Accepted manuscript

Title: Young people with long-term health challenges experiences in transition to adulthood: a qualitative metasynthesis

Running head: Young people with long-term health challenges in transition

Author details:

Anurajee RASALINGAM, Faculty of Health Sciences, Department of Nursing and Health Promotion, Oslo Metropolitan University, Norway

Liv FEGRAN, Faculty of Health and Sport Sciences, Department of Health and Nursing Science, University of Agder, Norway

Idunn BREKKE, Norwegian Institute of Public Health, Division of Child Health and Development, and Professor at Faculty of Health Sciences, Department of Nursing and Health Promotion, Oslo Metropolitan University, Norway

Sølvi HELSETH, Faculty of Health Sciences, Department of Nursing and Health Promotion, Oslo Metropolitan University, Norway

Corresponding Author:
Anurajee Rasalingam
Faculty of Health Sciences,
Department of Nursing and Health Promotion
Oslo Metropolitan University, Oslo Norway
Email: anrasa@oslomet.no

Conflict of interest:

The authors declare that they have no conflicts of interest.

Author contributions

AR: Conception and design of study, literature search, screening, data extraction, risk of bias assessment, analysis and interpretation of data, manuscript writing and revision.

LF: Conception and design of study, screening, risk of bias assessment, performed critical revisions during the review process and paper development.

IB: Conception and design of study, screening, risk of bias assessment, performed critical revisions during the review process and paper development.

SH: Conception and design of study, screening, risk of bias assessment, interpretation of data, performed critical revisions during the review process and paper development.

ABSTRACT

Aims: The aim of this study was to describe the experiences of the transition to adulthood for young people with long-term health challenges.

Design: The metasynthesis approach was based on the guidelines by Sandelowski and Barroso for synthesizing qualitative research.

Data sources: Seven electronic databases: CINAHL, Medline, Embase, PsycINFO, Web of Science, Scopus and SocIndex were searched on 6-10 February 2020.

Review Methods: Studies were critically appraised using the Joanna Briggs critical appraisal tool. Qualitative data were extracted, meta-summarised, then meta-synthesized.

Findings: Nineteen qualitative studies were included in this review. Six themes illustrated experiences in the transition to adulthood: wishing for an "ordinary" life, significance of close network, working towards independence, in need of systemic resources and services, psychosocial challenges and keeping a positive attitude.

Conclusion: Young people with long-term health challenges wished for as "ordinary" a life as possible in the future. In the transition to adulthood, they gradually gained more competence in self-management skills and knowledge and strived to become more independent. By having a positive attitude and utilising other coping strategies, young people can work on some of the difficulties they experience in this phase. However, to achieve and maintain independence young people with long-term health challenges are dependent on the support of a close network and systemic support and services.

Impact: The findings highlight the need to help alleviate the fears and worries of young people with long-term health challenges and create opportunities for successful transition to adulthood

by increased awareness and interventions from policy-makers and professionals within the health and social system.

1. **INTRODUCTION**

Advances and improvements in health care and medicine enable young people who experience serious health challenges to grow up to reach adulthood and participate in society in diverse ways (Bélanger & Surís, 2016; Perrin, Anderson, & Van Cleave, 2014). Long-term health challenges are commonly defined as presenting with three key features: prolonged duration, unlikely to resolve spontaneously and diminished ability to be completely cured (Goodman, Posner, Huang, Parekh, & Koh, 2013). Each long-term health challenge is unique in its intensity of treatment demands and degree of life intrusion (Michaud, Suris, & Viner, 2004). However, despite the unique challenges associated with each health diagnosis, there is a high degree of common experiences across diagnoses (Nguyen, Stewart, & Gorter, 2018). Long-term health challenges can result in similar stressful experiences when growing up, such as academic setbacks (Brekke & Reisel, 2017; Champaloux & Young, 2015; McKinley Yoder & Cantrell, 2019) greater likelihood of being victims of bullying compared to healthy peers (Pinquart, 2017) and impaired physical wellbeing compared to healthy peers (Silva et al., 2019). Having a long-term health challenge may therefore have a significant impact on a young person's life.

The present article focuses on the transition to adulthood among young people with long-term health challenges. A transition is characterised by an unstable passage between two more stable life periods. In this review, the transition to adulthood is a developmental transition, which

requires the person to incorporate new knowledge, to alter behaviour and therefore to change the definition of self in social contexts (Meleis, 2010). During the transition, vulnerabilities are often revealed as they are "related to transition experiences, interactions, and environmental conditions that expose individuals to potential damage, problematic or extended recovery, or delayed or unhealthy coping" (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000, p. 12). Nurses are uniquely present to intervene throughout the transitioning process when working with young individuals with any medical condition (Meleis et al., 2000). Knowledge about young people with long-term health challenges' experiences of the transition to adulthood would be especially useful in the development of preventive holistic patient-centred nursing interventions.

1.1 Background

The "emerging adulthood" theory developed by Arnett (2000, 2015) describes a stage in the life-course from the late teens through the twenties, characterising the age period as one of identity exploration, feeling "in-between", instability, self-focus and possibilities. Emerging adulthood is a distinct phase that involves many changes, and the discovery of who we are and who we would like to become. Hence, this transitional period is marked by high expectations and aspirations, but it is also a time of emotional insecurity and uncertainty, because the lives of young people are so unsettled (Arnett, 2015). Some of the most common aspects of the transition to adulthood for all emerging adults are increased independence, transition from school to work and from living in the parental home to independent living (Arnett, 2015). However, long-term health challenges might affect developmental milestones. Results from a meta-analysis by Pinquart (2014) showed that young people with chronic pediatric illness had lower rates of completing higher education, finding employment, lower income, leaving the parental home, marrying and becoming parents compared to healthy peers. In a recent review investigating the

