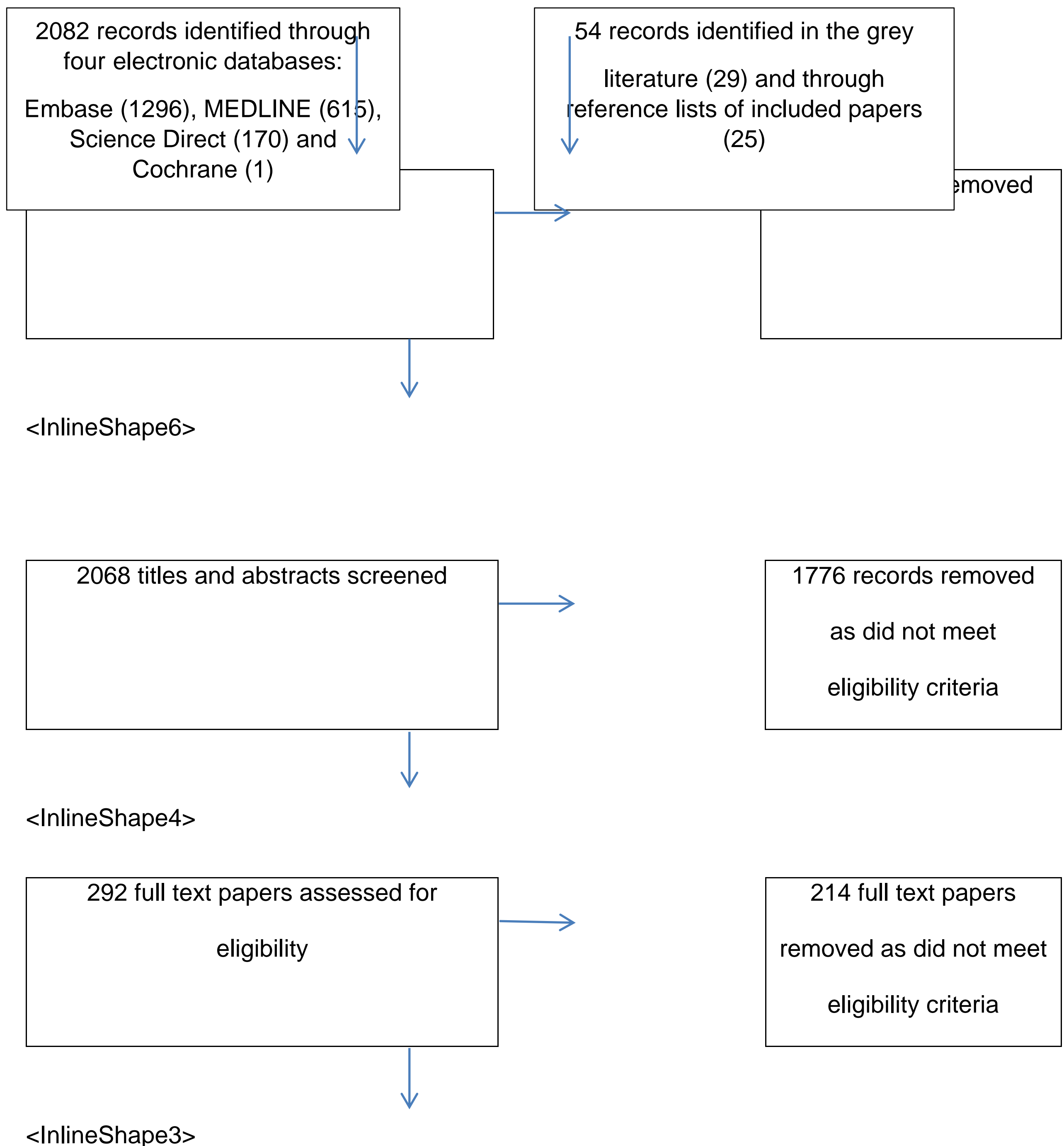
Flow diagram illustrating search process



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78 papers included in synthesis

Data extraction and quality appraisal

Data were collected using a standardised data extraction tool developed for a previous realist review (O'Halloran et al., 2014) drawing on insights from the RAMESES standards (Wong et al., 2013). In addition to information extracted related to methods used, this tool also documents information related to the intervention, mechanism, context and outcome, associated with a realist literature review. Realist synthesis allows for the inclusion of a wide variety of studies but also examines the methodological quality of studies in order to allow moderation of findings. Methodological rigour was assessed using the relevant Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme, 2015) and this information is included in Table Two.

Identifying CMO configurations

The process of analysing and synthesising the data involved two reviewers (HK and PO) independently reading each text, populating the data extraction forms, seeking to identify the range of interventions associated with an effective transition, searching for explicit or implicit programme theories, and theorising about how context and mechanisms interacted to produce outcomes of interest. The iterative process involved in analysing the papers led to the identification of CMO configurations, or assumptions of how each

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intervention is supposed to work, related to the facilitators in the transition to adult care. Potential CMO configurations were generated by two reviewers (HK and PO) who then discussed their findings and came to an initial consensus. The CMO configurations were then shared with co-authors for critique and validation, leading to a final consensus on the CMO configurations.

Results

78 papers were included in the review. 11 were literature reviews, 65 were observational designs and two were clinical trials (Table Two: Supplemental File).

Methodological rigour

Of the 78 research studies, 33 were rated as having strong methodological rigour, 36 as having moderate rigour and four as having weak methodological rigour. The remaining five documents were reports such as those published by the Care Quality Commission, so rigour could not be assessed. This information is included in Table Two. Whilst many of the studies demonstrated methodological rigour in relation to their chosen method, in terms of the traditional hierarchy, the evidence base was weak (Balshem et al., 2011).

Interventions to enhance transition

Six interventions were identified that were intended to enhance the transition to adult care and lead to positive outcomes in the transition process. These are an early start to the transition process; effective communication and collaboration between children's and adult service providers; orientating the young adult to adult services and optimising

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relationships with children's and adult service providers who demonstrate a person centred and individualised approach; the engagement of a key worker; interdisciplinary and interagency joint working and the development of an autonomous young adult throughout the transition process.

Populations

Populations represented include young adults with life-limiting conditions, palliative care, cystic fibrosis, cerebral palsy, human immunodeficiency virus and acquired immunodeficiency deficiency syndrome, congenital heart disease, Duchenne muscular dystrophy, spinal muscular atrophy, malignant neoplasms, cancer, end stage renal disease, nephrotic syndrome and multiple sclerosis. This information is included in Table two: Supplemental File.

Context Mechanism Outcome (CMO) configurations

The six interventions identified above are now discussed in greater detail and presented as CMO configurations.

