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ADOLESCENTS WITH CHRONIC HEALTH CONDITIONS IN TRANSITION OF CARE

– Needs and support

Anna Alanen

TURUN YLIOPISTON JULKAISUJA – ANNALES UNIVERSITATIS TURKUENSIS
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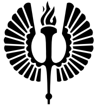

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ABSTRACT

To ensure that adolescents with chronic health conditions have continuous high-quality care, it is vital that their process of transition from paediatric to adult healthcare is constantly assessed and improved. Addressing adolescents' medical and psychosocial needs may lead to better health outcomes and a smooth transition to adult healthcare.

This thesis aimed to evaluate the healthcare needs and the support of adolescents aged 15-24 years with chronic health conditions across the transfer of care. Data were gathered through surveys across the transfer of care at three stages: at the children's hospitals; one year; and two years, after the transfer of care in Finland and Australia. This study was comprised of four studies; a cross-sectional study, two longitudinal studies and a systematic review. The cross-sectional study explored the healthcare needs related to associations of age, transition readiness with care-related anxiety of adolescents (n = 512). It also compared adolescents' and their parents' perceptions of transition readiness and health self-management (n = 322). The first longitudinal study with data gathered before and after the transfer of care (adolescents n = 440), also focused on healthcare needs: (changes in anxiety; care experiences; and the impact of chronic health conditions; and their associations with each other). The second longitudinal study examined healthcare support related to psychosocial aspects of care and the use of secure digital health services among the Finnish participants at three time points (n = 163). Finally, a systematic review described digital transition interventions with health coaching elements developed for adolescents with chronic health conditions.

The results of this study suggested that good health knowledge and positive health behaviour may be associated with lower care-related anxiety levels at the children's hospital. High condition impact and negative care experiences were associated with higher levels of care-related anxiety across the transfer of care. Time alone with doctors and discussions on confidentiality were at a suboptimal level across the transfer of care. Focusing on confidentiality and person-centred care may help to identify adolescents in the highest need of support. Digital health interventions need to be well-integrated into care, easy to use, personalised, and show potential to engage and motivate health self-management among adolescents.

To conclude, the results strengthen the understanding that tailored transition interventions, starting at 12 years of age, which encompass psychosocial aspects and goal-driven care, may improve transitional care. The results reflect the different dimensions of person-centred care, comprising measures on; self-reported condition impact; care experiences; care-related anxiety; transition readiness; and psychosocial discussions. Digital interventions as part of usual care may provide chronically ill adolescents with efficient and accessible care. Health coaching shows positive results and may be integral to future digital healthcare.

KEYWORDS: adolescents, chronic conditions, transition, transition readiness, digital health services, anxiety, psychosocial assessment, health coaching

TURUN YLIOPISTO
Lääketieteellinen tiedekunta
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TIIVISTELMÄ

Pitkäaikaissairaiden nuorten hoidon siirtymävaiheen kehittäminen ja arviointi ovat tärkeitä jatkuvan ja laadukkaan hoidon varmistamiseksi. Nuorten hoidon ja psykososiaalisen tuen tarpeen huomioiminen voivat johtaa parempiin terveystuloksiin ja sujuvampaan siirtymiseen aikuisten terveydenhuollon palveluihin.

