

**Adolescents' and young adults' transition experiences when transferring from  
paediatric to adult care: A qualitative metasynthesis**

Liv Fegran, PhD<sup>a,b</sup>, Elisabeth O.C. Hall PhD<sup>d</sup>, Lisbeth Uhrenfeldt PhD<sup>d,e</sup>, Hanne Aagaard  
PhD<sup>c,d</sup>, Mette Spliid Ludvigsen, PhD<sup>c</sup>

Corresponding author: Liv Fegran

University of Agder

Post Box 422, NO-4604 Kristiansand, Norway

Telephone: +47 99 24 88 32

Liv.fegran@uia.no

<sup>a</sup> University of Agder, Kristiansand, Norway, <sup>b</sup> Sørlandet Hospital, Kristiansand, Norway,

<sup>c</sup> Department of Renal Medicine, Aarhus University Hospital, Denmark, <sup>d</sup> Department of

Public Health, Aarhus University, Aarhus, Denmark, <sup>e</sup> Horsens Hospital Unit, Horsens,

Denmark

The authors have no conflicts of interest.

**Funding statement:** This study was partly funded by the University of Agder, Norway,  
Familien Hede Nielsen Foundation and the Nurses' Research Foundation, Denmark.

## **Acknowledgements**

The authors thank Professor Gabriele Meyer, Witten/Herdecke University, Germany, for useful comments on earlier drafts of this article, and librarian Ellen Sejersted, University of Agder, Norway, for help with literature searches.

## **Abbreviations**

PRANSIT – Patient Transition in Transfer

## **Author contributions**

Liv Fegran (LF), Mette Spliid Ludvigsen (MSL), Lisbeth Uhrenfeldt (LU), Hanne Aagaard (HAa) and Elisabeth O.C. Hall (EOCH) contributed substantially to the conception and design of the study. LF, MSL and EOCH were responsible for acquisition, analysis and interpretation of data. LF, MSL and EOCH drafted the article. LF, MSL, EOCH, LU and HAa critically reviewed the manuscript for important intellectual content and approved the version to be published.

## ABSTRACT

*Objectives:* The objective of this study was to synthesize qualitative studies of how adolescents and young adults with chronic diseases experience the transition from paediatric to adult care.

*Design:* The review is designed as a qualitative metasynthesis and is following Sandelowski and Barroso's guidelines for synthesizing qualitative research.

*Data sources:* A literature search was conducted in the databases PubMed, Ovid, Scopus, Cumulative Index to Nursing and Allied Health Literature (CINAHL), ISI Web of Science, and Nordic and German databases covering the period from 1999 to November 2010. In addition, forward citation snowball searching was conducted in the databases Ovid, CINAHL, ISI Web of Science, Scopus and Google Scholar.

*Review methods:* Of the 1143 records screened, 18 studies were included. Inclusion criteria were qualitative studies in English, German or Nordic languages on adolescents' and young adults' transition experiences when transferring from paediatric to adult care. There was no age limit, provided the focus was on the actual transfer process and participants had a chronic disease. The studies were appraised as suitable for inclusion using a published appraisal tool. Data were analysed into metasummaries and a metasynthesis according to established guidelines for synthesis of qualitative research.

*Results:* Four themes illustrating experiences of loss of familiar surroundings and relationships combined with insecurity and a feeling of being unprepared for what was ahead

were identified: facing changes in significant relationships, moving from a familiar to an unknown ward culture, timing of transfer and achieving responsibility.

*Conclusions:* Young adults' transition experiences seem to be similar across diagnoses and cultures. Feelings of not belonging and of being redundant during the transfer process are striking. Appreciating young adults' need to be acknowledged and valued as competent collaborators in their own transfer is crucial, and may protect them from additional health problems during a vulnerable phase.

*Keywords:* Adolescent, Chronic Disease, Hospital, Metasynthesis, Review, Transfer, Transition, Young adult

### **What is already known about the topic?**

- Despite the development of various transition models, transfer from paediatric to adult wards is a challenge for patients, their families and professionals.
- Most studies focus on professionals' and parents' view of the adolescents' transfer.

### **What this paper adds**

- This metasynthesis demonstrates that transition from paediatric to adult wards is a time of insecurity that engenders feelings of not belonging among adolescents and young adults with chronic conditions.
- Young adults express a need to be acknowledged as competent contributors during the transfer process.
- Experiences of transfer are comparable across diagnoses and cultures.

## **1.0 Introduction**

Increasing numbers of adolescents with life-threatening conditions are surviving into adulthood, and consequently more of them will experience the transfer from paediatric to adult care (Rutishauser et al., 2011, Tong et al., 2008). The prevalence of chronic conditions in adolescence ranges from 7% to 15% (Michaud et al., 2004), and transition to adult care has thus become an important issue (Bell and Sawyer, 2010, Hersh et al., 2009, Tuchman et al., 2010). Transition within a hospital adolescent context is defined as: “The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems” (Blum et al., 1993, p. 570). In this study, we use the concepts “transfer” to mark the purposeful movement of adolescents from paediatric to adult care and “transition” when referring to the personal experiences of the transfer (Meleis, 2010, Meleis et al., 2000).