achievement of psychosocial developmental milestones such as social, autonomy and psychosexual domains, the development of young people who had grown up with a chronic disease was delayed in all three domains (Maurice-Stam, Nijhof, Monninkhof, Heymans, & Grootenhuis, 2019). Personal barriers such as physical limitations (Osgood, Foster, & Courtney, 2010) as well as environmental barriers (Cook, Jack, Siden, Thabane, & Browne, 2016; Stewart et al., 2014; Waldboth, Patch, Mahrer-Imhof, & Metcalfe, 2016) have been reported as roadblocks to a successful transition to adulthood. For young people living with long-term health challenges, the transition to adulthood also involves the transition from child-oriented to adult-oriented health systems (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014). Hence, they need to learn two sets of skills, both general life skills, including management of independent living, relationships, higher education, work and leisure activities (Furlong, 2017), and health maintenance skills, including management of their condition and its treatment (Lambert & Keogh, 2015; Paterson, Nayda, & Paterson, 2012). The development of such skills and increasing responsibility can create heavy demands and contribute to persistent stress that may reduce quality of life. Quality of life can be conceptualized as psychological wellbeing. Quality of life implies that the individual's sense of wellbeing is sensitive to the effects of life events that are either positive or negative (Naess, 2001).

Previous systematic reviews and metasyntheses have primarily focused on perspectives on adolescents with long-term health challenges' transfer from pediatric to adult health care (Betz, Lobo, Nehring, & Bui, 2013; Fegran et al., 2014), or parental or family perspectives on health care transfer and the transition to adulthood, focusing on a few specific health diagnoses (Heath, Farre, & Shaw, 2017; Waldboth et al., 2016). Thus, a systematic review and metasynthesis on how young people with various long-term health challenges (somatic condition or physical

disability) experience the critical phase of transition to adulthood may provide important and relevant evidence on this topic.

2. **THE REVIEW**

2.1 Aims

The aim of this review was to systematically interpret and synthesize the evidence from qualitative studies of young people with long-term health challenges' experiences of the transition to adulthood. The objectives were to identify evidence of: (1) young people's expectations and aspirations about their future, (2) their experiences of self-management and support in the transition to adulthood, (3) their experiences of quality of life in the transition to adulthood.

2.2 Design

This metasynthesis was conducted according to a pre-specified protocol published in Prospero, registration number: CRD42020146755. The review was designed as a qualitative metasynthesis and followed the approach outlined by Sandelowski and Barroso (2007). A metasynthesis refers to a systematic process aimed at representing an interpretive integration of findings that emerge from qualitative studies. Consistent with this methodology, we formulated the purpose and rationale for the study, strategically searched the literature, critically appraised the included studies, and extracted and grouped the findings into what Sandelowski and Barroso (2007) refer to as qualitative metasummaries and finally formed the metasynthesis.

2.3 Search methods

To identify eligible qualitative studies, a comprehensive search strategy was developed in collaboration with a research librarian. Systematic searches were conducted in seven electronic databases: CINAHL (EBSCOhost), Medline, Embase, PsycINFO (all via Ovid), Web of Science, Scopus and SocIndex. The search covered all studies published between 2009 and 6-10 February 2020. These databases were considered most appropriate for our literature searches because they cover articles within the fields of health and social sciences. The search strategy included the keywords "adolescent OR young adult OR emerging adult OR teenager OR youth" AND "chronic disease OR chronic condition OR long-term illness OR disabled person OR disabled OR disabilit* AND "transition OR transition to adult care OR future OR envision OR aspiration". The search strategy was modified to fit each database. In addition to the systematic search, we reviewed the reference lists of all the articles included. The time limitation was set because this review aimed to consider studies that are more relevant to the current situation of young people with long term-health challenges and the transition to adulthood. A study was eligible for inclusion if: (1) it is a peer-reviewed primary study (2) focuses on young people's experiences of the transition to adulthood (3) participants have a long-term somatic condition or physical disability and (4) the study is published in English or a Nordic language. Studies in which the focus was on the transfer from pediatric to adult healthcare were excluded, as were studies focusing on young people with mental illnesses or diagnoses.

2.4 Search outcomes

The systematic searches resulted in 4,763 records from the databases after removal of duplicates. First, titles and abstracts were screened by the first author (A.R) and one of the other authors (L.F, I.B, S.H) independently in the screening programme Rayyan (Ouzzani, Hammady,

Fedorowicz, & Elmagarmid, 2016), and any uncertainties or challenges related to the study

inclusion were discussed until consensus was achieved. Studies that appeared to be potentially

relevant (n=73) were read in full text by two authors (A.R and I.B) and any disagreement was

resolved by discussion. In total, 19 articles were included in this review based on their relevance

to the inclusion and exclusion criteria, and only one study was identified through the reference

list search in the included studies. The inclusion process according to PRISMA guidelines

(Moher, Liberati, Tetzlaff, Altman, & Group, 2009) is reported in Fig. 1.

2.5 Quality appraisal

Two reviewers, using the standardised ten-item critical appraisal checklist from the

Joanna Briggs Institute, assessed the methodological quality of the studies independently (the

Qualitative Assessment and Review Instrument (JBI-QARI)) (Lockwood et al., 2017). The

quality of the studies were discussed between the reviewers until reaching consensus. The

congruence between the research methodology and objectives, methods used to collect data,

analysis methods and interpretations of findings was well addressed in most of the studies. All

the studies scored "yes" to the question: "is the patient's voice adequately represented?".

However, questions regarding philosophical perspectives, researchers' theoretical and cultural

backgrounds and their influence on the findings were poorly addressed. As recommended by

Sandelowski and Barroso (2007), no reports congruent with the purpose of our metasynthesis

were excluded for methodological reasons. The findings are presented in Table 1.