Tässä väitöskirjassa arvioidaan pitkäaikaissairaiden 15–24-vuotiaiden nuorten terveydenhuollon tarpeita ja saatavilla olevaa tukea hoidon siirtyessä lasten sairaalasta aikuisten terveydenhuollon palveluihin. Aineisto kerättiin kyselytutkimuksella Suomessa ja Australiassa kolmessa eri ajankohdassa: lastensairaalassa, vuosi ja kaksi vuotta siirtymän jälkeen. Tutkimus koostui neljästä osasta: poikkileikkaustutkimus, kaksi pitkittäistutkimusta ja systemaattinen katsaus. Poikkileikkaustutkimuksessa tarkasteltiin nuorten (n= 512) hoidon tarpeita: (iän, siirtymävalmiuden ja hoitoon liittyvän ahdistuksen yhteyksiä) sekä vertailtiin nuorten ja heidän vanhempiensa (n= 322) näkemyksiä siirtymävalmiudesta ja itsehoidosta. Pitkittäistutkimuksessa vertailtiin muutoksia nuorten (n= 440) tarpeissa (hoitoon liittyvässä ahdistuneisuudessa, hoitokokemuksissa ja sairauden koetussa vaikutuksessa elämään sekä näiden välisiä yhteyksiä hoidon siirtymän aikana). Toinen pitkittäistutkimus tarkasteli suomalaisten osallistujien saamaa terveydenhuollon hoidon tuen muotoja (psykososiaalisen tuen arviointia ja digitaalisten terveyspalveluiden käyttöä) kolmessa eri ajankohdassa (n= 163). Systemaattisella katsauksella kuvattiin pitkäaikaissairaille nuorille kehitettyjä siirtymävaiheen digitaalisia terveysvalmennus elementtejä hyödyntäviä interventioita.

Tutkimuksen tulokset osoittivat, että hyvä terveyteen liittyvä tietotaito oli yhteydessä alhaisempaan hoitoon liittyvään ahdistukseen lastensairaalassa. Itse arvioitu sairauden suurempi vaikutus elämään ja negatiiviset hoitokokemukset olivat yhteydessä suurempaan hoitoon liittyvään ahdistukseen siirtymän aikana. Luottamuksellisuudesta keskusteleminen ja lääkärin tapaaminen ilman vanhempia olivat siirtymävaiheen aikana puutteellisia. Luottamuksellisuuteen ja yksilölliseen hoitoon keskittymällä pystytään paremmin tunnistamaan eniten tukea tarvitsevat nuoret. Digitaalisten terveysinterventioiden tulisi olla hyvin integroituja hoitoprosessiin, helppokäyttöisiä, yksilöllisiä ja nuoria omahoitoon motivoivia.

Tutkimuksen tulokset vahvistavat käsitystä siitä, että 12- vuoden iässä aloitetut, tavoitteelliset ja psykososiaalisen näkökulman sisältävät siirtymävaiheen interventiot voivat parantaa siirtymävaiheen hoitoa. Tulokset heijastavat yksilökeskeisen hoidon eri ulottuvuuksia sisältäen nuorten itse raportoimia sairauden vaikutuksia elämään, hoitokokemuksia, hoitoon liittyvää ahdistusta, siirtymävalmiutta ja psykososiaalisia keskusteluja. Digitaaliset interventiot voivat tarjota pitkäaikaissairaille nuorille tehokasta ja helposti saavutettavaa lisäarvoa hoitoon. Terveysvalmennus on osoittanut positiivisia tuloksia ja voi olla keskeinen osa tulevaisuuden digitaalista terveydenhuoltoa.

AVAINSANAT: nuoret, pitkäaikainen sairaus, siirtymävaihe, siirtymävalmius, digitaaliset terveyspalvelut, ahdistus, psykososiaalinen arviointi, terveysvalmennus

Table of Contents

Abstract **4**

Tiivistelmä **5**

Table of Contents **6**

Abbreviations **8**

List of Original Publications **10**

1 Introduction **11**

2 Review of the Literature **13**
2.1 Adolescents with chronic health conditions and healthcare needs 13
2.1.1 Health self-management of chronic health conditions 14
2.1.2 The impact of chronic health conditions 15
2.1.3 Care-related anxiety 16
2.1.4 Care experiences 16
2.1.5 Care culture and adolescent care 17
2.2 Transition of care 18
2.2.1 Transition readiness 19
2.2.2 Transition and person-centred care 21
2.3 Adolescents with chronic health conditions and support 21
2.3.1 Psychosocial support 21
2.3.2 Digital health services 23
2.3.3 Digital transition health services 23

3 Aim **26**

4 Materials and Methods **27**
4.1 Study design 28
4.1.1 Study design of the survey study 29
4.1.2 Study settings and participants for the survey study 30
4.1.3 Data Collection for the survey study 31
4.1.4 Data collection instruments for the survey study 32
4.1.5 Statistics of the survey study 34