Despite numerous recommendations during recent decades, the transfer from paediatric to adult care continues to pose challenges for adolescent patients, their parents and health-care professionals (Jalkut et al., 2009, Masding et al., 2010, McDonagh and Kelly, 2010).

Adolescents and young adults often experience their transfer as disjointed, and adjusting to transfer appears difficult (Crowley et al., 2011). Patients and families find it hard to leave the familiar paediatric environment (Alpay, 2009, Anthony et al., 2009, Rutishauser et al., 2011), health-care professionals in paediatric settings express mixed feelings about relinquishing responsibility for patients (Clarizia et al., 2009), and staff on adult wards are not always properly prepared to receive the transferred young patients (Peter et al., 2009, Rapley and Davidson, 2010, Suris et al., 2009).

Adolescence is in itself a developmental transition from childhood to adulthood, with an onset that includes pubertal maturation and a conclusion marked by increased self-identity and independence. Adolescents with chronic conditions also have to acknowledge their

condition; they have to adjust their situation of living with a chronic condition to other life transitions such as moving from school to work or from living at home to independent living (Jurasek et al., 2010, van Groningen et al., 2012). In the midst of these transitions, adolescents with chronic conditions also experience being transferred from paediatric to adult health care (McLaughlin et al., 2008). Research on transfer and transition is mostly based on surveys and other quantitative methods, but exploring the experiences of transfer using a qualitative approach can capture a deeper understanding of young adults' own challenges (Rutishauser et al., 2011). The strength of a qualitative approach is that it explores subjective experiences; it discovers patterns and variations from which hypotheses can emerge (Polit and Beck, 2010). The purpose of this literature review was to synthesize qualitative findings on how young people with chronic conditions experience the transfer from paediatric to adult health care.

## **2.0 Method**

The review was designed as a qualitative metasynthesis and follows Sandelowski and Barroso's (2007) guidelines for synthesizing qualitative research. A qualitative metasynthesis is a scientific inquiry with a specific focus aimed at systematically interpreting and integrating findings in reports of qualitative research. This metasynthesis was conducted in five steps: formulating the purpose and rationale, searching for and retrieving qualitative research reports, critically appraising the included studies, classifying the findings and synthesizing the findings. The Scandinavian–German research group PRANSIT (Patient Transition in Transfer), consisting of five nurse researchers, completed the review as an initial phase in the development of a planned intervention to improve patient transfer in the health-care system (Campbell et al., 2000).

## 2.1 Search and retrieval of qualitative research studies

A valid research synthesis depends on the comprehensive retrieval of relevant qualitative reports to include in the metasynthesis (Sandelowski and Barroso, 2007). To fulfil the purposes of this review, studies were required to meet the following criteria: (1) the study includes adolescents' or young adults' own descriptions of experiences with an accomplished transfer from a paediatric to an adult ward; (2) participants have a chronic physical disease; and (3) the study is published in English, German or a Nordic language. Searches were conducted during 2010 in nine databases covering the period between 1999 and November 2010. Two of the authors (LF and MSL) developed a search strategy using the key words “teenager OR young adult OR adolescent” AND “chronic disease OR special health care need” AND “transfer OR transition” AND “qualitative study OR phenomenology OR grounded theory OR hermeneutics” AND “hospital OR intra-hospital”. In collaboration with a librarian, the search strategy was modified to fit each database. Following the search, studies eligible for inclusion were subject to forward chaining and ancestry searching in reference lists. Almost 50% of the included studies were retrieved through sources other than the initial database search and, as presented in Figure 1, the flow diagram was repeatedly adjusted to reflect all steps in the inclusion process.

## 2.2 Selecting and appraising studies for synthesis

Two of the authors (LF and MSL) screened the studies' titles and abstracts and individually appraised relevant studies following the Critical Appraisal Checklist for Interpretive and Critical Research (Joanna Briggs Institute, 2008). The included studies were examined to determine whether they met the study objective and inclusion criteria. We evaluated congruence between aims, methodology, data collection and analysis methods. The results are



presented in Table 1 (complete results available on request). Any uncertainty about whether a study should be included was discussed by the PRANSIT research group until consensus was reached. The literature search and appraisal resulted in 18 studies with a total sample of 368 adolescents or young adults who had a chronic physical condition.

### 2.3 Analysis

In line with Sandelowski and Barroso's (2007) suggestions, two approaches to qualitative research synthesis were used: qualitative metasummaries and qualitative metasynthesis. Qualitative *metasummaries* are quantitatively oriented aggregations of qualitative findings across the included studies. Qualitative *metasynthesis* offers novel interpretations of the target findings from the primary studies as a whole. The target findings to be included in the metasynthesis were quotations from young adults, or primary researchers' interpretations of young adults' experiences (Sandelowski and Barroso, 2007). Non-target findings were parents' or health-care professionals' descriptions, imported findings from other studies, authors' descriptions of analytical procedures or discussions of findings. The target findings from the articles were imported into NVivo9 (QSR International, Southport, UK).