2.6 Data abstraction and synthesis

In the analysis process the first author extracted, aggregated, interpreted and synthesized findings in the included studies and discussed this with the other authors (Sandelowski & Barroso, 2007). As suggested by Sandelowski and Barroso (2007), we first conducted a qualitative metasummary, which is a quantitatively oriented aggregation of qualitative research findings across the included studies. The aggregation of qualitative data included information about authors, year of publication, country of origin, study method, purpose of study, population and main findings. Secondly, a qualitative metasynthesis was conducted, which is an interpretive integration of findings across the included studies. The synthesis followed the approach to thematic analysis technique by Braun and Clarke (2006). The extracted text derived from the primary studies' findings sections was read and reread several times to become familiar with the content. Initial codes were subsequently developed, and these coded statements were grouped into categories, and themes were identified, reviewed and named. The relevant findings to be included were young people's quotations or primary researchers' interpretations of young people's experiences regarding quality of life, self-management and support, and their future expectations and aspirations in the transition to adulthood.

3. FINDINGS

The findings are presented as metasummaries supported by tables and as metasynthesis presented in six themes.

3.1 Metasummaries

The characteristics of the included studies are presented in Table 2 (see online file for supplementary information), metasummaries of the included studies in Table 3 and the age of the

participants in Fig. 2. The studies represent three continents, all Western countries. The studies

included a total of 282 emerging adults with long-term health challenges. Sixteen various long-

term health challenge diagnoses are represented in this metasynthesis. Most studies used

individual semi-structured interviews as data collection method, and content analysis as data

analysis method.

3.2 Metasynthesis

The experiences of young people with long-term health challenges in the transition to

adulthood were synthesized into six themes: wishing for an "ordinary" life, significance of close

network, working towards independence, in need of systemic resources and services,

psychosocial challenges and keeping a positive attitude.

3.2.1 Wishing for an "ordinary" life

Wishing for an "ordinary" life referred to young people's future aspirations and expectations. As

they approached adulthood, they wished to be given more opportunities to participate and

contribute to society and have more choices in becoming independent (Abbott & Carpenter,

2014; Kola, Turner, & Dhingra, 2015; Ridosh, Braun, Roux, Bellin, & Sawin, 2011). One young

person living with a long-term neurological condition stated: "When they place jobs and

colleges, they don't place it so it's easy for people with disabilities to get into it" (Kola et al.,

2015, p. 160). Achievement of higher education and employment was seen as an important step

towards adult identity (Gibson et al., 2014). Although participants were interested in various

future career paths, some discovered that their first career choice might be unrealistic due to

some specific needs related to their long-term health challenge (Lankhorst et al., 2017; Lindsay,

Cagliostro, Leck, & Stinson, 2019). Therefore, they considered or chose to study in fields where they believed they could succeed in work settings (Berry & Domene, 2015). Another important marker of adult identity was being able to live independently (Gibson et al., 2014; Kola et al., 2015): "I think it's important to be able to move out on your own, because your parents aren't always going to be there. And they can't just hold your hand your entire life" (Hamdani, Mistry, & Gibson, 2015, p. 1149). Some participants looked forward to this new chapter of increased independence, whereas others were more reluctant, mostly due to the potential loss of care from family members (Gibson et al., 2014; Peeters, Hilberink, & van Staa, 2014). One young man living with duchenne muscular dystrophy stated: "Yeah, just scary or frightening. I always need help a lot. I'm going to want someone to be there all the time" (Hamdani et al., 2015, p. 1148). Participants' desire for a family of their own one day was an issue in most of the studies. However, this also raised concerns about the medical and practical aspects of this (Higham, Ahmed, & Ahmed, 2013; Peeters et al., 2014). One young woman living with cerebral palsy stated that "If I want to have a family, how do I function and have people that I'm responsible for?" (Bagatell, Chan, Rauch, & Thorpe, 2017, p. 84). Living with the awareness of their limitations and challenges in different areas of life, young individuals experienced fear and worries about how the future would unfold for them (Bjorquist, Nordmark, & Hallstrom, 2015; Higham et al., 2013).

3.2.2 Significance of close network

The significance of the participants' close network in this phase was an issue in most of the studies. Family members, especially parents, were particularly important. One young woman living with type 1 diabetes stated that: "My mum has always told me not to be ashamed of

myself or my illness. According to her, I can do everything I want, and that's what always motivated me" (Carlsund & Söderberg, 2019, p. 421). In addition to providing emotional support (Labore, Mawn, Dixon, & Andemariam, 2017; Lindsay et al., 2019), parents provided financial assistance (Babic & Dowling, 2015; Fair, Rupp, Mitchell, & Gatto, 2018) and practical care (Babic & Dowling, 2015; Gibson et al., 2014): "The people I care about the most is family, because they're supportive, and can help you go over challenges, and can help you with different - with your care and things like that." (Hamdani et al., 2015, p. 1148). Young people experienced that friends were supportive (Babic & Dowling, 2015; Carlsund & Söderberg, 2019), and provided practical support, as well as appearing to enhance community involvement and social interactions (Berry & Domene, 2015, p. 82). Some experienced being in relationships that were understanding and supportive: "My boyfriend is fantastic. Sometimes at night if I act corny, he measures my blood glucose, just in case. He even keeps me company when meeting my diabetes team" (Carlsund & Söderberg, 2019, p. 422). Young individuals took comfort in the encouragement and motivation of medical providers who were familiar with their condition: "they influence me a lot because a lot of the nurses and the doctors that I have, they were with me since I was a little girl and they've watched me growing up. They're rooting for me, so that really helps" (Fair et al., 2018, p. 168).