CMO1. Early start to the transition process. An early commencement to the transition process is reported by a range of authors to contribute to an effective transition (Chambers, 2015; Care Quality Commission, 2014; Fegran et al., 2014; Sharma et al., 2014; Begley, 2013; Chaudhry et al., 2013; Lidstone, 2013; Tuchman and Schwartz, 2013; Gravelle et al., 2012; van Staa et al., 2011; Fair et al., 2010; Valenzuela et al., 2009; Reid et al., 2004; Madge and Bryon, 2002; Scal, 2002). The transition process

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begins when the young adult and their parents/carers are informed by service providers at an early stage to expect a move from children's to adult services when they reach an age when they would be expected to be using adult services. The age to transfer to adult services was reported to be variable across different jurisdictions. As an illustration, it is reported young adults with cystic fibrosis could transfer to adult services from 16 years in the Republic of Ireland (Begley, 2013) whilst in France the age to transfer was reported to be 22 years (Dugueperouz et al., 2008). 18 years is more commonly reported, or recommended to be the approximate age for the young adult to transfer to adult services (de Mulder et al., 2012; Gravelle et al., 2012; van Staa et al., 2011; Anderson et al., 2002; Boyle et al., 2001) across jurisdictions and medical conditions.

The transition process is typically triggered by an individual raising the issue, although who this is and how it comes about varies. There is a lack of clarity on when the process should commence but with some consensus on 14 years (Chambers, 2015; Care Quality Commission, 2014). An early start appears to work by bringing the coming change to the attention of everyone involved and provides time for responses to be formulated. In other words, it provides an opportunity for a phased and gradual approach, which may be used, or not, in a variety of ways. This includes making plans and preparing for the transition (Care Quality Commission, 2014; Valenzuela et al., 2009), learning about adult services, helping the young adult to develop the skills necessary to negotiate adult services (Fair et al., 2010) and meeting with adult service providers with a view to developing a collaborative relationship (van Staa et al., 2011). The time to think, reflect, learn, plan and make relationships with adult service providers appears to trigger a

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mechanism of enhanced self-efficacy in the young adult and their parents/carers in relation to engaging with adult services. The intended outcome of an early intervention is a young adult who has had time to consider and adjust to the coming change, leading to them more readily attending clinic appointments and adhering to health management plans. These outcomes may be more likely if enabling contextual factors are present, such as an encouraging and optimistic attitude from paediatric staff about the move to adult services as this can influence a positive response in young adults (Wiener et al., 2009; Brumfield and Lansbury, 2004). However, although an early start is necessary, it is not sufficient as time made available should be used productively to implement other interventions.

CMO2. Effective communication and collaboration between children's and adult service providers. Continuous effective communication and collaboration between children's and adult services about the young adults' current and anticipated needs throughout the transition process is thought to contribute to an effective transition for the young adult (Chaudhry et al., 2013; Huang et al., 2011; van Staa et al., 2011; Fair et al., 2010; Wiener et al., 2009; Por et al., 2004; Madge and Bryon, 2002; Forbes et al., 2002; Steinkamp et al., 2001). Effective communication is evidenced by the successful passage of information between services on the evolving needs of the young adult and their parents/carers (Forbes et al., 2002) leading to the development of a collaborative and structured transition plan. As adult service providers become familiar with the care of the young adult, they have the opportunity to gain the necessary skills, resources and confidence to provide a suitable service, thus reducing the risk of gaps in service

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provision and, therefore, contributing to providing continuity of care. This outcome is more likely to be achieved if enabling contextual factors are available such as children's services being able to identify a well-resourced, interested and capable adult service provider with condition-specific knowledge (Noyes et al., 2014; Chaudhry et al., 2013; Steinkamp et al., 2001). If a capable adult service is not available, or gaps exist in training needs in staff (Care Quality Commission, 2014), then – returning to CMO1 – an early start to transition can provide time for adult services to prepare the environment by identifying the resources required, addressing the training needs of service providers, and strengthening relationships between children's and adult teams to facilitate communication (Beresford, 2013; Doug et al., 2011; Steinkamp et al., 2001).

CMO3. Orientating the young adult to adult services and optimising relationships with children's and adult service providers who demonstrate a person-centred approach. Adult services are reported to be very different from children's services (Huang et al., 2011) in that they typically have fewer supporting staff, a higher patient load, less consultation time (van Staa et al., 2011) and a more formal approach (Soanes and Timmons, 2004), all of which can have an alienating effect on some young adults. In that context, this intervention involves service providers demonstrating a person-centred (Noyes et al., 2014) and individualised approach to care (Care Quality Commission, 2014; Fegran et al., 2014; (Kirk and Fraser, 2014; Nieboer et al., 2014; Noyes et al., 2014; Chaudhry et al., 2013; Rosenburg-Yunger et al., 2013; van Staa et al., 2011; Watson et al., 2011; Wiener et al., 2009; Soanes and Timmons, 2004; Scal, 2002; Boyle et al., 2001), with the young adult being valued, respected (Cook et al., 2013) and

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acknowledged as a co-expert (Doug et al., 2011). A person-centred approach acknowledges the personhood of the young adult and respects and values their contribution in their care whilst giving them the opportunity to explore the new adult environment and form new relationships. This approach can trigger a mechanism of a young adult feeling a greater sense of involvement in their care and an enhanced sense of well-being (McCormack et al., 2010*)*. This intervention is considered to lead to an outcome of a young adult who is interested and engaged in their care, adhering to their disease management strategies with a sense of commitment to engage in adult services. This outcome is more likely to be achieved if enabling contextual factors focus on orientating the young adult to the philosophy, organisation and delivery of adult services such as an early introduction to adult service providers prior to the transfer (McCann et al., 2014; Sharma et al., 2014; Begley, 2013, Chaudhry et al., 2013; Tierney et al., 2013; Fair et al., 2010; Madge and Bryon, 2002; Boyle et al., 2001); joint outpatient appointments or transition clinics in which the young adult meets with representatives from both children's and adult services (Fegran et al., 2014; Kirk and Fraser, 2014; McCann et al., 2014; Chaudhry et al., 2013; Gravelle et al., 2012; Crowley et al., 2011; Rutishauser et al., 2011; Madge and Bryon, 2002; Westwood et al., 1999) or phased orientation visits to the new outpatient and inpatient adult unit in advance of the transfer (Chaudhry et al., 2013; Brumfield and Lansbury, 2004; Steinkamp et al., 2001).