The synthesis was inspired by Ricoeur (1976) and guided by a phenomenological–hermeneutic analysis strategy comprising three interrelated steps: naïve reading, structural analysis and critical interpretation. First, three of the authors (LF, MSL and EH) performed naïve readings of the extracted text to obtain preliminary ideas about the content. Next the text was independently and interactively read and structured into categories and themes, constituting the main overarching theme. Finally, the themes and summaries were aggregated and critically interpreted.

NVivo9 was used to calculate the magnitude of the extracted findings. The interstudy frequency effect sizes (Table 2) indicated the prevalence rate of each theme, whereas the

intrastudy intensity effect sizes (Table 2) identified the concentration of findings in each report (Sandelowski and Barroso, 2007). The use of effect sizes provides more complex levels of understanding of the meaning of transfer for young adults (Onwuegbuzie, 2003).

### **3.0 Findings**

On appraising the included studies, we found that most studies presented findings clearly based on the data collected. The primary researchers discussed their findings within a broader context, making conclusions and suggestions for application and/or further research.

Descriptions of philosophical perspectives and their influence on the findings were, however, poorly presented. No studies congruent with the purpose of our study were excluded because of quality flaws.

#### **3.1 Metasummaries**

Characteristics of the included studies are presented in Table 1, metasummaries of characteristics of the included studies in Table 3, and age of participants and age at transfer in Figure 2.

Independence, relationship with professionals, differences in ward cultures and process and timing of transfer were the issues that received the most emphasis in the studies (Table 2). All sub-themes had an effect size of 88%, meaning that 16 of the 18 studies were represented in each theme (Table 2). No theme was over- or under-represented, and all sub-themes served as the empirical basis for the qualitative metasynthesis.

## 3.2 Metasynthesis

The metasynthesis of adolescents' and young adults' experiences of transition from paediatric to adult wards revealed that they felt themselves to be in a kind of limbo between different cultures during transition. Their experiences were synthesized into four sub-themes: facing changes in significant relationships, moving from a familiar to an unknown ward culture, timing of transfer and achieving responsibility (Table 4). These sub-themes are elaborated in the following.

### 3.1.1 Facing changes in significant relationships

Facing changes in significant relationships refers to the adolescents' and young adults' descriptions of the transfer process as jumping from pillar to post, indicating the change as a feeling of letting go of something familiar without knowing what the future might bring. Significant relationships were described as crucial during this void (Reiss et al., 2005, Wiener et al., 2009). Significant others could be professionals such as nurses or doctors, or peers such as friends or other people with chronic illness whom the adolescents or young adults met through the health services.

Relationships in the paediatric setting may have started early in life and gradually transformed into something more than a professional relationship (Kirk, 2008). The paediatric ward developed into a second home and nurses became like family members (Soanes and Timmons, 2004). The ambience in paediatric units was experienced as informal and individual; the patients felt comfortable and developed close relationships with the professionals (Patterson and Lanier, 1999): "The nurses had more time to spend with you . . . just spending that real quality time with you and just treating you like you were a real person" (Brumfield and Lansbury, 2004, p. 227). The connection with the paediatric staff sometimes

continued after transfer: “So, I left the clinic but I didn’t leave them” (Valenzuela et al., 2011, p. 136).

Relationships in adult care were quite different. There, doctors and nurses were described as being impersonal and disease-focused, and it was difficult to establish relationships with them. The ambience in the adult ward was busy and superficial, sometimes leaving the young adults with the feeling of being an obstacle: “I always felt the [doctor’s] time is valuable and I’m always wasting their time as well, so I always try and rush through” (Jones et al., 2003, p. 347). Despite this, the doctors’ and nurses’ expectation that patients would take care of themselves was a boost to the adolescents’ and young adults’ self-confidence: “Basically they are pushing me, but they are letting me take the steps. It’s helping me see that I’m helping myself and it is not only them helping me” (Valenzuela et al., 2011, p. 5).

Peers with a similar chronic disease offered crucial support in managing life as a grown-up. Being with familiar people such as friends or peers was helpful during the transition process, and provided opportunities to discuss feelings, share experiences and reduce anxiety:

And she says to me the same things that other people have been saying, but she came at it from a different position, because she had been there. She wasn’t a doctor or a nurse, or a parent, or somebody that was hard for me to listen to. I could listen to her, because I knew that she had already been there. (Patterson and Lanier, 1999, p. 51)

Conversely, meeting older people with the same disease was challenging, because the young people were confronted with their future prognosis.