3.2.3 Working towards independence

Young people strived to become independent and worked on managing their own care and daily tasks. They experienced the process of self-management in different ways, based on their own attitudes, the severity of their diagnosis and degree of parental involvement. Through trial and error, they sought to gain better control and understanding of their long-term health challenge

and thus recognised the need to take care of themselves: "you're not a little kid any longer" (Labore et al., 2017, p. 74). This included taking charge of their medical management (Carlsund & Söderberg, 2019; Labore et al., 2017; Peeters et al., 2014), making hospital appointments and communicating directly with their physicians regarding treatment plans (Labore et al., 2017; Peeters et al., 2014). But also finding their own solutions to specific problems they encountered (Lankhorst et al., 2017) and incorporating practical strategies for coping with everyday living with respect to housing, leisure activities and transportation (Kola et al., 2015; Lankhorst et al., 2017). One young man explained how his mother motivated him from an early age to manage his own care: "So gradually, she gave me my own responsibilities and that kind of led me to eventually manage a lot of the stuff on my own" (Hamdani et al., 2015, p. 1148). Conversely, some participants experienced overprotective parents, which hindered them in exploring and doing things on their own (Hallberg, Stavropoulos, Mohlin, & Hagberg, 2012; Ridosh et al., 2011).

3.2.4 In need of systemic resources and services

In the transition to adulthood, young people experienced a lack of knowledge about and difficulties in finding services and support regarding higher education, employment and health care (Bjorquist et al., 2015; Kola et al., 2015). Many found it challenging that the support they received growing up, from a personal assistant in school to extra time to complete tasks, and other services were significantly cut entering adulthood: "cut back and back until you hardly see them anymore as an adult" (Bagatell et al., 2017, p. 82). They were often frustrated by the lack of coordination between various agencies and service providers, and having to continually document their need for personal care attendants (Bagatell et al., 2017). The initial period at the

university was experienced as intense and chaotic for some of the participants. There was a lack of support for students with disabilities, and participants thus had to take most of the responsibility for their own study situation (Lang, 2015). One young woman stated how she relied on support from her brother who attended the same university as her: "I wouldn't have been able to be at university for this long, especially at the beginning. My carers [personal care assistants] didn't show up in the mornings to get me out of bed and stuff and so I had assessments on that day, like presentations, so [Dan] would have to get me out of bed" (Wedgwood, 2011, p. 446). Some experienced a lack of financial support that made their living situation during studies problematic (Babic & Dowling, 2015; Bagatell et al., 2017). Others had finished their education and training but were at home during the day without meaningful activity: "I made an appointment to see the Disability Employment Advisor at the job centre, but she wasn't much good to be honest. She pretty much said straight away that there wouldn't be any work that I'd be able to do. I was hoping for a bit more of a positive approach than that" (Abbott & Carpenter, 2014, p. 1197).

3.2.5 Psychosocial challenges

Participation in activities and socialisation with peers was perceived as important in the transition to adulthood (Bjorquist et al., 2015). However, many of the participants experienced limitations on active or frequent interaction with people of the same age (Bjorquist et al., 2015; Ridosh et al., 2011), and difficulties making contact and entering into friendships or a relationship (Lankhorst et al., 2017; Wedgwood, 2011). Bullying, such as "kids making fun" and "people staring" was something that had been a problem for many of them growing up and in the transition to adulthood (Bagatell et al., 2017; Hallberg et al., 2012; Ridosh et al., 2011). Some

experienced feelings of insecurity when meeting new people, and feared being disliked by others due to their diagnosis as described by Lankhorst et al. (2017): "I've always hidden my cystic fibrosis, I don't like being different, cause I've always kind of worried that people will think like things about me" (Higham et al., 2013, p. 377). Young individuals who had feelings of fear and anxiety or problems accepting the long-term health challenge perceived limitations in their social life: "I'm not confident with anything to be honest. It's because of my epilepsy. Because I'm always too scared to try like new things, because I'm scared that if I try something it's going to trigger something. You know like shaking or trigger a fit" (Kola et al., 2015, p. 159). Conversely, young individuals, who had better understanding of their long-term health challenge were able to acknowledge their limitations and develop strategies for social participation (Kola et al., 2015).

3.2.6 Keeping a positive attitude

Keeping a positive attitude was presented as an active, deliberate strategy for facing some of the challenges they experienced in the transition to adulthood (Berry & Domene, 2015; Gibson et al., 2014). For some young people, this meant not engaging with negative thoughts and pitying themselves, and instead having a positive outlook on life: "you know there are challenges, times when things are a little harder, you just want to not deal with them, um, especially with, like a disability. But yeah, if I wasn't determined, I don't know what kind of person I would be. Especially having duchenne muscular dystrophy you can't be the kind of person who gives up easily" (Gibson et al., 2014, p. 103). Growing up with long-term health challenges gave them the knowledge that "life is short and precious" and to take it day-by-day (Abbott & Carpenter, 2014; Labore et al., 2017). Having a plan for the day and bringing along necessities such as pain

medication made it easier to live every day to the fullest. This also gradually gave them control of their disease (Labore et al., 2017). One young woman living with spina bifida stated: "I think you build your inner strength as you go. You become tougher each day. You realise you can do certain things that no one else thinks you can" (Ridosh et al., 2011, p. 871). Furthermore, for some young individuals it was important to focus on their abilities and accept the long-term health challenge (Ridosh et al., 2011).

4. **DISCUSSION**

The present study reports findings from the first broad metasynthesis on the experiences of young people with long-term health challenges in the transition to adulthood. More specifically, the study provides knowledge about young people's future expectations and aspirations, self-management and support and quality of life during this phase.