CMO4. The engagement of a key worker. This intervention entails the identification of a minimum of one person in a key worker role (Care Quality Commission, 2014; Kirk and Fraser, 2014; McCann et al., 2014; Nieboer et al., 2014; Noyes et al., 2014; Chaudhry

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et al., 2013; Gleeson et al., 2012; Watson et al., 2011), sometimes referred to as a transition coordinator (Kelly, 2014; Crowley et al., 2011). This key worker fulfils the role of patient advocate by gaining the attention of relevant service providers on the young adult's behalf, and in doing so, bringing the needs of the young adult to the awareness of those who can actively respond. The key worker has an overarching view of the young adult's transition to adult care with responsibilities for coordinating the transition process (Care Quality Commission, 2014; Kirk and Fraser, 2014; Begley, 2013) and negotiating cross agency care (Noyes et al., 2014). An expansion of the role could include identifying and addressing the training needs of adult service providers and supporting professionals in understanding the complex health needs of young adults when admitted onto an adult ward (Chamberlain and Kent, 2005). The mechanism triggered in response to the advocacy of the key worker, is a young adult who builds confidence through the development of trust in this therapeutic relationship. This is thought to be one of the most important components in the young adult continuing to engage with services (Forbes et al., 2002*)*. The outcome associated with this intervention is a more streamlined transition process as appropriate service providers will be engaged who can be more time efficient and productive in mobilising colleagues leading to a reduced likelihood of a gap in service provision when the young adult transfers to adult care. This outcome is more likely to be achieved if contextual factors are available such a keyworker who is familiar with the culture and organisation of services along with experience of working with young adults. Furthermore, a keyworker role that spans both children's and

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adult services could fulfil an integrating function between both services (Gleeson et al., 2012) creating a bridge between services.

CMO5. Interdisciplinary and interagency joint working. This intervention relates to the joint working of a range of disciplines and agencies in the transition process (Chambers, 2015; Noyes et al., 2014; Lidstone, 2013; Gravelle et al., 2012; Wiener et al., 2009; Flume et al., 2004; Por et al., 2004). These include health and social care services (Marsh et al., 2011), primary care (Care Quality Commission, 2014; Lidstone, 2013), education and the voluntary sector. This intervention appears to trigger a mechanism whereby paediatric professionals in each discipline and agency identify their adult counterpart in a timely fashion to ensure adequate skills and resources are available when the young adult transfers to adult care. This integrated approach provides an opportunity for health care professionals and agencies to develop a transition plan or protocol (Nieboer et al., 2014; Por et al., 2004), contributing to the assessment and management of the young adults' needs with a focus on their own speciality, helping to address the multifaceted needs of the young adult (McDonagh and Viner 2006). The intended outcome of this intervention is the establishment of trust, collaboration and accountability through the construction and establishment of a cohesive team with a continuing focus on the young adult and their family (Forbes et al., 2002). This outcome will be more likely to be achieved if enabling contextual factors are present such as the availability of staff, finance and resources to support an interdisciplinary and interagency approach which in practice means the availability of matching disciplines and agencies in both children's and adult services. An ongoing and committed response is also

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required from disciplines and agencies for joint working throughout the transition process to manage evolving needs. General practitioners/primary care physicians are notably absent from the transition literature, which is surprising given that their role providing care over the lifetime should make them well placed to provide continuity of care for the transitioning patient (Scal, 2002), as recognised by the Care Quality Commission (2014).

CMO6. Development of an autonomous young adult throughout the transition process. This intervention takes the form of a graduated approach to the development of the young adults' autonomy throughout the transition process (Newman et al., 2016; Fegran et al., 2014; Mackie et al., 2014; Beresford, 2013; Chaudhry et al., 2013; Schwartz et al., 2013; Tuchman and Schwartz, 2013; Gleeson et al., 2012; Woodward et al., 2012; Huang et al., 2011; Lugasi et al., 2011; Marsh et al., 2011; Rutishauser et al., 2011; van Staa et al., 2011; Fair et al., 2010; Soanes and Timmons, 2004; While et al., 2004; Zack et al., 2003; Madge and Bryon, 2002; Westwood et al., 1999), suggested as a roadmap to care (DiFazio et al., 2014). This involves the adolescent assuming increasing responsibility for their healthcare (Gleeson et al., 2012; Huang et al., 2011; Fair et al., 2010), becoming socially and medically independent of their parents/caregivers (van Staa et al., 2011). This intervention is thought to trigger the mechanism of increasing the young adult's knowledge, self-efficacy, confidence and sense of empowerment over the years preceding the transfer to adult care as a result of growing independence in managing their medical condition. Service providers who adopt this intervention as part of their care should contribute to the intended outcome of developing the young adult's level of independence in managing their medical condition and also their skills in

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negotiating the adult health care system resulting in them feeling transition ready (van Staa et al., 2011) and promoting their engagement in adult services. This outcome if more likely to be achieved if a range of contextual factors are available such as children's service providers recognising the expectation in the adult environment is one of autonomy and are committed to fostering the development of self-management skills in the young adult (Fair et al., 2010). Strategies to facilitate the development of autonomy include service providers interacting more with the young adult (Chaudhry et al., 2013), involving the young adult in an increasing capacity in decision making (van Staa et al., 2011), encouraging the young adult to independently establish relationships with service providers (Zack et al., 2003) and encouraging them to become more knowledgeable about their medical condition. Service providers have used lone consultations, where parents are not present (Nieboer et al., 2014, Chaudhry et al., 2013, Gleeson et al., 2012; Tuchman et al., 2008; Zack et al., 2003) to promote the development of the young adults' decision making skills and enhance their involvement in their medical management. The young adult needs to actively participate, and also be physically well and cognitively able to engage with the strategies used to promote their knowledge and skills in developing their autonomy. Parents/carers also need to engage in the process of changing their role from one of providing care to supporting care by relinquishing some control, which will facilitate the young adult becoming more independent in managing their care (Fair et al., 2010). However, given their central role in their child's care in their earlier years, parents can find it challenging to step aside and cede control while the young adult develops their self-management skills (Nieboer et al., 2014; van Staa et al., 2011),

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related to feelings of being marginalised and not having access to relevant information needed to continue to support the management of their child's health. In order for the parent/carer support to be sustained, there should be a focus on strengthening the young adult's independence without undermining parental involvement (van Staa et al., 2011).

There are a range of factors that can determine the young adults' transition readiness such as their level of autonomy, with tools available to determine transition readiness such as the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) (Schwartz et al., 2013) and the Transition Readiness Assessment Questionnaire (TRAQ) (Sawicki et al., 2011*).* Age has been reported as being used as a single criterion, or the most important decision when determining when to transfer the young adult to adult services (Begley, 2013; Rutishauser et al., 2011; Anderson et al., 2002), however, it is suggested age should not be used as a single indicator when determining transition readiness (Soanes and Timmons, 2004), with some arguing that young adults should not transfer to adult services until they are able to function in an adult clinic with the skills and knowledge to manage their illness independently (Fegran et al., 2014; Viner, 2000). A person-centred approach to transition will require flexibility in the timing of transfer. The expectation in the adult health environment is that patients should exercise a degree of autonomy (Soanes and Timmons, 2004), with autonomy and independence considered milestones of transition readiness. However, despite this expectation, and the reported enthusiasm from young adults in developing their autonomy (Lugasi et al., 2011; Tuchman et al., 2008; Madge and Bryon, 2002) young

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adults transferring to adult care have demonstrated low levels of independence (Gleeson et al., 2012).

Discussion

This realist literature review provides insights into the range of interventions considered to contribute to an effective transition from children's to adult services for young adults with life-limiting conditions. A realist literature review entails a particular approach to the literature – seeking to build theory in relation to the mechanisms at work in various organisational contexts. Consequently, we have attempted to look beneath the surface of transition processes and understand how they work, bringing out the importance of how these processes stimulate and interact with the thoughts, feelings, and decision-making of the people involved; and showing how the physical, social, and organisational contexts influence those decisions and subsequent outcomes.

