



Review

Living a normal life in an extraordinary way: A systematic review investigating experiences of families of young people's transition into adulthood when affected by a genetic and chronic childhood condition



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ABSTRACT

Introduction: The transition into adulthood is a developmental stage within the life cycle. A chronic childhood condition can disrupt this transition and create major challenges for both the young person and his or her family. Little is known about families' experiences when living with a rare genetic disease. Therefore, the purpose of this literature review was to understand experiences of families living with a chronic childhood disease during transition into adulthood by integrating evidence.

Method: A systematic review using an integrative approach to data inclusion and analysis comprising qualitative, quantitative and other methodological studies about a range of genetic and chronic childhood diseases was undertaken to identify relevant information. Databases searched were PubMed, Cochrane Library, PsychINFO, CINAHL, and AMED, using the search terms (1) family, caregivers, young adult, adolescent; (2) adolescent development, transitional programs, transition to adult care; (3) muscular dystrophy, spinal muscular atrophy, cystic fibrosis, haemophilia and sickle cell disease. Study findings were critically appraised and analyzed using critical interpretive synthesis.

Results: A total of 8116 citations were retrieved. 33 studies remained following the removal of duplicates, papers unrelated to genetic childhood conditions and families' experiences of the transition into adulthood. Findings provided three perspectives: (1) the young person's perspective on how to "live a normal life in an extraordinary way" and "manage a chronic and life threatening disease"; (2) the parent perspective on the "complexity of being a parent of a chronically ill child" and "concerns about the child's future" and (3) the sibling perspective on "concerns about the siblings future".

As a consequence of the genetic childhood condition, during the ill family members' transition into adulthood all family members were at risk for psychosocial difficulties as they mutually influenced each other. Previous research focused predominately on the individual illness experience, and less emphasis was put on the family perspective.

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Conclusions: Young people and their family members experienced multiple challenges and not only for the ill individual but also there were consequences and health risks for the whole family system. Therefore, a family systems perspective to research and care is indicated to assist affected families to cope with their complex life and health situation.

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What is already known about this topic?

- Individuals affected by genetic conditions with an onset in childhood now live longer than ever before and an increasing number of young people reach adulthood.
- Chronic childhood conditions have an impact on the young persons' health and life situation and, as a consequence, influence quality of life of the whole family system.

What this paper adds

- Young people affected by chronic childhood disease and their family members experience multiple challenges imposed by the chronic condition and the developmental stage that the young person is in.
- The affected young person and his or her parents and siblings are at risk for psychosocial and emotional difficulties which may lead to developmental difficulties and health problems.
- A family systems approach to research and care is indicated to assist families to cope with major life transitions and their complex health and life situation.

1. Background

Diseases are defined as rare, when they affect less than 5 out of 10,000 individuals ([Commission of the European Communities, 2008](#)). Although individual diseases are defined as rare, rare diseases are collectively common ([Elliot, 2015](#)) and the total impact should not be underestimated. Approximately 30 million European and 25 million North American patients are currently affected by one out of 5000–6000 different rare or orphan diseases ([Schieppati et al., 2008](#); [Wästfelt et al., 2006](#)). More than two thirds of these diseases involve children or adolescents ([Boycott et al., 2014](#)). The majority are genetic in origin and frequently they are life-threatening, life-limiting or chronically debilitating. Their impact on the quality of life of the affected young individual and his or her family is significant ([Drotar, 1981](#); [Neill, 2010](#); [Rolland and Williams, 2005](#); [Samson et al., 2009](#); [Sobralnske, 2013](#)).

Families may suffer from psychosocial, emotional and physical difficulties ([Pangalila et al., 2012](#)). Moreover, chronic childhood diseases are associated with a substantial economic burden including direct, indirect and informal costs. [Landfeldt et al. \(2014\)](#), for instance, estimated a conservative amount of societal and household financial burden per patient per annum for rare genetic neuromuscular conditions at between \$80,120 and \$120,910 and \$58,440 and \$71,900, respectively. Thus, families may face economic hardship, feel stressed by inadequate services and are often under-supported ([Elliot, 2015](#)).

The delineated socio-psychological and economic burden increases with disease progression. This implies that the longer that children with progressive conditions live, the greater their physical dependence and need for assistance will be. Families face new challenges as chronically ill children are now living longer than ever before because of progress in health care and medicine ([Bushby et al., 2005](#); [Drotar, 1981](#); [Kohler et al., 2009](#)). Today, most individuals with rare chronic and genetic conditions such as cystic fibrosis or severe neuromuscular disease survive adolescence and reach adulthood. Thus, families have to deal with their children's increasing need for care and potential challenges, which are largely unexplored.

The transition into adulthood is a time of intense and focused transition and personal development for all young people but the process can be even more challenging for individuals affected by a chronic childhood disease ([Arnett, 2000](#); [Bill and Knight, 2007](#); [Christie and Viner, 2005](#); [Mietzel, 2002](#); [Monteith, 2004](#)). The challenges are from multiple perspectives and family members play an important role during this developmental stage, as the whole family needs to reorganize ([McGoldrick et al., 2013](#); [Miller et al., 2006](#)). Young individuals need sufficient freedom to develop their skills in decision making, in taking responsibility for themselves and becoming more independent. Parents, on the contrary, need to be more flexible and to permit their child's independence. For the child's development it is essential that families find a balance between single family members' needs and family functioning ([McGoldrick et al., 2013](#); [Patterson, 1991](#); [Rolland, 1994](#)). For families affected by a genetic childhood condition, they have to also balance management of their child's illness and this might affect their functioning which has potential repercussions for the young person, their siblings and the parents.

Families have to assist the young person in managing the transition to adulthood whilst also managing a serious disease, requiring a family centred approach to care ([Miller et al., 2006](#); [Rolland and Williams, 2005](#); [Rolland, 2012](#); [Segrin and Flora, 2011](#)).

The transition into adulthood was identified as a particularly sensitive and challenging time for young individuals living with chronic childhood condition and their families. This is influenced by the fact that the young person is expected to grow and probably wants to be more independent at the same time as their physical disability and dependence on their families' support increases. By assisting these families in their adjustment, young people and their families are prevented from becoming isolated and left to cope with the disease and the effects on family relationships ([Miller et al., 2006](#); [Rolland and Williams, 2005](#)).

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