### 3.1.2 Moving from a familiar to an unknown ward culture

Moving from a familiar to an unknown culture refers to the experiences of transfer from a familiar, safe children's ward to an unknown adult ward and, in particular, adapting to the cultural differences between the paediatric and adult health-care environments:

In the paediatric unit they were surrounded with cartoon covered walls, games, play therapists and other children. Now they were sitting in an all-adult waiting room covered with HIV specific posters and information. (Miles et al., 2004, p. 309)

Entering the adult ward also changed their patient status. Whereas the paediatric professionals had treated their health problems in collaboration with their parents, they themselves now had to deal with, for example, questions concerning the long-term effects of their chronic disease:

At the paediatric centre they'd talk to the parents and say, you must make sure your child takes medication. At the adult centre, like they tell you the benefits of it, they tell you what happens if you don't take it, and leave it in your hands so, they give you a lot of control . . . they do talk to you like you're an adult, it is your decision. (Kirk, 2008, p. 570)

Young adults require maturity and responsibility if they are to take care of their own health in adult care (Reiss et al., 2005, Wiener et al, 2009). After the transfer, scheduled follow-ups in paediatric units were transformed into appointments that the young adults had to initiate themselves. Some adjusted and found the new freedom beneficial, whereas others wanted a break from disease-focused routines and dropped out:

“I was going to [paediatric care] all my life for the first 21 years, all the time,” said one young adult. “I kind of got burned out on going. All the medical talk, you never know what they are talking about ever. So now, I basically just go to the doctor when I need something.” (Patterson and Lanier, 1999, p. 49)

### 3.1.3 Timing of transfer

The timing of transfer based on biological age was an issue in most of the studies. Although the age of 16 years or so is generally viewed as an appropriate time to start preparing for transfer, the studies suggest that the actual time of transfer should be decided by considering age and readiness:

Age doesn't matter; you could have someone at 16 and be ready for transition, or someone going towards 20 who's not ready. I know you have to go at [some] point but I think it should be when the young person decides. (Soanes and Timmons, 2004, p. 107)

Preferably, the process of leaving the paediatric setting would start with dissociation from the younger children:

I changed at the time when I was about mid-teens . . . and that's when I thought, thank God I'm going to a different clinic where it's not as noisy with all the kids running around . . . you just feel out of place. (Brumfield and Lansbury, 2004, p. 228)

Despite feeling ready for transfer, the young adults felt that paediatricians continued to treat them as though they were small children, lecturing them about medications and compliance: “I thought . . . if only the [paediatric] doctors knew that we were becoming adults, you know, we were in our mid-teens thinking, they still treat us as if we were ten years old.” (Brumfield and Lansbury, 2004, p. 228)

A sudden transfer was experienced as the most unsatisfactory. Lack of preparedness made the adolescents and young adults feel redundant and unwanted. They were left “abandoned, dumped or shuffled around”. Experiencing concurrent transitions such as illness, graduation from school, moving to a university city or leaving home was also challenging; it was as if things were “piled up” on them (Soanes and Timmons, 2004, p. 108).

Patients appreciated collaboration between the two hospital settings, although, in their experience, continuity of care was not always present. The adult-care provider might have little knowledge about the transferred patient’s condition, making the young adult worried about not receiving the right level of care (Tuchman et al., 2008). They tired of retelling their life story and described the transition as being in no man’s land (Anthony et al., 2009, Patterson and Lanier, 1999, Valenzuela et al., 2011).

#### 3.1.4 Achieving responsibility

Achieving responsibility refers to the shift in ownership of the disorder and self when being transferred (Wiener et al., 2009). The young adults experienced this shift in different ways because of their own attitudes, severity and time of onset of their disorder, and parents’ and doctors’ incentives: “You’re kind of thrown into becoming an adult in terms of your health, and that can be kind of scary” (McCurdy et al., 2006, p. 313).

Reluctance to assume responsibility could arise because, in many ways, they were still dependent on their parents:

You're not self-sufficient yet. You still live with your parents. They provide and care for you and still know everything about you. You've almost reached adulthood, but if there's something on your mind, you still turn to your parent. (Moons et al., 2009, p. 320)

Conversely, the transfer forced movement towards independence: "You would be embarrassed if there was an 80-year-old and you were sitting there with your mum!" (Soanes and Timmons, 2004, p. 109).

Meeting the expectations and challenges of becoming a grown-up had an impact on young adults and their accountability: "I kind of think of it as a job. I feel like I am going to work, because it is like working, because I'm setting up my machine, take myself off and then I leave" (Braj et al., 1999, p. 43).

The young people sought knowledge about their disease and its treatment, as well as general issues such as pregnancy, smoking, sexuality, and alcohol and drug use (Patterson and Lanier, 1999, Østlie et al., 2007), and they appreciated being involved in decision-making (Hauser and Dorn, 1999, Shaw et al., 2004):

The most important thing to me when transferring to the adult clinic was that all the decisions were made with me involved and I was able to talk about what was going to happen when I saw the doctors, which I never had a chance to do in the children's clinic. (Wray and Maynard, 2008, p. 571)

Parents could be supportive in preparing their children for independence by, for instance, asking whether their presence was wanted during consultations. However, transition



could be a time of discord because of parental reluctance to let go of their responsibility and allow the young adult to take over (Kirk, 2008, Stabile et al., 2005): “My mom doesn’t want to let go. She has flat out told me. You put 18 years into your child’s health and it becomes your health as well” (Tuchman et al., 2008, p. 560). Some young adults were hesitant, ready to take over full responsibility but afraid of being considered ungrateful by their parents:

It’s quite difficult, because my mom and dad have been great, really supportive, but there’s times when you’ve been going to speak up. You think I just wish I’d come on my own. I’m like 19/20 years old now, I really don’t need you to come and hold my hand anymore. (Shaw et al., 2004, p. 774)

#### **4.0 Discussion**

This metasynthesis based on 18 primary qualitative studies and 368 participants offers a comprehensive understanding of how adolescents and young adults with chronic diseases experience the transfer from paediatric to adult wards. The findings reveal that, irrespective of diagnosis and country of origin, young adults experience the transfer between hospital wards in much the same way.