One of the challenges in this review was that many of the papers focused on both life-limiting conditions and chronic conditions that are not considered life-limiting (Fortuna et al., 2012; van Staa et al., 2011; Watson et al., 2011; Soanes and Timmons, 2004; While et al., 2004), so it was not possible to exclusively focus on interventions specific to life-limiting conditions. Only a small number of papers had the terminology palliative care or life-limiting conditions highlighted as part of their focus (Kirk and Fraser, 2014; Noyes et al., 2014; Doug et al., 2011; Marsh et al., 2011). Another challenge experienced was that interventions exist in complex social systems so it was difficult to determine which specific interventions led to outcomes. For example, an early start and a key worker can

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both be implemented in one setting, so it is not possible to conclusively state which intervention led to positive outcomes.

Papers in this review represented 17 countries in five continents. 31 of the 78 papers originated from the United States of America and this was followed by of 19 of the 78 papers from the United Kingdom. A comparative analysis of transition approaches between countries identified no significant differences. Cystic fibrosis was the most commonly represented medical condition in this review with 36 of the 78 papers including a focus on this medical condition. This was followed with 21 of the 78 papers including a focus on the Human Immunodeficiency Virus (HIV). There were no significant differences noted between medical conditions. Overall, the issues reported related to the transition to adult services were similar across geographical locations and medical conditions, with the exception of variability in the age to transfer to adult services. This is reflected in reports that transition issues are not unique to medical conditions or specific to any one type of provider (Okumura, 2009).

Six interventions were identified as associated with a successful transition to adult care, all of which were thought to improve the services on offer and encourage the young adult to engage appropriately with those services, evidenced through attendance at clinics, adherence to medications and disease management plans, with the expectation this will reduce morbidity and mortality (Fair et al., 2011). In general, the studies did not capture the young adults' perspectives regarding their rationale for engaging with the interventions. Conspicuous by their absence were outcomes related to personal,

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relational or social factors, or to the young adults' transitions in other areas of life such as education and employment. Another notable absentee in the literature is the general practitioner with only a small number of papers highlighting the potential role of primary care in the transition process (Care Quality Commission, 2014; Lidstone, 2013; Scal, 2002). Given that primary care practice is not typically demarcated according to the age of the patient, and that continuity of person-centred care is thought to be intrinsic to the role of the general practitioner (Royal College of General Practitioners, 2013), this is a striking omission. There is some evidence that parents are reluctant to involve the general practitioner due to poor experiences of care (Aldiss et al., 2015); and are anxious about turning to the general practitioner when their child leaves children's services – although some are pleasantly surprised at the good service they receive once they are relying on the general practitioner (Murphy and Mackay, 2015). This would seem to strengthen the argument for general practitioners being involved and supported by specialist colleagues well before the transition.

Turning to the CMOs, we can identify some commonalities, especially in terms of the mechanisms at work. This is not surprising given that mechanisms in this context are largely identified with human agency, and are, therefore, likely to be shared by many of the people involved. For example, in CMO3 and CMO6 we theorise that the young adults' engagement with services is more likely when the intervention provides the opportunity for them to gain knowledge, confidence and self-efficacy in relation to decision-making about their care, and so empowers them to engage more effectively with service providers. One caveat here, is that the rhetoric of empowerment may work

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to the detriment of young adults whose conditions may seriously limit their capacity and appetite for autonomous living and engagement with service providers (Schmidt et al., 2016). For example Hamdani et al. (2015) found that although young adults with Duchenne muscular dystrophy appeared to accept the goal of increasing independence, in practice few gained employment or moved out of the family home, choosing instead to focus on maintaining a positive attitude in the present. The goal of empowered independence can become pernicious if it translates into an expectation amongst staff that young adults must develop the skills to 'succeed' in the environment of adult services (Tanner et al., 2016). In other words, rather than expect every young adult with a life-limiting condition to work intensely to navigate adult services, we should configure adult services to work for them. It is also important to note the overarching influence of CMO1, an early start to the transition process. Although this intervention is necessary, it is not sufficient as it provides the opportunity for the other interventions to have their desired effect. Conversely, a late start will reduce the time available for other interventions to be implemented and for mechanisms to develop.

Related to CMO6, whilst this intervention of developing an autonomous young adult throughout the transition process is reported to promote an effective transition to adult services, there are two underlying assumptions associated with this intervention. The first assumption relates to children having low, or no level of autonomy. The alternative view is that many children are competent agents and should be treated as partners in resolving problems, avoiding the paternalistic mode of service provision (Goh, 2013). Irrespective of one's orientation, the importance of placing the young adult at the centre

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of the transition process is crucial as under the Convention of the Rights of the Child (United Nations, 1989) children have the right to freedom of expression which involves the right to seek, receive and impart information. The second assumption relates to the view that the young adult should conform to the systems approach to care delivery rather than an approach that can demonstrate flexibility in providing individualised care which accommodates autonomous young adults. Whilst it is argued that transition readiness should be, in part, determined by when a young adult is able to independently negotiate the adult environment, this assumes that the young adult should adapt to the norms and rules set by the adult environment. Arguably, the adult service environment should consider an approach that is able to respond to the varying competencies and capabilities catered for by children's services, rather than the young adult meeting the criteria set by the adult environment. Service providers in children's and adult services could attempt to reduce the complexities associated with the transition process by closing the cultural gap between services. This may mean children's service providers further recognising children as active social agents in their care as well as adult services interacting with parents/carers.

The CMOs shared some characteristics of context. For example, a recurring theme is the need for adequate resources such as a well-equipped adult service with knowledgeable service providers and equivalent disciplines. Further enabling contextual factors across CMO configurations include the availability of transition strategies such

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as lone consultations and orientation initiatives. It appears that where service providers have resources only to meet their immediate responsibilities, they may not take the time to communicate in a person-centred way with young adults, and may lack the capacity to network effectively with other services and disciplines, or to release service providers as key workers (CMO2, CMO3 and CMO4). On the other hand, interventions are more likely to succeed in a context where service providers have appropriate skills, knowledge and relevant training (CMO1, CMO2, CMO3 and CMO5).

Conclusions and recommendations

Although there appears to be a consensus in the literature that the six interventions identified can improve transition outcomes, at least in terms of the young adult appropriately engaging with health services, evidence for effectiveness in this population is weak, highlighting a need for clinical trials of carefully defined interventions which will contribute to an effective transition. We have demonstrated the impact of human motivation and organisational and social context on the implementation of what are complex interventions, showing the need for multi-method approaches, such as realist evaluation, to explain the outcomes of interventions. Given this complexity, it is unlikely that standardised, uniform interventions will work across multiple contexts. We would argue that interventions need to be tailored to their context and focused not only on organisational procedures but on equipping patients, families and staff to engage with each other effectively. Our findings suggest service providers should adopt a diagnostic approach, appraising local networks and resources bearing in mind relevant contextual

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factors such as staff expertise and capacity, and proximity and availability of services; assessing goals and capabilities with the young adults; and concentrating dedicated transition resources on measures to empower young people to play a full part in decision-making in relation to their conditions. Specific recommendations related to improving the transition to adult care are made in Table Three.