4.1.6 Study sampling and data collection of the systematic review 35
4.2 Ethical considerations 36

5 Results 38
5.1 Characteristics of the participants 38
5.2 Health self-management skills at transfer of care 39
5.3 Factors affecting transition readiness 41
5.4 Assessment of psychosocial aspects across transfer of care . 46
5.5 Use of digital health services 48
5.6 Exploring digital transition health interventions 49

6 Discussion 51
6.1 Chronically ill adolescents' needs during transition 51
6.2 Chronically ill adolescents received support 54
6.3 Suggestions for future research and practical implications 58

7 Conclusions 60

Acknowledgements 62

References 65

List of Figures, Tables and Appendices 76

Original Publications 77

Abbreviations

Am I on TRAC	Taking Responsibility for Adolescent/Adult Carequestionnaire
AFHS	Adolescent Friendly Hospital Survey
AUS	Australia
COVID- 19	Coronavirus Disease
EUC	The European Commission
FIN	Finland
Good2Go	Good to go program
GRADE	The Grade of Recommendations Assessments, Development and Evaluation criteria
HEEADS	Home; Education/employment; peer group Activities; Drugs; Sexuality; and Suicide/depression
HEEADSSS	Home; Education/employment Eating; peer group Activities; Drugs; Sexuality; Suicide/depression; and Safety issues
HRQoL	Health Related Quality of Life
NHC	New Children's Hospital
STAI	State-Trait Anxiety Inventory short form
TIDier	Template for Intervention Description and replication
TRAQ	Transition readines assessment questionnaire
Transition-Q	Transition Questionnaire
Kanta	Kanta Services are a set of digital services that store citizens' social welfare and health care data
Omaolo	National online service for social welfare and healthcare
ParTNerSTEPs	Parents in Transition – a Nurseled Support and Transfer Education Program
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyse
RCH	Royal Childrens Hospital
REDcap	Research Electronic Data Capture

TENK	Finnish Academy Board on Research Integrity (Tutkimuseettinen Neuvottelu Kunta)
SAHM	Society for Adolescent Health and Medecine
UNC TRxANSITION	University of North Carolina Transition scale
WHO	World Health Organisation
WMA	World Medical Association

List of Original Publications

This dissertation is based on the following original publications, which are referred to in the text by their Roman numerals:

I. Tornivuori, A., Kallio, M., Culnane, E., Pasanen, M., Salanterä, S., Sawyer, S., Kosola, S. Transition readiness and anxiety among adolescents with a chronic condition and their parents: A cross-sectional international study. *Journal of Advanced Nursing*. 2023; 2: 756-764

II. Alanen, A., Kallio, M., Culnane, E., Pasanen, M., Salanterä, S., Sawyer, S., Kosola, S. Anxiety and care experiences in adolescents with chronic health conditions: an international, longitudinal study across the transfer of care. *BMJ Paediatrics Open.* 2024;8:e002836.

III. Alanen, A., Kallio, M., Salanterä, S., Kosola, S. Adolescent with chronic health conditions- Psychosocial support and digital health service use across transfer of care; a longitudinal study. *(Manuscript)*

IV. Tornivuori, A.,Tuominen, O., Salanterä, S., Kosola, S. A systematic review on randomised controlled trials: Coaching elements of digital services to support chronically ill adolescents during transition of care. *Journal of Advanced Nursing*. 2020; 06:1293-1306

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1 Introduction

The management of chronic health conditions during adolescence, a time of many changes, may be a great challenge for adolescents. Adolescents strive for independence by developing an identity separate from that of their closest family and forming new independent relationships outside of the home. This development also reaches the healthcare environment for adolescents with chronic health conditions, and relationships with caregivers or healthcare professionals can change (Blum et al., 1993; Zhou et al., 2016). Adolescents may push boundaries while learning critical thinking, communication skills and self-expression. Furthermore, peer pressure and conflicts with authoritative persons can cause turbulence. Therefore, supportive relationships with adults, parents and healthcare professionals who are aware of these developmental issues are crucial and can facilitate healthy development during adolescence (Ratliff et al., 2023; Thomsen et al., 2022). Research involving adolescents has resulted in significant knowledge on how adolescents differ from children and adults (Santelli et al., 2003), and these differences need to be acknowledged as an important factor in contributing to positive health outcomes and smooth transitions in healthcare (Azzopardi et al., 2024).