Overall, the study participants had mixed feelings in connection with transfer. In contrast to the dynamic transfer process envisaged in various programmes, most adolescents were unprepared. They experienced transfer as a time of not belonging; their relationship with health-care professionals changed, and their increased responsibility for their disease management challenged their transition experiences (Schultz, 2012, Tong et al., 2012). This finding is supported by other studies that demonstrate that cultural differences between

paediatric and adult care create significant barriers to continuity of care in connection with transfer (Goodhand et al., 2011, McDonagh, 2008, van Staa et al., 2011c).

The adolescents talked at length about the importance of significant relationships with professionals, families and friends who support them in living with a chronic condition. They particularly emphasized the challenges in the changing relationships with professionals in connection with transfer. Their previous experience of managing their chronic condition in close collaboration with parents and paediatric health-care professionals becomes irrelevant, and their feeling of being redundant or unwanted as collaborators is striking. These findings support research demonstrating that, in paediatric wards, clinicians negotiate treatment and care through parents with little involvement from children (Coyne et al., 2011, Donnelly and Kilkelly, 2011, Hallström and Elander, 2004), whereas in adult wards, adolescents are expected to be autonomous and independent (Hait et al., 2009). Both the young adults and the health professionals in adult care should be ready to invest the necessary time and support to prepare young adults to take responsibility for their own health. Issues such as allowing sufficient time for consultations, active listening by doctors and nurses and anticipation of young adults' involvement may positively influence the young adults' experience of themselves as valuable contributors (Christie and Viner, 2005).

Loosening the close relationships between adolescents, parents and professionals as part of the transfer process is also a demanding manoeuvre (Goodhand et al., 2011, van Staa et al., 2011a). It is hard for young adults to become independent if their parents have difficulty letting go of their responsibility. Our finding about the challenges for young adults in assuming responsibility for their disease management is supported by van Staa et al.'s (2011c) study indicating that parents of adolescents with chronic diseases appear to be more concerned than their children about the adolescents' ability to be autonomous.

During mid-adolescence (13–15 years), emotional separation from parents is combined with stronger peer identification (Christie and Viner, 2005). Support from peers during transfer preparations, especially young people with similar chronic conditions, may therefore help the young adults adjust to their life as grown-ups. The support of valued peers might be used more systematically during the process of transition to adult care.

Our findings about the importance of timing and preparation for transfer in collaboration with the adolescents are also supported by quantitative studies (Sawicki et al., 2011). The staff assisting adolescents during the transfer process may contribute to bridging the gap between paediatric and adult care (Lundin et al., 2008, McDonagh, 2008). Wards especially designed for adolescents give those needing hospital care the opportunity to create their own space in the hospital environment (Riis Olsen and Harder, 2011). Such wards have been shown to improve care, particularly for older adolescents (Hutton, 2010, Viner, 2007). However, professionals' attitude is crucial irrespective of the type of ward, and adjusting to the patients' individual needs rather than merely expecting them to fit in is always critical for adolescents, regardless of their health condition (Hutton, 2008).

An interesting finding concerned the age at transfer. Most of the studies in this metasynthesis indicate age as the transfer parameter. However, only half of the included studies explore the issue of age at transfer; and the adolescents themselves cited readiness and maturity as being more important than biological age. The *onset* of preparation for transfer at 16 years seems to be appropriate, while the age of 18–19 years *and older* is estimated as the best time (McDonagh and Kelly, 2010). The issue of maturity is supported by neuroscience research that indicates that adolescent brain development extends into the early 20s (Johnson et al., 2009, Rutishauser et al., 2011). Care for the young adult should therefore be based on a combination of the patient's individual needs and biological age (Rapley and Davidson, 2010).

The metasynthesis reveals that adolescence creates specific challenges for people with chronic conditions. A variety of adolescents and young adults are involved in the transfer process, from those in middle adolescence (13–15 years), who are developing their psychosocial independence, to those in late adolescence (16–18 years), who are developing their personal identity, personal goals and moral values (Goodhand et al., 2011). Health care should include a focus on maintaining meaningful age-appropriate relationships while gradually transferring responsibility from parents to the young adults (Christie and Viner, 2005, van Staa et al., 2011b, van Staa et al., 2011c).

According to Meleis (2010, p. 63), “knowledge is empowering to those who develop it, those who use it and those who benefit from it”. Adolescence is a critical stage in the transition to adulthood, and not being able to live up to expectations or not being seen and heard may cause additional stress, leading to health problems such as depression (Dundon, 2006). Whereas successful transitions create independent young adults who can manage their situation of living with a chronic condition, failed transitions may negatively affect young adults’ health, leading to increased admission rates and non-adherence to treatment recommendations (Dundon, 2006, Goodhand et al., 2011, White, 2008).