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Declaration of conflicting interests

There are no conflicting interests.

Contribution of the paper

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.

ACCEPTED MANUSCRIPT

References

Aldiss, S., Ellis, J., Cass, H., Pettigrew, T., Rose, L,L. And Gibson, F. (2015) Transition From Child to Adult Care - 'It's Not a One-Off Event': Development of Benchmarks to Improve the Experience. *Journal of Pediatric Nursing*. 30(5), pp, 638-647.

Agwu, A. L., Lee, L., Fleishman, J. A., Voss, C., Yehia, B. R., Althoff, K. N., Rutstein, R., Mathews, W. C., Nijhawan, A., Moore, R. D., Gaur, A. H. and Gebo, K. A. (2015) Aging and Loss to Follow-up Among Youth Living With HIV in the HIV Research Network. *Journal of Adolescent Health,* 56, pp. 345-351.

Anderson, D. L., Flume, P.A., Hardy, K.K. and Gray, S. (2002) Transition Programs in Cystic Fibrosis Centres: Perceptions of Patients. *Pediatric Pulmonology*, 33, pp. 327-331.

Annunziato, R.A., Emre, S. and Shneider, B.L., Barton, C. Dugan, C. A. and Shemesh, E. (2007) Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatric Transplantation*, 11, pp. 608-614.

Annunziato, R. A., Parkar, S., Dugan, C. A., Barsade, S., Arnon, R., Miloh, T., Iyer, K., Kerkar, N. and Shemesh, E. (2011) Brief Report: Deficits in Health Care Management Skills Among Adolescent and young adult Liver Transplant Recipients Transitioning to Adult Care Settings. *Journal of Pediatric Psychology,* 36(2), pp. 55-59.

ACCEPTED MANUSCRIPT

Archer, M. S. (2003) *Structure, Agency and the Internal Conversation.* Cambridge: University Press.

Astbury, B. and Leeuw, F. L. (2010) Unpacking Black Boxes: Mechanisms and Theory Building in Evaluation. *American Journal of Evaluation,* 31(3), pp. 363-381.

Balshem, H., Helfand, M., Schunemann, H.J, Oxman, A. D., Kunz, R., Brozek, J., Vist, G. E., Falck-Ytter, Y., Meerpohl, J., Norris, S. and Guyatt, G. H. (2011) GRADE guidelines: 3. Rating the quality of evidence. *Journal of Clinical Epidemiology*, 64(4), pp. 401–406.

Begley, T. (2013) Transition to adult care for young people with long-term conditions. *British Journal of Nursing*, 22(9), pp. 1234-1238.

Beresford, B. (2013) *Making a difference for young adults: Supporting health transition for young people with life-limiting conditions: Researching evidence of positive practice. A Briefing for the All Party Parliamentary Group on Hospice and Palliative Care.* York: The National Council for Palliative Care, Together for Short Lives, Help the Hospices.

Beresford, B. and Stuttard, L. (2014) Young adults as users of adult healthcare: experiences of young adults with complex or life-limiting conditions. *Clinical Medicine,* pp. 404-408.

Bhaskar, R. (2008) *A Realist Theory of Science.* 2nd edn., Oxford: Routledge.

ACCEPTED MANUSCRIPT

Blum, R., Garrell, D. and Hodgman, C. (1993) Transition from child-centred to adult health-care systems for adolescents with chronic conditions: a position paper of the society for Adolescent Medicine. *Journal of Adolescent Health*, 14, pp. 570-576.

Boyle, M. P., Farukhi, Z. and Nosky, M. L. (2001) Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatric Pulmonology*, 32, pp. 428-436.

Breakey, V., Blanchette, P. and Bolton-Maggs, H. B. (2010) Towards comprehensive care in transition for young people with haemophilia. *Haemophilia,* 16, pp. 848-857.

Brumfield, K. and Lansbury, G. (2004) Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disability and Rehabilitation,* 26(4), pp. 223-234.

Campbell, F., O'Neill, P.M., While, A. and McDonagh, J. (2012) *Intervention protocol: Interventions to improve transition of care for adolescents from paediatric services to adult services* (Protocol). United Kingdom: *The Cochrane Collaboration.*

Care Quality Commission (2014) *From the pond into the sea: children's transition to adult health services.* Gallowgate: Care Quality Commission.

Chamberlain, M.A. and Kent, R.M. (2005) The needs of young people with disabilities in transition from paediatric to adult services. *Europa Medicophysica*, 41(2), pp. 111-123.

ACCEPTED MANUSCRIPT

Chambers, L. (2015) *Stepping Up: A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions.* Bristol: The Information Standard, Together for Short Lives.

Chaudhry, S. R., Keaton, M. and Nasr, S. Z. (2013) Evaluation of a Cystic Fibrosis Transition Program from Pediatric to Adult Care. *Pediatric Pulmonology,* 48, pp. 658-665.

Cook, K., Siden, H., Jack, S., Thabane, L. and Browne, G. (2013) Up against the System: A Case Study of Young Adult Perspectives Transitioning from Pediatric Palliative Care. *Nursing Research and Practice* DOI: http://dx.doi.org/10.1155/2013/286571.

Critical Appraisal Skills Programme (CASP) (2015) *Critical Appraisal Skills Programme: Making sense of evidence.* Available at: http://www.casp-uk.net/ (Accessed 01 September 2016).

Crowley, R., Wolfe, I. and Locke, K. (2011) Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood,* 96, pp. 548-553.

de Mulder, M. , Yebra, G., Navas, A., de Jose, M. I., Gurbindo, M. D., Gonzalez-Tome, M. I., Mellado, M. J., Saavedra-Lozano, J., Munoz-Fernandez, M. A., de Ory, S. J., Ramos, J. T. and Holguin, A. (2012) High Drug Resistance Prevalence among Vertically HIV-infected Patients Transferred from Pediatric Care to Adult Units in Spain. *PLOS one,* 7(12), pp. 1-9.

ACCEPTED MANUSCRIPT

Department of Health (2006) *Transition: getting it right for young people: National Service Framework for Children, young people and maternity Services.* London: Department of Health.

Department of Health (2008) Transition: moving on well. *A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability. London:* Department of Health.

DiFazio, R. L., Harris, M., Vessey, J. A., Glader, L. and Shanske, S. (2014) Opportunities lost and found: Experiences of patients with cerebral palsy and their parents transitioning from pediatric to adult healthcare. *Journal of Pediatric Rehabilitation Medicine,* 7, pp. 17-31.