4.1 Discussion of findings

The findings of this study clearly indicate that young people with long-term health challenges have the same future expectations and aspirations as their healthy peers, in accordance with other studies that demonstrate their wish for an "ordinary" life (Lambert & Keogh, 2015; Waldboth et al., 2016). However, in doing so, young people also reflected on the difficulties they were facing because of their long-term health challenge. According to the work of Arnett (2015), a strong indicator of becoming an adult today means becoming self-sufficient and learning to stand alone as an independent person. By exploring possibilities, young people learn more about who they are and what they want out of life. The young people in the present review talked about the limitations in their possibilities to become independent, referring to

barriers to participating and contributing to society. This finding is supported by other research that demonstrates young individuals with long-term health challenges' experiences of feeling neglected by society (Jaeger, Röjvik, & Berglund, 2015; Törnbom, Törnbom, & Sunnerhagen, 2013). Young people with long-term illnesses experience particular challenges in education and employment trajectories (Maslow, Haydon, McRee, Ford, & Halpern, 2011). Therefore, our finding that they chose to study in fields where they believed they could succeed in work settings, despite being interested in other career paths, is not surprising. Furthermore, Beal and Crockett (2010) found in their study that young people's expectations for the future are often grounded in what they believe about their skills, capacities and the opportunities available to them.

The significance of a close network for young individuals growing up with long-term health challenges is in line with previous studies (Schuh, Sundar, & Hagner, 2015; Suris, Michaud, & Viner, 2004). Although, young individuals gradually gained more self-management knowledge and skills, parents were still strongly involved in their lives and some young people experienced them as too protective. This finding is supported by other studies (Hullmann et al., 2010; Jetha et al., 2014) revealing that parents have a hard time "letting go". According to Arnett (2015) for some emerging adults, their parents' reluctance to let them go is mirrored by their own reluctance to take on responsibilities. Thus, the sense of being in-between occurs when emerging adults continue to rely on their parents in some ways, so that their movement toward self-sufficiency is incomplete. This may be explained by the fact that many of the participants in our study seemed to be burdened by the societal expectation for self-management and independence and desire to meet the transition norms for their age group, while also struggling with fear and worries about their own inability to cope because of their long-term health

challenge. The transition to adulthood was further complicated by the significant drop in systemic services and support. The review identified this as a "critical turning point" in the transition process. From the transition theory perspective of Meleis (2010), a "critical point" is often associated with an increased awareness of change or difference, and is identified as a period of heightened vulnerability. Fragmented, inadequate and unpredictable services and support increased difficulties with independent living and enrolment in university. In addition, some had less support from their parents due to being apart. These co-occurring situational transitions emphasised this period as a time of instability (Arnett, 2015). Joly (2015) points out in her study that independence in adulthood among young people with medical complexity necessitates dependence, and as suggested in our findings, the level of dependence was higher for young individuals, for whom self-management is more highly emphasised. The previous notion that young people with long-term health challenges did not survive into adulthood (Perrin et al., 2014), may have contributed to policy-makers and professionals not adequately considering their needs and abilities in the adult system (Hamdani, Jetha, & Norman, 2011; Joly, 2015). Transition is neither a static nor finite process (Meleis, 2010), thus limiting transition support to pediatric care may be counterproductive.

Our findings showed that emerging adults experienced psychosocial challenges in the transition to adulthood, which negatively affected their quality of life. Although, peer connectedness was something that they highly desired, they described limitations in social participation and difficulties in making contact and starting friendships or relationships. These findings are consistent with the study by Waldboth et al. (2016), which indicates that young people with long-term health challenges are more isolated in the transition to adulthood and have difficulty belonging to a peer group. As in previous research (Kaushansky et al., 2017; Lambert

& Keogh, 2015), some young individuals talked about not disclosing their long-term health challenge due to fear of being perceived as different. There is evidence that emerging adulthood is a period associated with greater sensitivity to fear and negative stimuli as a function of brain maturation, greater control over emotional reactions comes with age (Williams et al., 2006). However, despite some of the challenges and uncertainties they experienced in the transition to adulthood, the participants talked about how they believed in having a positive attitude and focusing on their abilities, instead of "pitying themselves". The use of such psychological coping strategies has shown to improve quality of life (Musekamp, Bengel, Schuler, & Faller, 2016). Furthermore, Arnett (2015) describes how in emerging adulthood, there is a growing self-knowledge and self-understanding among young people. As they move away from the confusion of adolescence, they become more capable of reflecting on what is not working in their lives and what they can do to make it better.

4.2 Limitations

One limitation is the lack of cultural and geographical breadth in this metasynthesis. The included studies were predominated by research from Europe and North America, resulting in findings from Western countries and societies, and it is therefore difficult to generalise the findings to other cultures. Another limitation is that this metasynthesis excluded young people with mental conditions' experiences in the transition to adulthood, which might have strengthened the study. Additionally, the exclusion of quantitative studies may have led to findings being omitted. However, the exclusion was supported by the aim of this review, which was to identify the experiences of young people in the transition to adulthood, thus the qualitative method was deemed expedient.

5. **CONCLUSION**

The findings of this metasynthesis indicate that the transition to adulthood is a challenging phase for young people with long-term health challenges. Despite some of the challenges they experienced, young people wished for as "ordinary" a life as possible in the future. This meant gaining independence and relying less on parents to lead a full life. However, the experience of discontinuity of systemic support is a critical event in the transition process. There is a need for adequate follow-up into adulthood through integrated and coordinated systemic services and support to provide young people with more opportunities for independent living, higher education and labour market participation. When young people, parents and service providers collaborate, the transition to adulthood can be experienced as more gradual, age appropriate and in a client and family-centred manner (Nguyen et al., 2018). Nurses play a central role in the treatment of disease and the promotion of healthy behaviour in working with young people with long-term health challenges (Meleis, 2010). Additionally, the way nurses interact with the young person may mark, in great part, the young person's behaviour towards the long-term health challenge. Having a person-centred and not only disease-centred focus, by inquiring beyond purely medical issues, for instance asking about family, friends and school can contribute to support the young person in the transition to adulthood (Bélanger & Surís, 2016). To increase our knowledge and improve young people's transition experiences, further research is needed to explore cultural nuances between different practice settings and living environments as this influences transition experiences and access to care.