Commonalities in caring for adolescents across different conditions are greater than the differences, and transition health services may therefore be developed generically (Bomba et al., 2017; Grasemann et al., 2023; Schmidt et al., 2016). Healthcare systems are complex, involving several stakeholders, particularly in the context of caring for adolescents with chronic health conditions across the transition of care. Several stakeholders, such as the adolescents themselves; their parents; schools; paediatric hospitals; and adult healthcare facilities together with multi-professional teams, are required to ensure the continuity of care, coordination and seamless communication across different healthcare systems (Leung et al., 2021).

As adolescents with chronic health conditions grow up, their care will transfer from paediatric hospitals to adult sites. This process is called transition, and it is the purposefully planned process of guiding adolescents with chronic health conditions from child-centred care to adult healthcare. When developing healthcare transition services, there is a need to involve the adolescents themselves because, without their

insights and wishes, the services might not meet their requirements and, therefore, prevail to be ineffective (Bomba et al., 2017). Health coaching may facilitate collaborative healthcare in which the individual is consciously and deliberately taking an active part. The aim is, through individual goal-setting, to achieve a better quality of life with the person as an active part of the decision-making (Ghasemiardekani et al., 2024). Health coaching is a non-patronizing, motivational relationship where individual needs are taken into consideration (Barr & Tsai, 2021). Furthermore, as technology develops and enables patients to collect health data and communicate easily, health coaching may have an important part in the development of healthcare (Klein et al., 2013; Rutjes et al., 2022; Veen et al., 2017). However, current research shows that chronically ill adolescents encounter disruption in care, face poor communication and poor preparation for changes in care (Driver et al., 2022; Van Staa & Sattoe, 2014). Digital services in healthcare are evolving rapidly, and there is an increasing need for innovative solutions that effectively address healthcare challenges. As a result, there is a need to identify how patient groups gain from digital health services and by what measures (de Sousa et al., 2022; Domhardt et al., 2021; Li et al., 2024).

There is limited international longitudinal transition research on the healthcare needs and available support for adolescents with chronic health conditions across the transfer of care. This study's aim is to evaluate the healthcare needs and support of adolescents aged 15-24 years with chronic health conditions across the transfer of care in two countries, Finland and Australia. The understanding was built by exploring: health self-management; the impact of chronic health conditions; health-related anxiety; care experiences; and transition readiness, to identify the healthcare needs of adolescents with chronic health conditions. Furthermore, the available and received healthcare support was explored: (psychosocial; digital health; and health coaching support) across the transfer of care.

2 Review of the Literature

2.1 Adolescents with chronic health conditions and healthcare needs

Increasing numbers of adolescents (10-24 years) with chronic health conditions reach adulthood due to the prevalence of diseases (ex., Diabetes, bowel diseases, congenital heart diseases) and advances in medicine (Sawyer et al., 2018; WHO, 2021). The need for ongoing medical attention characterises chronic health conditions in children and adolescents; some conditions can be congenital, and others are diagnosed under the age of 18 years. The challenges that chronic health conditions pose for the adolescent can impact developmental processes and may affect lifelong health behaviour (Russo, 2022; Sawyer et al., 2007).

Adolescence and early adulthood (10-24 years) is a crucial period where the brain is still maturing, responsibilities shift, and peer relations become central. This period may be divided into early adolescence (10-14 years), late adolescence (15-19) and young adulthood 20-24 years (Patton. et al., 2016). Research by Sawyer et al. 2018 argues that the age range of 10-24 is a more inclusive definition; as it aligns with growth patterns and recent understanding of life phases and brain maturation (Sawyer et al., 2018). In summary, adolescence is a vulnerable, complex period marked with: social; cognitive; emotional; and physical changes. Acknowledging these phases can help in supporting adolescents through this critical development phase. Adolescents' understanding of risks and decision-making is influenced by their cognitive and psychosocial development and thus need support and guidance (Blakemore & Robbins, 2012; Patton. et al., 2016; Sawyer et al., 2018).