#### 4.1 Strengths and limitations

One limitation is that several studies were excluded because of a lack of data on young adults’ experiences of transfers. However, the number of eligible studies and number of participants ( $n = 368$ ) was sufficient to perform a metasynthesis providing in-depth knowledge of young adults’ own transition experiences. To explore transition experiences across diagnoses, all somatic chronic conditions were included. Including mental conditions might have strengthened the study; however, this could have reduced the transferability of findings. The findings do not indicate that age or gender is significant with regard to the young adults’

experiences; however, this may be more apparent in studies with a more homogeneous selection of participants. The decision not to exclude studies with limited descriptions of methods may be questioned; however, the fact that data are relatively equally distributed across the sub-themes (Table 2) may strengthen the validity of findings regardless of the methodological quality of some studies. The relationships between participants and researchers in the primary studies may have influenced the findings. On the other hand, researchers' knowledge of and relationship with the participants may have been crucial for recruiting participants and collecting data. Reflections on the researchers' role might have increased the individual studies' validity and reliability.

For us, performing the study as part of a research group was stimulating but also demanding. We have endeavoured to identify clearly individual researchers' contributions and the various judgements made during the research process. This is a strength of the present study, and can contribute to the methodological development of conducting metasyntheses (Paterson et al., 2009).

## **5.0 Conclusion**

The findings of this metasynthesis support previous research indicating that transition is a challenging phase for adolescents and young adults. The feelings of not belonging and of being redundant are especially striking, and managing the transition from the young adults' perspective seems to be crucial. It appears that assessing preparedness as part of individual transfer plans would reduce the young adults' experiences of being insignificant as collaborators in their own care. In the present metasynthesis, the experiences of transition for young adults with chronic diseases appear to be generic; however, to increase our knowledge and improve transfer to adult wards, further research that includes participants across diagnoses and cultures may be advantageous. Transitional programmes that focus on the

effectiveness of health outcomes but fail to reflect a holistic view of adolescents' experiences (Crowley et al., 2011) should be critically reviewed.

## References

- Alpay, H., 2009. Transition of the adolescent patient to the adult clinic. *Peritoneal Dialysis International* 29 (Suppl 2), S180–S182.
- Anthony, S.J., Kaufman, M., Drabble, A., Seifert-Hansen, M., Dipchand, A.I., Martin, K., 2009. Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *American Journal of Transplantation* 9 (3), 614–619.
- Bell, L.E., Sawyer, S.M., 2010. Transition of care to adult services for pediatric solid-organ transplant recipients. *Pediatric Clinics of North America* 57 (2), 593–610.
- Blum, R.W., Garell, D., Hodgman, C.H., Jorissen, T.W., Okinow, N.A., Orr, D.P., Slap, G.B., 1993. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health* 14 (7), 570–576.
- Braj, B., Picone, G., Children, H.F., Cross, N., Pearlman, L., 1999. The lived experience of adolescents who transfer from a pediatric to an adult hemodialysis centre. *CANNT Journal* 9 (4), 41–46.
- Brumfield, K., 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), 223–234.
- Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A.L., Sandercock, P., Spiegelhalter, D., Tyrer, P., 2000. Framework for design and evaluation of complex interventions to improve health. *British Medical Journal* 321 (7262), 694–696.
- Christie, D., Viner, R., 2005. Adolescent development. *British Medical Journal* 330 (7486), 301–304.
- Clarizia, N.A., Chahal, N., Manlhiot, C., Kilburn, J., Redington, A.N., McCrindle, B.W., 2009. Transition to adult health care for adolescents and young adults with congenital

- heart disease: perspectives of the patient, parent and health care provider. *Canadian Journal of Cardiology* 25 (9), e317–e322.
- Coyne, I., O’Neill, C., Murphy, M., Costello, T., O’Shea, R., 2011. What does family-centred care mean to nurses and how do they think it could be enhanced in practice? *Journal of Advanced Nursing* 67 (12), 2561–2573.
- Crowley, R., Wolfe, I., Lock, K., McKee, M., 2011. Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood* 96 (6), 548–553.
- Donnelly, M., Kilkelly, U., 2011. Child-friendly healthcare: delivering on the right to be heard. *Medical Law Review* 19 (1), 27–54.
- Dundon, E., 2006. Adolescent depression: a metasynthesis. *Journal of Pediatric Health Care* 20 (6), 384–392.
- Goodhand, J., Hedin, C.R., Croft, N.M., Lindsay, J.O., 2011. Adolescents with IBD: the importance of structured transition care. *Journal of Crohn’s and Colitis* 5 (6), 509–519.
- Hait, E.J., Barendse, R.M., Arnold, J.H., Valim, C., Sands, B.E., Korzenik, J.R., Fishman, L.N., 2009. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of adult gastroenterologists. *Journal of Pediatric Gastroenterology and Nutrition* 48 (1), 61–65.
- Hallström, I., Elander, G., 2004. Decision-making during hospitalization: parents’ and children’s involvement. *Journal of Clinical Nursing* 13 (3), 367–375.
- Hauser, E.S., Dorn, L., 1999. Transitioning adolescents with sickle cell disease to adult-centered care. *Pediatric Nursing* 25 (5), 479–488.
- Hersh, A.O., Pang, S., Curran, M.L., Milojevic, D.S., von Scheven, E., 2009. The challenges of transferring chronic illness patients to adult care: reflections from pediatric and