Conflict of Interest statement

The authors have no conflicts of interest

References

Abbott, D., & Carpenter, J. (2014). 'Wasting precious time': Young men with Duchenne muscular dystrophy negotiate the transition to adulthood. *Disability & Society, 29*(8), 1192-1205. doi:http://doi.org/10.1080/09687599.2014.916607

Arnett, J. J. (2000). Emerging adulthood: a theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469-480. doi:http://doi.org/10.1037/0003-066X.55.5.469

Arnett, J. J. (2015). *Emerging adulthood: The winding road from the late teens through the twenties* (2nd ed.). New York: Oxford University Press.

Babic, M. M., & Dowling, M. (2015). Social support, the presence of barriers and ideas for the future from students with disabilities in the higher education system in Croatia. *Disability & Society, 30*(4), 614-629. doi:http://doi.org/10.1080/09687599.2015.1037949

Bagatell, N., Chan, D., Rauch, K. K., & Thorpe, D. (2017). "Thrust into adulthood": Transition experiences of young adults with cerebral palsy. *Disability & Health Journal, 10*(1), 80-86. doi:https://doi.org/10.1016/j.dhjo.2016.09.008

Beal, S. J., & Crockett, L. J. (2010). Adolescents' Occupational and Educational Aspirations and Expectations: Links to High School Activities and Adult Educational Attainment. *Developmental Psychology, 46*(1), 258-265. doi:http://doi.org/10.1037/a0017416

Bélanger, R. E., & Surís, J. C. (2016). Adolescents with chronic conditions. In *International Handbook on Adolescent Health and Development: The Public Health Response* (pp. 293-305): Springer International Publishing.

Berry, S. J., & Domene, J. F. (2015). Supporting postsecondary students with sensory or mobility impairments in reaching their career aspirations. *Career Development and Transition for Exceptional Individuals, 38*(2), 78-88. doi:http://doi.org/10.1177/2165143413490792

Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook, 61*(5), 311-336. doi:http://doi.org/10.1016/j.outlook.2013.01.008

Bjorquist, E., Nordmark, E., & Hallstrom, I. (2015). Living in transition - experiences of health and well-being and the needs of adolescents with cerebral palsy. *Child: Care, Health & Development, 41*(2), 258-265. doi:https://doi.org/10.1111/cch.12151

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:http://doi.org/10.1191/1478088706qp063oa

Brekke, I., & Reisel, L. (2017). The impact of birthweight and adolescent health on educational attainment. *Scandinavian Journal of Educational Research, 61*(1), 60-75. doi:http://doi.org/10.1080/00313831.2015.1066442

Carlsund, Å., & Söderberg, S. (2019). Living with type 1 diabetes as experienced by young adults. *Nursing Open, 6*(2), 418-425. doi:http://doi.org/10.1002/nop2.222

Champaloux, S. W., & Young, D. R. (2015). Childhood Chronic Health Conditions and Educational Attainment: A Social Ecological Approach. *Journal of Adolescent Health, 56*(1), 98-105. doi:http://doi.org/10.1016/j.jadohealth.2014.07.016

Cook, K. A., Jack, S. M., Siden, H., Thabane, L., & Browne, G. (2016). Investing in Uncertainty: Young Adults with Life-Limiting Conditions Achieving Their Developmental Goals. *Journal of Palliative Medicine, 19*(8), 830-835. doi:http://doi.org/10.1089/jpm.2015.0241

Fair, C. D., Rupp, S., Mitchell, J., & Gatto, A. (2018). "I'm Not Fragile. I'm Not Limited": Career Aspirations of Youth With Perinatally Acquired HIV. *Rehabilitation Counseling Bulletin, 61*(3), 164-174. doi:http://doi.org/10.1177/0034355217711852

Fegran, L., Hall, E. O. C., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: A qualitative metasynthesis. *International Journal of Nursing Studies, 51*(1), 123-135. doi:http://doi.org/10.1016/j.ijnurstu.2013.02.001

Furlong, A. (2017). *Routledge handbook of youth and young adulthood* (2nd ed.). London: Routledge.

Gibson, B. E., Mistry, B., Smith, B., Yoshida, K. K., Abbott, D., Lindsay, S., & Hamdani, Y. (2014). Becoming men: Gender, disability, and transitioning to adulthood. *Health: an Interdisciplinary Journal for the Social Study of Health, Illness & Medicine, 18*(1), 95-114. doi:https://doi.org/10.1177/1363459313476967

Goodman, R. A., Posner, S. F., Huang, E. S., Parekh, A. K., & Koh, H. K. (2013). Defining and measuring chronic conditions: imperatives for research, policy, program, and practice. *Preventing Chronic Disease, 10*, E66. doi:http://doi.org/10.5888/pcd10.120239

Hallberg, U., Stavropoulos, D., Mohlin, B., & Hagberg, C. (2012). Living with Crouzon syndrome: transition from childhood to adulthood. *Scandinavian Journal of Disability Research, 14*(3), 199-211. doi:http://doi.org/10.1080/15017419.2011.558239

Hamdani, Y., Jetha, A., & Norman, C. (2011). Systems thinking perspectives applied to healthcare transition for youth with disabilities: a paradigm shift for practice, policy and research. *Child: Care, Health and Development, 37*(6), 806-814. doi:http://doi.org/10.1111/j.1365-2214.2011.01313.x

Hamdani, Y., Mistry, B., & Gibson, B. E. (2015). Transitioning to adulthood with a progressive condition: best practice assumptions and individual experiences of young men with Duchenne muscular dystrophy. *Disability & Rehabilitation, 37*(13), 1144-1151. doi:https://doi.org/10.3109/09638288.2014.956187