Adolescents with chronic health conditions, like their healthy peers, experience an increase in responsibilities, such as additional social, educational- or work-related issues, but with an added burden of taking care of their health. Previous research shows that adolescents with chronic health conditions may be at increased risk of poorer educational and work-related outcomes than their healthy peers. The additional challenges that adolescents with chronic health conditions encounter may lead to mental health challenges (Maslow et al., 2011; Russo, 2022).

Risks to the health and well-being of adolescents may be based on both social and behavioural aspects. Social aspects include changes in the influence of family,

friends and the impact of social media. Behavioural aspects include both the personal behaviour and the behaviours of peers may influence the health and well-being of adolescents (Santelli et al., 2003; Santos et al., 2016). Risk behaviour (such as: physical inactivity; unhealthy eating habits; early initiation of sexual activity; unsound sexual practices; smoking; using cannabis; alcohol or illegal drug use; risky driving, antisocial and aggressive behaviour) that can negatively affect health, can be considered a normal developmental aspect of adolescence (Russo, 2022; Sawyer et al., 2007; Surís et al., 2008). However, adolescents with chronic health conditions are more prone to this kind of risky health behaviour (Jin et al., 2017; Russo, 2022; Ssewanyana et al., 2017; Suris & Akre, 2015). Therefore, addressing the psychological aspects of care is essential (Catanzano et al., 2021; Fazel et al., 2021). The long-term health outcomes of chronic health conditions rely upon disease knowledge, the continuity of care, health self-management and the capacity to engage in self-care (Joo, 2023; Riegel et al., 2019).

2.1.1 Health self-management of chronic health conditions

The management of chronic health conditions in adolescence may be a major challenge for the individual, the family and the healthcare team (Rasalingam et al., 2021; Ssewanyana et al., 2017; Surís et al., 2008). Best health self-management practices are generally for approaches aimed at adults (Barlow et al., 2002; Lozano et al., 2018). Therefore, it does not take into consideration the paediatric or youth development phases and the important role their parents or caregivers have in care. At the children's hospitals, before the transfer of care, health self-management is more of a shared management with the parents or carers and evolves with the increased independence of the youth (Lozano et al., 2018; Traino et al., 2022).
Health self-management is one of the key elements that adolescents with chronic health conditions need to master when growing up, as responsibility shifts from the parents towards the young person themselves. Health self-management requires an understanding of the health problem and motivation for engagement in self-care (Barlow et al., 2002; Russo, 2022). For adolescents, the process of health self-management is influenced by multiple stakeholders such as the adolescents, peers, the family and the healthcare professionals (Nightingale et al., 2022).

Health self-management includes tasks and routines in everyday life that strengthen the health and well-being of individuals with chronic health conditions (Riegel et al., 2019; Russo, 2022). This includes tasks such as managing medication, nutrition, physical activity and healthy life habits (Lozano et al., 2018; Russo, 2022). Nutrition, maintaining a healthy diet, and regular physical activity are keystones for improving overall well-being. Medication self-management includes adherence to prescribed treatment, renewing prescriptions and incorporating an understanding of

why the medicine is prescribed and its possible side effects. Setting realistic goals and developing problem-solving skills are also important in enforcing health self-management (Lozano et al., 2018; Russo, 2022).