- adult rheumatology at a US academic center. *Pediatric Rheumatology Online Journal* 7, 13.
- Hutton, A., 2008. An adolescent ward; “In name only?” *Journal of Clinical Nursing* 17 (23), 3142–3149.
- Hutton, A., 2010. How adolescent patients use ward space. *Journal of Advanced Nursing* 66 (8), 1802–1809.
- Jalkut, M.K., Allen, P.J., 2009. Transition from pediatric to adult health care for adolescents with congenital heart disease: a review of the literature and clinical implications. *Pediatric Nursing* 35 (6), 381–387.
- Joanna Briggs Institute, 2008. Joanna Briggs Institute reviewers’ manual: 2008 edition. The Joanna Briggs Institute, Adelaide.
- Johnson, S.B., Blum, R.W., Giedd, J.N., 2009. Adolescent maturity and the brain: the promise and pitfalls of neuroscience research in adolescent health policy. *Journal of Adolescent Health* 45 (3), 216–221.
- Jones, K., Hammersley, S., Shepherd, M., 2003. Meeting the needs of young people with diabetes: an ongoing challenge. *Journal of Diabetes Nursing* 7 (9), 345–350.
- Jurasek, L., Ray, L., Quigley, D., 2010. Development and implementation of an Adolescent Epilepsy Transition Clinic. *Journal of Neuroscience Nursing* 42 (4), 181–189.
- Kirk, S., 2008. Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development* 34 (5), 567–575.
- Lundin, C.S., Øhrn, I., Danielson, E., 2008. From multidimensional support to decreasing visibility: a field study on care culture in paediatric and adult diabetes outpatient clinics. *International Journal of Nursing Studies* 45 (2), 180–190.

- Masding, M.G., Klejdys, S., MacHugh, B., Gale, S., Brown, A., McAulay, A., 2010. Non-attendance at a diabetes transitional clinic and glycaemic control. *Practical Diabetes International* 27 (3), 109–110i.
- McCurdy, C., DiCenso, A., Boblin, S., Ludwin, D., Bryant-Lukosius, D., Bosompra, K., 2006. There to here: young adult patients' perceptions of the process of transition from pediatric to adult transplant care. *Progress in Transplantation* 16 (4), 309–316.
- McDonagh, J.E., 2008. Young people first, juvenile idiopathic arthritis second: transitional care in rheumatology. *Arthritis and Rheumatism* 59 (8), 1162–1170.
- McDonagh, J.E., Kelly, D.A., 2010. The challenges and opportunities for transitional care research. *Pediatric Transplantation* 14 (6), 688–700.
- McLaughlin, S.E., Diener-West, M., Indurkha, A., Rubin, H., Heckmann, R., Boyle, M.P., 2008. Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices. *Pediatrics* 121 (5), e1160–e1166.
- Meleis, A.I., 2010. *Transitions theory: middle-range and situation-specific theories in nursing research and practice*. Springer, New York.
- 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.
- Michaud, P.A., Suris, J.C., Viner, R., 2004. The adolescent with a chronic condition. Part II: healthcare provision. *Archives of Disease in Childhood* 89 (10), 943–949.
- Miles, K., Edwards, S., Clapson, M., 2004. Transition from paediatric to adult services: experiences of HIV-positive adolescents. *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV* 16 (3), 305–314.
- Moons, P., Pinxten, S., Dedroog, D., Van Deyk, K., Gewillig, M., Hilderson, D., Budts, W., 2009. Expectations and experiences of adolescents with congenital heart disease on

- being transferred from pediatric cardiology to an adult congenital heart disease program. *Journal of Adolescent Health* 44 (4), 316–322.
- Onwuegbuzie, A.J., 2003. Effect sizes in qualitative research: a prolegomenon. *Quality and Quantity* 37 (4), 393–409.
- Paterson, B.L., Dubouloz, C.-J., Chevrier, J., Ashe, B., King, J., Moldoveanu, M., 2009. Conducting qualitative metasynthesis research: insights from a metasynthesis project. *International Journal of Qualitative Methods* 8 (3), 22–33.
- Patterson, D.L., Lanier, C., 1999. Adolescent health transitions: focus group study of teens and young adults with special health care needs. *Family and Community Health* 22 (2), 43–58.
- Peter, N.G., Forke, C.M., Ginsburg, K.R., Schwarz, D.F., 2009. Transition from pediatric to adult care: internists' perspectives. *Pediatrics* 123 (2), 417–423.
- Polit, D.F., Beck, C.T., 2010. *Essentials of nursing research: appraising evidence for nursing practice*. Lippincott Williams & Wilkins, Philadelphia.
- QSR International Pty Ltd, 2011. <http://www.qsrinternational.com/>
- Rapley, P., Davidson, P.M., 2010. Enough of the problem: a review of time for health care transition solutions for young adults with a chronic illness. *Journal of Clinical Nursing* 19 (3–4), 313–323.
- Reiss, J.G., Gibson, R.W., Walker, L.R., 2005. Health care transition: youth, family, and provider perspectives. *Pediatrics* 115 (1), 112–120.
- Ricoeur, P., 1976. *Interpretation theory: discourse and the surplus of meaning*. Texas Christian University Press, Fort Worth.
- Riis Olsen, P., Harder, I., 2011. Caring for teenagers and young adults with cancer: a grounded theory study of network-focused nursing. *European Journal of Oncology Nursing* 15 (2), 152–159.