Heath, G., Farre, A., & Shaw, K. (2017). Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling, 100*(1), 76-92. doi:http://doi.org/10.1016/j.pec.2016.08.011

Higham, L., Ahmed, S., & Ahmed, M. (2013). Hoping to Live a "Normal" Life Whilst Living with Unpredictable Health and Fear of Death: Impact of Cystic Fibrosis on Young Adults. *Journal of Genetic Counseling, 22*(3), 374-383. doi:http://doi.org/10.1007/s10897-012-9555-1

Hullmann, S., Wolfe-Christensen, C., Ryan, J., Fedele, D., Rambo, P., Chaney, J., & Mullins, L. (2010). Parental Overprotection, Perceived Child Vulnerability, and Parenting Stress: A Cross-Illness Comparison. *Journal of Clinical Psychology in Medical Settings, 17*(4), 357-365. doi:http://doi.org/10.1007/s10880-010-9213-4

Jaeger, G., Röjvik, A., & Berglund, B. (2015). Participation in society for people with a rare diagnosis. *Disability and Health Journal, 8*(1), 44-50. doi:http://doi.org/10.1016/j.dhjo.2014.07.004

Jetha, A., Badley, E., Beaton, D., Fortin, P. R., Shiff, N. J., Rosenberg, A. M., . . . Gignac, M. A. M. (2014). Transitioning to Employment with a Rheumatic Disease: The Role of Independence, Overprotection, and Social Support. *Journal of Rheumatology, 41*(12), 2386-2394. doi:http://doi.org/10.3899/jrheum.140419

Joly, E. (2015). Transition to Adulthood for Young People with Medical Complexity: An Integrative Literature Review. *Journal of Pediatric Nursing, 30*(5), e91-103. doi:https://doi.org/10.1016/j.pedn.2015.05.016

Kaushansky, D., Cox, J., Dodson, C., McNeeley, M., Kumar, S., & Iverson, E. (2017). Living a secret: Disclosure among adolescents and young adults with chronic illnesses. *Chronic Illness, 13*(1), 49-61. doi:http://doi.org/10.1177/1742395316655855

Kola, S., Turner, J., & Dhingra, K. (2015). Challenging lives: An exploratory qualitative study of Quality of life in young adults living with a chronic neurological condition. *International Journal of Developmental Disabilities, 61*(3), 156-165. doi:http://doi.org/10.1179/2047387713Y.0000000034

Labore, N., Mawn, B., Dixon, J., & Andemariam, B. (2017). Exploring Transition to Self-Management Within the Culture of Sickle Cell Disease. *Journal of Transcultural Nursing, 28*(1), 70-78. doi:http://doi.org/10.1177/1043659615609404

Lambert, V., & Keogh, D. (2015). Striving to Live a Normal Life: A Review of Children and Young People's Experience of Feeling Different when Living with a Long Term Condition. *Journal of Pediatric Nursing, 30*(1), 63-77. doi:http://doi.org/10.1016/j.pedn.2014.09.016

Lang, L. (2015). Responsibility and participation in transition to university – voices of young people with disabilities. *Scandinavian Journal of Disability Research, 17*(2), 130-143. doi:http://doi.org/10.1080/15017419.2013.817355

Lankhorst, I. M. F., Baars, E. C. T., Wijk, I. V., Janssen, W. G. M., Poelma, M. J., & van der Sluis, C. K. (2017). Living with transversal upper limb reduction deficiency: limitations experienced by young adults during their transition to adulthood. *Disability & Rehabilitation, 39*(16), 1623-1630. doi:https://doi.org/10.1080/09638288.2016.1206632

Lindsay, S., Cagliostro, E., Leck, J., & Stinson, J. (2019). Career aspirations and workplace expectations among youth with physical disabilities. *Disability and Rehabilitation*, 1-12. doi:http://doi.org/10.1080/09638288.2019.1671505

Lockwood, C., Porrit, K., Munn, Z., Rittenmeyer, L., Salmond, S., Bjerrum, M., . . . Stannard, D. (2017). Chapter 2: Systematic reviews of qualitative evidence. In Aromataris E & M. Z (Eds.), Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute. Retrieved from https://reviewersmanual.joannabriggs.org/. doi: https://doi.org/10.46658/JBIRM-17-02

Maslow, G. R., Haydon, A., McRee, A. L., Ford, C. A., & Halpern, C. T. (2011). Growing up with a chronic illness: Social success, educational/vocational distress. *Journal of Adolescent Health, 49*(2), 206-212. doi:http://doi.org/10.1016/j.jadohealth.2010.12.001

Maurice-Stam, H., Nijhof, S. L., Monninkhof, A. S., Heymans, H. S. A., & Grootenhuis, M. A. (2019). Review about the impact of growing up with a chronic disease showed delays achieving psychosocial milestones. *Acta Paediatrica, 108*(12), 2157-2169. doi:http://doi.org/10.1111/apa.14918

McKinley Yoder, C. L., & Cantrell, M. A. (2019). Childhood Disability and Educational Outcomes: A Systematic Review. *Journal of Pediatric Nursing, 45*, 37-50. doi:http://doi.org/10.1016/j.pedn.2019.01.003

Meleis, A. I. (2010). *Transitions theory : middle-range and situation-specific theories in nursing research and practice*. New York: Springer.