Regardless of chronic health conditions, adolescents still have several common health self-management elements and fundamental generic needs that they need to master (Schmidt et al., 2016; Varty et al., 2020). For adolescents, health self-management needs to be supported by their families and healthcare professionals (Rasalingam et al., 2021), and for adolescents to master the new care responsibilities, they need to be tailored to an age-appropriate level (Lozano et al., 2018). Collaborative methods used by healthcare professionals could facilitate the transition of responsibility from the parent to the adolescent and strengthen their ability for health self-management (Kivelä et al., 2014; Thomsen et al., 2024). As a result, there is a need to better understand how emotional and social aspects can be improved to support adolescents with chronic health conditions and their ability for health self-management (Sawyer et al., 2007; Van Staa & Sattoe, 2014). Also, an assessment of the youth's abilities to participate in self-care is an important factor in health to support health self-management (Lozano et al., 2018). Further research on effective health self-management support for adolescents with chronic health conditions (Gauci et al., 2021), and on the impact the chronic health condition has on the daily life of adolescents is needed.

2.1.2 The impact of chronic health conditions

The impact of chronic health conditions on adolescents can affect various aspects of life, including health behaviour, emotional well-being, social interactions and educational performance (Denny et al., 2014; Russo, 2022). Chronic health conditions may lead to limitations, such as low engagement in daily physical activities and absence from education due to hospitalisations or medical appointments (Denny et al., 2014). Continuous blood sugar monitoring or visible insulin pumps for persons with type I diabetes, or persons with inflammatory bowel disease who may experience stress causing worsening of the symptoms, may feel restrictions in social engagement and weighted emotional well-being (Patton & Clements, 2016; Puolanne et al., 2017). Adolescents who have experienced kidney or liver transplants at a very young age may have adherence problems to the medication that is part of the care, with immediate negative side effects due to medication neglect (Rohan & Winter, 2021; Yazigi, 2017). All of the above-mentioned experiences may enforce feelings of being different and contribute to limitations in everyday life. These limitations due to their chronic health conditions may impact friendships, romantic relationships and overall participation in social activities (Denny et al., 2014; La Greca et al., 2002). Providing holistic, person-

centred comprehensive support that encompasses all aspects of life is needed to support appropriate self-care (Riegel et al., 2019) and reduce the impact of chronic health conditions on a young person's everyday life (Lozano et al., 2018). Research indicates that high condition impact may affect adolescents' mental health, especially regarding anxiety and depression (Berkelbach van der Sprenkel et al., 2022).

2.1.3 Care-related anxiety

In adolescence, anxiety is often related to the different developmental stages and may be a reaction to new experiences and challenges. It is a common experience while growing up and can arise from concerns about lack of control, unpredictable events, and uncertainty regarding the future (Fazel et al., 2021; Garcia & O'Neil, 2021; Pao & Bosk, 2011). It is important to differentiate between normal anxiety and anxiety disorders for early recognition and efficient treatment. If left untreated, anxiety can affect normal psychological development and lead to insomnia, restlessness, difficulty concentrating, and poor academic performance (Garcia & O'Neil, 2021). Adolescents with chronic health conditions have a higher incidence of anxiety than their healthy peers (Cobham et al., 2020; Fazel et al., 2021; Sansom-Daly et al., 2012). Therefore, early recognition and continuous treatment of the psychological aspects of chronic health conditions are called for (T. Allen et al., 2022; Bomba et al., 2017; Fazel et al., 2021). Adolescents who are significantly impacted by their condition may also experience greater anxiety (Cobham et al., 2020) and feel less prepared for the transfer of care (Huang et al., 2021). It is important to create interventions that support positive care experiences and health self-management which reduces anxiety (Bomba et al., 2017; Huang et al., 2021).

To acknowledge how to support adolescents with anxiety, it is important to understand the care experiences of adolescents with chronic health conditions.

2.1.4 Care experiences

Research shows that adolescents report poorer care experiences than adults (Driver et al., 2022; Hargreaves & Viner, 2012). Adolescents' healthcare needs differ from those of children and adults, and guidelines on adolescent-friendly health services have been published. The guidelines emphasise the significance of providing high-quality standard care and addressing the specific needs of adolescents in healthcare delivery (Crossen, 2017; Sawyer et al., 2014; WHO, 2023). Positive care experiences can guide and support adolescents as they develop towards independence. Positive care experiences can also help an adolescent strengthen their ability for health self-management (Rasalingam et al., 2021).