Doug, M., Adi, Y., Williams, J., Kelly, D., Petchey, R. and Carter, Y. H. (2011) Transition to adult services for children and young people with palliative care needs: a systematic review. *Archives of Disease in Childhood,* 96, pp. 78-84.

Dugueperoux, I., Tamalet, A., Sermet-Gaudelus, I., Le Bourgeois, M., Gerardin, M., Desmazes-Dufeu, N. and Hubert, D. (2008) Clinical Changes of Patients with Cystic Fibrosis during Transition from Pediatric to Adult Care. *Journal of Adolescent Health,* 43, pp. 459-465.

Fair, C. D., Sullivan, K. and Gatto, A. (2010) Best practices in transitioning youth with HIV: Perspectives of pediatric and adult infectious disease care providers. *Psychology, Health and Medicine,* 15(5), pp. 515-527.

ACCEPTED MANUSCRIPT

Fair, C.D., Sullivan, K. and Gatto, A. (2011) Indicators of transition success for youth living with HIV: perspectives of pediatric and adult infectious disease care providers. *Aids Care,* 23(8), pp. 965-970.

Fegran, L., Hall, E. O. C., Uhrenfeldt, L., Aagaard, H. and Ludvigsen, M. S. (2014) Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: A qualitative metasynthesis. International *Journal for Nursing Studies,* 51, pp. 123-135.

Flume, P.A., Taylor, L.A., Anderson, D.L., Gray, S. and Turner, D. (2004) Transition Programs in Cystic Fibrosis Centres: Perceptions of Team Members. *Pediatric Pulmonology*, 37, pp. 4-7.

Forbes, A., While, A., Ullman, R., Lewis, S., Mathes, L and Griffiths, P. (2002) *A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability: Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D*. London: NCCSDO**.**

Fortuna, R.J., Halterman, J.S., Pulcino, T. and Robbins, B. W. (2012) Delayed Transition of Care: A National Study of Visits to Paediatricians by Young Adult Academics. *Pediatrics*, 12(5), pp. 405-411.

Gilleland, J., Amaral, S., Mee, L. and Blount, R. (2012) Getting Ready to Leave: Transition Readiness in Adolescent Kidney Transplant Recipients. *Journal of Pediatric Psychology,* 37(1), pp. 85-96.

ACCEPTED MANUSCRIPT

Gleeson, H., McCartney, S. and Lidstone, V. (2012) 'Everybody's business': transition and the role of adult physicians. *Clinical Medicine*, 12(6), pp. 561-566.

Goh, E.C.L. (2013) Reconceptualization of children as active agents in social work practice: A theoretical shift. Paper presented at the 3rd Global Conference: Childhood: A Persons Project, Oxford University, UK.

Goossens, E., Stephani, I., Hilderson, D., Gewillig, M., Budts, W., Van Deyk, K. and Moons, P. (2011) Transfer to Adolescents with congenital Heart Disease from Pediatric Cardiology to adult Health care. *Journal of American College of Cardiology,* 57(23), pp. 2368-2374.

Gravelle, A., Davidson, G. and Chilvers, M. (2012) Cystic fibrosis adolescent transition care in Canada: A snapshot of current practice. *Paediatrics and Child Health*, 17(10), pp. 553-556.

Hain, R., Devins, M., Hastings, R. and Noyes, J. (2013) Paediatric palliative care: development and pilot study of a 'Directory' of Life Limiting conditions. *BMC Palliative Care*, 12(43), pp. 1-5.

Hait, E., Arnold, J. H. and Fishman, L. N. (2006) Educate, Communicate, Anticipate-Practical Recommendations for Transitioning Adolescents with IBD to Adult health Care. *Inflammatory Bowel Disease,* 12(1), pp. 70-73.

Hamdani, Y., Mistry, B. and Gibson, B.E. (2015) Transitioning to adulthood with a progressive condition: best practice assumptions and individual experiences of young

ACCEPTED MANUSCRIPT

men with Duchenne muscular dystrophy. *Disability and Rehabilitation,* 37(13), pp. 1144–1151.

Higgins, A., O'Halloran, P. and Porter, S. (2012) Management of Long Term Sickness Absence: A Systematic Realist Review. *Journal of Occupational Rehabilitation*, 22, pp. 322-332.

Higgins, A., O'Halloran, P. and Porter, S. (2014) The Management of Long-Term Sickness Absence in Large Public Sector Healthcare Organisations: A Realist Evaluation Using Mixed Methods. *Journal of Occupational Rehabilitation,* 25(3), pp. 451-470.

Holmes-Walker, D. J., Llewellyn, A. C. and Farrell, K. (2006) A transition programme which improves diabetes control and reduces hospital admission rates in young adults with Type 1 diabetes aged 15–25 years. *Diabetic Medicine*, 24, pp. 764–769.

Huang, J.S., Gottschalk, M., Pian, M., Dillon, L., Barajas, D. and Bartholomew, L. K. (2011) Transition to Adult Care: Systematic Assessment of Adolescents with Chronic Illnesses and their medical teams. *The Journal of Pediatrics*, 159, pp. 994-998.

Kelly, D. (2014) Theory to reality: the role of the transition nurse coordinator. *British Journal of Nursing,* 23(16), pp. 890-895.

Kirk, S. and Fraser, C. (2014) Hospice support and the transition to adult services and adulthood for young people with life limiting conditions and their families: A qualitative study. *Palliative Medicine*, 28(4), pp. 342-352.

ACCEPTED MANUSCRIPT

Lidstone, V. (2013) *The role of hospices in supporting young people in transition from children to adult services: A working paper of the Commission into the Future of Hospice Care*. England: Help the Hospices.

Lugasi, T., Achille, M. and Stevenson, M. (2011) Patients' Perspective on Factors that Facilitate Transition from Child-centred to Adult-centred Health Care: A Theory integrated Metasummary of Quantitative and Qualitative Studies. *Journal of Adolescent Health*, 48, pp. 439-440.

Mackie, A.S., Islam, S., Magill-Evans, J., Rankin, K. N., Robert, C., Schuh, M., Nicholas, D., Vonder Muhll, I., McCrindle, B. W., Yasui, Y. and Rempel, G. R. (2014) Healthcare transition for youth with heart disease: a clinical trial. *Heart*, 100, pp. 1113-1118.

Madge, S. and Bryon, M. A (2002) Model for Transition from Pediatric to Adult Care in Cystic Fibrosis. *Journal of Pediatric Nursing,* 17(4), pp. 283-288.

Marsh, S., Cameron, M., Duggan, M., Rodrigues, J., Eisenstadt, N., Iskander, R. and Stone, J. (2011) *Young People with life-limiting conditions: transition to adulthood. Executive Summary of Phase 1 report for Marie Curie Cancer Care.* Available at: http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/Innovation/teenagers-transition/young-people-transition-psw-exec-summary.pdf (Accessed 01 September 2016).

Maxwell, J. A. (2012) *Realist approach for Qualitative Research.* London: Sage Publications.

