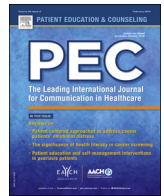




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Review article

Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences

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ABSTRACT

Objective: To understand how parents view and experience their role as their child with a long-term physical health condition transitions to adulthood and adult healthcare services.

Methods: Five databases were systematically searched for qualitative articles examining parents' views and experiences of their child's healthcare transition. Papers were quality assessed and thematically synthesised.

Results: Thirty-two papers from six countries, spanning a 17-year period were included. Long-term conditions were diverse. Findings indicated that parents view their child's progression toward self-care as an incremental process which they seek to facilitate through up-skilling them in self-management practices. Parental perceptions of their child's readiness, wellness, competence and long-term condition impacted on the child's progression to healthcare autonomy. A lack of transitional healthcare and differences between paediatric and adult services served as barriers to effective transition. Parents were required to adjust their role, responsibilities and behaviour to support their child's growing independence.

Conclusion: Parents can be key facilitators of their child's healthcare transition, supporting them to become experts in their own condition and care. To do so, they require clarification on their role and support from service providers.

Practice implications: Interventions are needed which address the transitional care needs of parents as well as young people.

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1. Introduction

Long-term physical health conditions (LTCs) affect significant and increasing numbers of adolescents in the UK [1]. Advances in treatment/technology mean that these young people are now more likely than ever to reach adulthood [2]. This will at some point, require them to assume a greater degree of independence and self-care than previously encountered [3], in addition to transferring from paediatric to adult services for ongoing health-care [4]. The need for effective transitional care and the benefits this provides in terms of maintaining engagement with healthcare throughout the life course and improving health outcomes is well established [5]. However, transition cannot be conceptualised as a young person-only phenomenon. Parents and adolescents together create the emotional environment necessary for the adolescent's adaptation to the demands of young adulthood [6,7]. Healthcare transition therefore also requires parents to adjust their care giving role, gradually relinquishing control of their child's LTC and supporting progression to young person autonomy [8,9]. Studies examining the role of family members during the transitional period [8,10,11] suggest parents face a range of new care challenges associated with their and their child's development, including adaptation to a changing role, allocation of treatment responsibilities and anxiety regarding their child's illness trajectory [12].

Despite recognition of the systemic nature of transition [7] and the effect of this developmental phase on shifting roles within family systems, previous reviews have focused on the perspectives of patients [13–15], transitional models [16,17] and healthcare practices [18,19]. Reviews have been carried out on the experience of parenting a child with a LTC [20] and on the effectiveness of interventions for parents of children and adolescents with chronic illness [21,22], however, these do not consider the experience of parenting a child with a chronic condition during their transition to adulthood and adult-services.

It is important to understand how parents experience their child's transition to adulthood because how parents manage and cope with their own change in roles and responsibilities will likely impact on both their child's transition to independent self-care as well as their own psychological well-being. Understanding the challenges that parents face, from their perspective, will further indicate support needs.

1.1. Aim & objectives

This review aimed to collect and synthesise primary research relating to how parents understand and experience their role as

their child with a LTC transitions to adulthood and adult healthcare services. The objectives were to: (a) understand how parents experience their care-giving role in relation to supporting their child's transition to adulthood/services; (b) understand how parents experience their care-giving role in relation to their own well-being; (c) make recommendations regarding how healthcare providers can support parents during their child's transition.

2. Methods

The review adopted a systematic search methodology in accordance with PRISMA guidance [23] and followed the analytic procedure for 'thematic' synthesis [24].

2.1. Eligibility criteria

To be included, papers had to report qualitative findings of primary research exploring parents' understanding and experiences of their role as their child with a LTC transitioned to adulthood and/or adult services. Parents included mothers, fathers and other primary care-givers (e.g. grandparents) of young people with long-term physical health conditions. In accordance with the WHO definition, an age range for young people of 10–24 years was stipulated. LTCs were defined as physical "illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely" [25]. This meant conditions that require on-going clinical care and self-management, for which medications are critical, and require follow-up at a clinic. Examples include diabetes mellitus and cystic fibrosis. As the review focused on physical health, mental health conditions such as anxiety and depression were excluded, as were learning difficulties such as autism. Papers reporting studies with mixed samples (e.g. perspectives of young people, parents and professionals), were included if data pertaining to parents were reported separately or could be separated by the reviewers. Studies with wholly young person or professional samples were excluded. No limits were placed on the year of publication; only studies reported in English were included.

2.2. Systematic search

Five electronic databases (Medline; CINAHL; EMBASE; PsycINFO; HMIC) were systematically searched to identify potentially eligible articles from inception until June 2015. Google Scholar was used to search for grey literature. A comprehensive search strategy was developed to include a combination of free text and index

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