Adolescent-friendly care includes confidentiality, accessibility, effective communication, and a respectful staff attitude. It also involves guideline-driven care, youth involvement, and an age-appropriate environment and focuses on the individuality of health outcomes (Crossen, 2017; Thomson et al., 2022). Integrated and well-coordinated health interventions that meet the adolescents' healthcare- and information needs, including peer support and discussions around psychosocial issues, are relevant for adolescent-friendly care (T. Allen et al., 2022; Ambresin et al., 2013; Bomba et al., 2017; Klein et al., 2014). Confidentiality, trust and feelings of being respected are adolescent-specific matters that impact care experiences (Chung et al., 2024). Time alone with healthcare professionals and the ability to raise and discuss health-related issues, such as the understanding of medical decisions and prescribed medication, contributes to preparing an adolescent for the shift in health self-management and strengthens positive care experiences (Bogart et al., 2024; Suris & Akre, 2015). In a qualitative meta-synthesis on adolescents' transition experiences, by Fegran et al. 2014 and updated by Varty et al., 2020, the results indicated that the care experiences of adolescents were similar across chronic health conditions, with feelings of not belonging and being ill-prepared for transfer of care (Fegran et al., 2014; Varty et al., 2020). It can be seen, therefore, that adolescents with chronic health conditions have a great need for developmentally appropriate health knowledge and psychosocial support that is integrated into care (T. Allen et al., 2022; Taylor et al., 2008).

2.1.5 Care culture and adolescent care

The challenge of improving the quality of medical care for adolescents and young adults is global, with investments in adolescent health specialists highly needed (Sawyer et al., 2019). The general upper age of care at paediatric hospitals differs globally, with the harshest upper age limit in resource-poor countries, hardly reaching the age of independence, and in high-income countries showing big variations (Sawyer et al., 2019). Also, funding sources differ greatly both globally and within countries and this has a big influence on the quantity and quality of care (SAHM, 2020). It can be seen, therefore, that adolescents encounter different care cultures when transitioning from children's hospitals to adult healthcare (Driver et al., 2022; Fegran et al., 2023). Cross-cultural research across transfer is scarce, but some emerging results show that the fundamental generic needs of adolescents with chronic conditions among various cultures and differing healthcare systems are similar (Bomba et al., 2018). Multicenter studies show evidence that generic transition interventions or programs are helpful for adolescents in preparing for transition (Grasemann et al., 2023; Schmidt et al., 2016). As a result, additional

research is necessary to examine cultural differences between living environments and care cultures, as these influence care transitions and experiences.

2.2 Transition of care

As adolescents with chronic health conditions grow up, their care will transfer from paediatric hospitals to adult healthcare. Transferring care from paediatric facilities to adult healthcare is called a transition (Sawyer et al., 1997). Transition is the purposefully arranged process of preparing adolescents with chronic health conditions and their parents for the shift in the healthcare settings and responsibilities (American Academy of Pediatrics et al., 2002; Blum et al., 1993), (Figure 1).

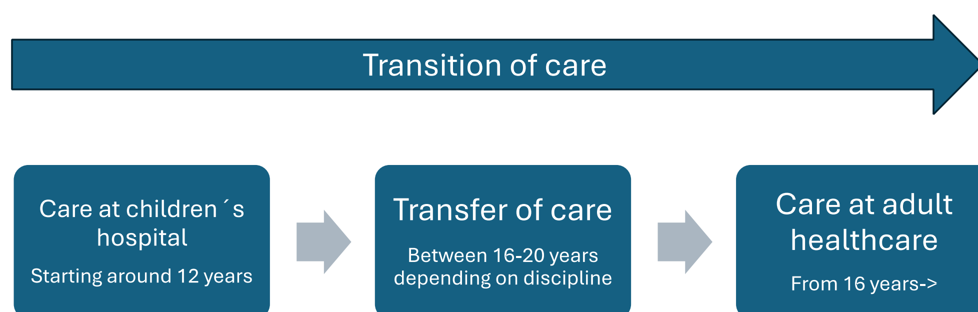


Figure 1. Transition of care.