ACCEPTED MANUSCRIPT

McCann, L., Kearney, N. and Wengstrom, Y. (2014) “It’s Just going to a New Hospital…That’s It.” Or Is It? An Experiential Perspective on Moving From Pediatric to Adult Cancer Services. *Cancer Nursing*, 37(5), pp. E23-E31.

McCormack, B., Karlsson, B., Dewing, J. and Lerdal, A. (2010) Exploring person-centredness: a qualitative meta-synthesis of four studies. *Scandinavian Journal of Caring Sciences,* 24(3), pp. 620-634.

McDonagh, J, E., Southwood, T. R. and Shaw, K. L. (2007) The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology*, 46, pp. 161–168.

McDonagh, J. E. and Viner, R. M. (2006) Lost in transition? Between paediatric and adult services. *British Medical Journal,* 332, pp. 435-436.

McGill, M. (2002) How Do We Organize Smooth, Effective Transfer from Paediatric to Adult Diabetes Care? *Hormone Research,* 57 (supplement 1), pp. 66-68.

Mellor, C. and Hain, R. (2010) Paediatric palliative care: not so different from adult palliative care? *British Journal of Hospital Medicine,* 7(1), pp. 36-39.

Murphy, J. and Mackay, M. (2015) Will anyone listen to us ? What matters to young people with complex and exceptional health needs and their families during health transitions: Final Report October. *CEN/NHS Scotland 2015.* Available at: http://www.cen.scot.nhs.uk/files/151027_TalkingMats_CEN%20report_V4.0.pdf (Accessed 27 March 2017).

ACCEPTED MANUSCRIPT

Newman, C. E., Person, A., Miller, A. and Brown, R. J. (2016) "Just take your medicine and everything will be fine". Responsibilisation narrative in accounts of transitioning young people with HIV into adult care services in Australia. *Aids Care,* 28(1), pp. 131-136.

Nieboer, A.P., Cramm, J.M., Sonneveld, H.M., Roebroeck, M. E., van Staa, A. and Strating, M. M. H. (2014) Reducing bottlenecks: professionals' and adolescents' experiences with transitional care delivery. *BMC Health Services Research*, 14(47), pp. 1-8.

Noyes, J., Pritchard, A., Rees, S., Hastings, R., Jones, K., Mason, H., Hain, R. and Lidstone, V. (2014) *Bridging the gap: Transition from Children's to Adult Palliative Care: Final report*. Bangor University.

O'Halloran, P., Scott, D., Reid, J. and Porter, S. (2014) Multimedia psychoeducational interventions to support patient self-care in degenerative conditions: A realist review. *Palliative and Support Care, 1*3(5), pp. 1–14.

Okumura, M. J. (2009) Growing up and getting old(er) with childhood onset chronic diseases: paving the way to better chronic illness care worldwide. *Journal of Adolescent Health,* 45, pp. 541-542.

Pawson, R. (2001) *Evidence Based Policy: II. The Promise of 'Realist Synthesis'.* ESRC UK Centre for Evidence Based Policy and Practice: London: Queen Mary University of London.

ACCEPTED MANUSCRIPT

Pawson, R. (2013) *The Science of Evaluation: A Realist Manifesto.* London: Sage Publications Ltd.

Pawson, R., Greenhalgh, T., Harvey, G. and Walshe, K. (2004) *Realist synthesis: an introduction. Research Methods an ESRC research programme:* Manchester: University of Manchester.

Pawson, R. and Tilley, N. (1997) *Realist Evaluation.* London: Sage Publications.

Pawson, R. and Tilley, N. (2004) *Realist Evaluation.* London: Sage Publications.

Por, J., Golberg, B., Lennox, V., Burr, P., Barrow, J. and Dennard, L. (2004) Transition of care: Health care professionals' view. *Journal of Nursing Management*, 12, pp. 354-361.

Reid, G.J., Irvine, J., McCrindle, W., Sananes, R., Ritvo, P. G., Siu, S. C. and Webb. G. D. (2004) Prevalence and Correlates of successful Transfer From pediatric to Adult Health Care Among a Cohort of Young Adults with Complex Congenital Heart Defects. *Pediatrics*, 113(3), pp. e197-e205.

Rosen, D. (1995) Between Two Worlds: Bridging the Cultures of Child Health and Adult Medicine. *Journal of Adolescent Health,* 17, pp. 10-16.

Rosenberg-Yunger, Z.R.S., Klassen, A.F., Amin, L., Granek, L., D'Agostino, N.M., Boydell, K. M., Greenberg, M. and Barr, R. D. (2013) Barriers and Facilitators of Transition from Pediatric to Adult Long-Term Follow-Up Care in Childhood Cancer Survivors. *Journal of Adolescent and Young Adult Oncology*, 2(3), pp. 104-111.

ACCEPTED MANUSCRIPT

Royal College of General Practitioners (2013) *Being a General Practitioner: core curriculum statement*. London: Royal College of General Practitioners.

Rutishauser, C., Akre, C. and Suris, J.C. (2011) Transition from pediatric to adult health care: expectations of adolescents with chronic disorders and their parents. *European Journal of Pediatrics,* 170, pp. 865-871.

Rycroft-Malone, J., Fontenla, M., Bick, D. and Seers, K. (2010) A Realistic Evaluation: the case of protocol-based care. *Implementation Science,* 5(38), pp. 1-14.

Sawicki, G.S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I. C., Livingood, W., Reiss, J. and Wood, D. (2011) Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ-transition readiness assessment questionnaire *Journal for Pediatric Psychology*, 36, pp. 160-171.

Scal, P. (2002) Transition for Youth with Chronic conditions: Primary Care Physicians' Approaches. *Pediatrics*, 110(6), pp. 1315-1321.

Schmidt, S., Herrmann-Garitz, C., Bomba, F. and Thyen, U. (2016) A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults. *Patient Education and Counselling,* 99(3), pp. 421–428.

Schwartz, L.A., Brumley, L.D., Tuchman, L.K., Barakat, L. P., Hobbie, W. L., Ginsberg, J. P., Daniel, L. C., Kazak, A. E., Bevans, K. and Deatrick, J. A. (2013) Stakeholder

ACCEPTED MANUSCRIPT

Validation of a Model of Readiness for Transition to Adult Care. *JAMA Pediatrics*, 167(10), pp. 939-946.

Schwartz, L. A., Tuchman, L. K., Hobbie, W. L. and Ginsberg, J. P. (2011) Social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: care, health and development*, 37(6), pp. 883-895.

Scott, R. (2011) Transition and caring for young adults; are you part of the solution? *Progress in Palliative Care*, 19(6), pp. 299-303.

Sharma, N., Willen, E., Garcia, A. and Sharma, T. S. (2014) Attitudes toward Transition in Youth with Perinatally Acquired HIV and Their Family Caregivers. *Journal of the Association of Nurses in Aids Care*, 25(2), pp. 168-175.

Soanes, C. and Timmons, S. (2004) Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *Journal of Child Health Care*, 8(2), pp. 102-112.