Meleis, A. I., Sawyer, L., Im, E.-O., Hilfinger Messias, D. A., & Schumacher, K. (2000). Experiencing Transitions: An Emerging Middle-Range Theory. *Advances in Nursing Science, 23*(1), 12-28. doi:http://doi.org/10.1097/00012272-200009000-00006

Michaud, P. A., Suris, J. C., & Viner, R. (2004). The adolescent with a chronic condition. Part II: healthcare provision. *Archives of Disease in Childhood*, 943-949. doi:http://doi.org/10.1136/adc.2003.045377

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, P. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of Internal Medicine, 151*(4), 264-269, W264. doi:http://doi.org/10.7326/0003-4819-151-4-200908180-00135

Musekamp, G., Bengel, J., Schuler, M., & Faller, H. (2016). Improved self-management skills predict improvements in quality of life and depression in patients with chronic disorders. *Patient Education and Counseling, 99*(8), 1355-1361. doi:http://doi.org/10.1016/j.pec.2016.03.022

Naess, S. (2001). Quality of life as psychological well-being. *Tidsskrift for Den Norske Laegeforening, 121*(16), 1940-1944. Retrieved from https://tidsskriftet.no/2001/06/kronikk/livskvalitet-som-psykisk-velvaere

Nguyen, T., Stewart, D., & Gorter, J. W. (2018). Looking back to move forward: Reflections and lessons learned about transitions to adulthood for youth with disabilities. *Child: Care, Health & Development, 44*(1), 83-88. doi:https://doi.org/10.1111/cch.12534

Osgood, D. W., Foster, E. M., & Courtney, M. E. (2010). Vulnerable populations and the transition to adulthood. *Future of Children, 20*(1), 209-229. doi:http://doi.org/10.1353/foc.0.0047

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan--a web and mobile app for systematic reviews.(Report). *Systematic Reviews, 5*(1). doi:http://doi.org/10.1186/s13643-016-0384-4

Paterson, G. A., Nayda, R. J., & Paterson, J. A. (2012). Chronic condition self-management: Working in partnership toward appropriate models for age and culturally diverse clients. *Contemporary Nurse, 40*(2), 169-178. doi:http://doi.org/10.5172/conu.2012.40.2.169

Peeters, M. A., Hilberink, S. R., & van Staa, A. (2014). The road to independence: lived experiences of youth with chronic conditions and their parents compared. *Journal of Pediatric Rehabilitation Medicine, 7*(1), 33-42. doi:https://doi.org/10.3233/PRM-140272

Perrin, J. M., Anderson, L. E., & Van Cleave, J. (2014). The rise in chronic conditions among infants, children, and youth can be met with continued health system innovations. *Health affairs (Project Hope), 33*(12), 2099-2105. doi:http://doi.org/10.1377/hlthaff.2014.0832

Pinquart, M. (2014). Achievement of Developmental Milestones in Emerging and Young Adults With and Without Pediatric Chronic Illness-A Meta-Analysis. *Journal of Pediatric Psychology, 39*(6), 577-587. doi:http://doi.org/10.1093/jpepsy/jsu017

Pinquart, M. (2017). Systematic Review: Bullying Involvement of Children With and Without Chronic Physical Illness and/or Physical/Sensory Disability-a Meta-Analytic Comparison With Healthy/Nondisabled Peers. *Journal of Pediatric Psychology, 42*(3), 245-259. doi:http://doi.org/10.1093/jpepsy/jsw081

Ridosh, M., Braun, P., Roux, G., Bellin, M., & Sawin, K. (2011). Transition in young adults with spina bifida: a qualitative study. *Child: Care, Health & Development, 37*(6), 866-874. doi:https://doi.org/10.1111/j.1365-2214.2011.01329.x

Sandelowski, M., & Barroso, J. (2007). *Handbook for synthesizing qualitative research*. New York: Springer.

Schuh, M. C., Sundar, V., & Hagner, D. C. (2015). Friendship is the ocean: Importance of friendship, acceptance, and leadership in the transition to adulthood. *Career Development and Transition for Exceptional Individuals, 38*(3), 152-161. doi:http://doi.org/10.1177/2165143414528031

Silva, N., Pereira, M., Otto, C., Ravens-Sieberer, U., Canavarro, M., & Bullinger, M. (2019). Do 8- to 18-year-old children/adolescents with chronic physical health conditions have worse health-related quality of life than their healthy peers? a meta-analysis of studies using the KIDSCREEN questionnaires. *An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation - An Official Journal of the International Society of Quality of Life Research, 28*(7), 1725-1750. doi:http://doi.org/10.1007/s11136-019-02189-7

Stewart, D., Law, M., Young, N. L., Forhan, M., Healy, H., Burke-Gaffney, J., & Freeman, M. (2014). Complexities during transitions to adulthood for youth with disabilities: person-environment interactions. *Disability & Rehabilitation, 36*(23), 1998-2004. doi:https://doi.org/10.3109/09638288.2014.885994

Suris, J. C., Michaud, P. A., & Viner, R. (2004). The adolescent with a chronic condition. Part I: developmental issues. *Archives of Disease in Childhood, 89*(10), 938-942. doi:http://doi.org/10.1136/adc.2003.045369

Törnbom, K., Törnbom, M., & Sunnerhagen, K. S. (2013). Experiences of participation in a Swedish society among adults with cerebral palsy or spina bifida: involvement and challenges. *Journal of Social Work in Disability & Rehabilitation, 12*(4), 256-271. doi:https://doi.org/10.1080/1536710X.2013.834783

Waldboth, V., Patch, C., Mahrer-Imhof, R., & Metcalfe, A. (2016). 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. *International Journal of Nursing Studies, 62*, 44-59. doi:https://doi.org/10.1016/j.ijnurstu.2016.07.007

Wedgwood, N. (2011). A Person with Abilities: The Transition to Adulthood of a Young Woman with a Severe Physical Impairment. *Young, 19*(4), 435-454. doi:http://doi.org/10.1177/110330881101900405

Williams, L. M., Brown, K. J., Palmer, D., Liddell, B. J., Kemp, A. H., Olivieri, G., . . . Gordon, E. (2006). The mellow years?: neural basis of improving emotional stability over age. *The Journal of neuroscience : the official journal of the Society for Neuroscience, 26*(24), 6422-6430. doi:http://doi.org/10.1523/JNEUROSCI.0022-06.2006