- Rutishauser, C., Akaré, C., 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 (7), 865–871.
- Sandelowski, M., Barroso, J., 2007. *Handbook for synthesizing qualitative research*. Springer, New York.
- Sawicki, G.S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I.C., Livingood, W., Reiss, J., Wood, D., 2011. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ – Transition Readiness Assessment Questionnaire. *Journal of Pediatric Psychology* 36 (2), 160–171.
- Schultz, R.J., 2012. Parental experiences transitioning their adolescent with epilepsy and cognitive impairments to adult health care. *Journal of Pediatric Health Care*, published online 07 May 2012.
- Shaw, K.L., Southwood, T.R., McDonagh, J.E., 2004. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology* 43 (6), 770–778.
- Soanes, C., 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), 102–112.
- Stabile, L., Rosser, L., Porterfield, K.M., McCauley, S., Levenson, C., Haglund, J., Christman, K., 2005. Transfer versus transition: success in pediatric transplantation brings the welcome challenge of transition. *Progress in Transplantation* 15 (4), 363–370.
- Suris, J.C., Akaré, C., Rutishauser, C., 2009. How adult specialists deal with the principles of a successful transition. *Journal of Adolescent Health* 45 (6), 551–555.

- Tong, A., Lowe, A., Sainsbury, P., Craig, J.C., 2008. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics* 121 (2), 349–360.
- Tong, A., Wong, G., Hodson, E., Walker, R.G., Tjaden, L., Craig, J.C., 2012. Adolescent views on transition in diabetes and nephrology. *European Journal of Pediatrics*, (Epub ahead of print).
- Tuchman, L.K., Schwartz, L.A., Sawicki, G.S., Britto, M.T., 2010. Cystic fibrosis and transition to adult medical care. *Pediatrics* 125 (3), 566–573.
- Tuchman, L.K., Slap, G.B., Britto, M.T., 2008. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development* 34 (5), 557–563.
- Valenzuela, J., Buchanan, C., Radcliffe, J., Ambrose, C., Hawkins, L., Tanney, M., Rudy, B., 2011. Transition to adult services among behaviorally infected adolescents with HIV – a qualitative study. *Journal of Pediatric Psychology* 36 (2), 134–140.
- van Groningen, J., Ziniel, S., Arnold, J., Fishman, L.N., 2012. When independent healthcare behaviors develop in adolescents with inflammatory bowel disease. *Inflammatory Bowel Diseases*, (Epub ahead of print).
- van Staa, A., Jedeloo, S., van der Stege, H., 2011a. “What we want”: chronically ill adolescents’ preferences and priorities for improving health care. *Patient Preference and Adherence* 5, 291–305.
- van Staa, A., van der Stege, H.A., Jedeloo, S., Moll, H.A., Hilberink, S.R., 2011b. Readiness to transfer to adult care of adolescents with chronic conditions: exploration of associated factors. *Journal of Adolescent Health* 48 (3), 295–302.

- van Staa, A.L., Jedeloo, S., van Meeteren, J., Latour, J.M., 2011c. Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health and Development* 37 (6), 821–832.
- Viner, R.M., 2007. Do adolescent inpatient wards make a difference? Findings from a national young patient survey. *Pediatrics* 120 (4), 749–755.
- White, P.H., 2008. On the road to adulthood for youth with rheumatic diseases: what health care professionals can do. *Arthritis Care and Research* 59 (8), 1054–1057.
- Wiener, L.S., Zobel, M., Battles, H., Ryder, C., 2007. "Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: assessing transition readiness." *Social Work in Health Care* 46 (1): 1-19.
- Wray, J., Maynard, L., 2008. Specialist cardiac services: what do young people want? *Cardiology in the Young* 18 (6), 569–574.
- Østlie, I.L., Dale, O., Moller, A., 2007. From childhood to adult life with juvenile idiopathic arthritis (JIA): a pilot study. *Disability and Rehabilitation* 29 (6), 445–452.

## **Tables and figures**

<b>Table 1</b>	Characteristics of included studies
<b>Table 2</b>	Intrastudy intensity effect sizes and interstudy frequency effect sizes of themes pertaining to young adults' experiences of transition
<b>Table 3</b>	Metasummary of characteristics of included studies
<b>Table 4</b>	Metasynthesis. Overarching theme, sub-themes and categories
<b>Figure 1</b>	The inclusion of studies by systematic literature search, forward citation search and other sources