Steinkamp, G., Ullrich, G., Muller, C., Fabel, H. and von der Hardt, H. (2001) Transition of adult patients with cystic fibrosis from paediatric to adult care- the patients' perspective before and after start- up of an adult clinic. *European Journal of Medical Research,* 6, pp. 85-92.

Tanner, A.E., Philbin, M.M., DuVal, A., Ellen, J., Kapogiannis, B., Fortenberry, J.D., Adolescent Trials Network for HIV/AIDS Interventions (2016) Transitioning HIV-Positive

ACCEPTED MANUSCRIPT

Adolescents to Adult Care: Lessons Learned From Twelve Adolescent Medicine Clinics. *Journal of Pediatric Nursing,* 31(5), pp. 537–543.

Tierney, S., Deaton, C., Jones, A., Oxley, H., Biesty, J. and Kirk, S. (2013) Liminality and transfer to adult services: A qualitative investigation involving young people with cystic fibrosis. *International Journal of Nursing Studies,* 50, pp. 738-746.

Together for Short Lives. Children's palliative care definitions (2013) Available at: http://www.togetherforshortlives.org.uk/assets/0000/4089/CPC_definitions.pdf (Accessed 01 September 2016).

Tuchman, L. and Schwartz, M. (2013) Health Outcomes Associated with Transition from Pediatric to Adult Cystic Fibrosis Care. *Pediatrics,* 132, pp. 847-853.

Tuchman, L. K., Slap, G. B. and Britto, M. T. (2008) Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child: care, health and development,* 34(5), pp. 557-563.

United Nations (1989) Convention on the Rights of the Child. Available at: http://www.ohchr.org/en/professionalinterest/pages/crc.aspx (Accessed 09 September 2016).

Valenzuela, J.M., Buchanan, C.L., Radcliffe, J., Ambrose, C., Hawkins, L. A., Tanney, M. and Rudy, B. J. (2009) Transition to Adult Services among Behaviourally Infected Adolescent with HIV-A Qualitative Study. *Journal of Pediatric Psychology*, 36(2), pp. 134-140.

ACCEPTED MANUSCRIPT

van Staa, A.L., Jedeloo, S., van Meeteren, J. and Latour, J. M. (2011) Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: care, health and development,* 37(6), pp. 821-832.

Van Walleghem, N., Macdonald, C. and Dean, H. (2006) Building connections for young adults with type 1 diabetes mellitus in Manitoba: feasibility and acceptability of a transition initiative. *Chronic Diseases in Canada,* 27, pp. 130-134.

Van Walleghem, N., MacDonald, C. A. and Dean, H. L. (2008) Evaluation of a Systems Navigator Model for Transition From Pediatric to Adult Care for Young Adults With Type 1 Diabetes. *Diabetes Care*, 31, pp. 1529-1530.

Viner, R. (1999) Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood,* 81, pp. 271-275.

Viner, R. (2000) Effective transition from paediatric to adult services. *Hospital Medicine*, 61(5), pp. 341-343.

Watson, A. R. (2000) Non-compliance and transfer from paediatric to adult transplant unit. *Pediatric Nephrology,* 14, pp. 469-472.

Watson, R., Parr, J.R., Joyce, C., May, C. and Le Couteur, A. S. (2011) Models of transitional care for young people with complex health needs: a scoping review. *Child: care, health and development,* 37(6), pp. 780-791.

ACCEPTED MANUSCRIPT

Westwood, A. T. R., Henley, L. D. and Willcox, P. (1999) Transition from paediatric to adult care for persons with cystic fibrosis: Patient and parent perspectives. *Journal of Paediatric and Child Health*, 35, pp. 443-445.

While, A., Forbes, A., Ullman, R., Mathes, L. and Griffiths, P. (2004) Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: care, health and development,* 30, pp. 439-452.

Wiener, L. S., Kohrt, B. A., Battles, H. B. and Pao, M. (2009) The HIV Experiences: Youth Identified barriers for Transitioning from Pediatric to Adult Care. *Journal of Pediatric Psychology,* 36(2), pp. 141-154.

Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J. and Pawson, R. (2013) RAMESES publication standards: realist syntheses. *BMC Medicine*, 11(21), pp. 1-14.

Woodward, J.F., Swigonski, N.L. and Ciccarelli, M.R. (2012) Assessing the Health, Function Characteristics, and Health Needs of Youth Attending a Noncategorical Transition Support Program. *Journal of Adolescent Health,* 51, pp. 272-278.

Zack, J., Jacobs, C.P., Keenan, P.M., Harney, K., Woods, E. R., Colin, A. A. and Emans, S. J. (2003) Perspectives of Patients with Cystic Fibrosis on Preventative Counseling and Transition to Adult Care. *Pediatric Pulmonology,* 36, pp. 376-383.

Table One: Search strategy

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1	transition$.mp.
2	transfer$.mp.
3	1 or 2
4	child$.mp.
5	adolescen$.mp.
6	young people.mp.
7	young adult$.mp.
8	4 or 5 or 6 or 7
9	exp after-hours care/
10	exp "delivery of health care integrated"/
11	exp managed care program$/
12	exp adolescent health services/
13	exp community health centers$/
14	community health nursing/
15	nursing practice.mp.
16	social support/
17	exp School health services/
18	exp home care services/
19	exp "quality of health care"/
20	exp pediatric nursing/
21	exp hospitals/
22	hospice care/

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23	exp palliative care/
24	exp neoplasms/
25	exp terminal care/
26	disabled persons/
27	service evaluation.mp.
28	exp program$ evaluation/
29	terminally ill/
30	life threat$.mp.
31	life limit$.mp.
32	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31
33	adult care.mp.
34	adult services.mp.
35	adult oriented health care.mp.
36	33 or 34 or 35
37	3 and 8 and 32 and 36
38	limit 37 to (english language and humans and yr="1995-2016")

Key:
$ = searches for variations of a word with the same stem
mp = searches in the Title, Abstract, Subject Heading, and Registry Word fields
exp = retrieves records that contain the specified term and any of its narrower, more specific terms
/ = the term is a valid controlled vocabulary term which has been searched in all the Subject Headings field of the database.

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Table Three

Recommendations for transition to adult care

- Successful transition should be seen as a core responsibility for both children's and adult services.
- Children's services should proactively introduce the prospect of transition to young adults and their parents/carers at an early stage and use the available time to make necessary preparations.
- Children's services should identify relevant adult service providers to alert them to the probability that young adults will be transferring to their care, and to build relationships with a view to developing cooperation.
- Once alerted to probable transfers, managers of adult services should complete an early assessment to determine if the environment and service providers are equipped to provide continuing care, and provide necessary training and resources.
- Interventions to aid transition should include a focus on increasing the young adults' confidence in decision-making and helping them develop collaborative relationships with adult services.
- The goals for transition should include those identified by young adults and extend beyond their engagement with health services.
- The multidisciplinary approach should be extended to include meaningful involvement of the general practitioner/primary care physician.

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- Service providers should consider how parents/carers can be supported throughout the transition process so they are not marginalised.