The transition of care is a complex process which depends on good coordination and continuity of healthcare (Sawyer et al., 1997; Zhou et al., 2016). The transition process is comprised of the preparation period, the actual transfer event, and the follow-up period at adult healthcare facilities (Blum et al., 1993; Campbell et al., 2016). Alongside the transfer of care the assessment of the development of health self-management and psychosocial skills is necessary to support and help adolescents with chronic health conditions adjust to adult healthcare (Chapados et al., 2024). Even though transition services emerged around 30 years ago, there are still gaps in the evidence on what works and how to follow up on the effects of the transfer of care (Blum et al., 1993; Schmidt et al., 2020).

Previous research indicates that the transition process, due to the complexity, has been associated with a decrease in health self-management and access to care that may in turn lead to poorer health outcomes and drop-out of care (Chapados et al., 2024; Killackey et al., 2023). Therefore, transition with early adequate coordination and communication with all stakeholders and appropriate parent involvement positively affects youth health and well-being. The consensus is that the process

needs to be started at an age-appropriate level, early enough, around the age of 12 (Colver et al., 2017; Thomsen et al., 2022).

Transition programs should facilitate the transfer of care through coordinated, flexible, developmentally relevant care supported by effective communication and the involvement of parents (SAHM, 2020; Schmidt et al., 2020; Thomsen et al., 2022; Van Staa et al., 2011). There are numerous transition programs for specific chronic conditions, but also generic programs to support adolescents with chronic health conditions in the transition process (Killackey et al., 2023). Holistic transition programs that include the parents, where the parents are kept well informed, may result in improved outcomes: for the families; the individual; health self-management; and the provision of individualized care (D. Allen et al., 2022; Fegran et al., 2023; J. C. Suris et al., 2017). During the transition period, the responsibility of the care often shifts from being orchestrated by the parents to becoming the responsibility of the adolescents themselves. It is important that the emerging adolescents can meet the healthcare professionals alone to establish confidential care (American Academy of Pediatrics et al., 2002; Chung et al., 2024; Thomsen et al., 2022). Research suggests that well-designed transition processes correlate with improved transition readiness, yet the most effective outcomes are still not agreed upon (Colver et al., 2018; Killackey et al., 2023; Schmidt et al., 2020).

In this study the following terms are used:
Transition of care- Referring to the whole transition process starting at around 12 years of age and reaching 24 years of age. This includes the period where care is being transferred from children's hospitals to adult healthcare.
Transfer of care- Referring to an event, when the care is transferred from children's hospitals to the adult healthcare.
Across transfer of care- Referring to several events: at the children's hospital; a year after the transfer of care; and two years after the transfer of care.

2.2.1 Transition readiness

Transition readiness, as in adolescents feeling both educationally and psychosocially ready to change healthcare facilities, anticipates a successful transition (Rasalingam et al., 2021). Transition readiness often measures both educational and behavioural aspects in healthcare: condition-related knowledge; and practical skills; including the capability to contact hospitals; reschedule appointments; and take overall responsibility for medical care. Assessing transition readiness is important to evaluate the needs of adolescents with chronic health conditions in transition. Several transition readiness tools have been developed to measure the outcomes of

transition readiness interventions (Killackey et al., 2023; Suris & Akre, 2015; Zhang et al., 2014). Some tools are validated, but others are checklists incorporated into practical care (Killackey et al., 2023). Psychometric evaluation of transition readiness tools may be limited or not rigorously tested (Killackey et al., 2023; Zhang et al., 2014). Transition readiness programs share several attributes, commonly they evaluate both health self-management abilities and communication skills (Chapados et al., 2024; Killackey et al., 2023; Sawicki et al., 2015). Assessments on transition readiness can involve participation from adolescents, their parents or caretakers and healthcare professionals (Moynihan et al., 2015; Schmidt et al., 2020). Many measures exist, but internal consistency and structural validity are still lacking, and no consensus has yet been reached (Killackey et al., 2023; Schmidt et al., 2020). The transition readiness measurements also need to be cross-culturally validated (Bomba et al., 2018; Schmidt et al., 2016), (Table 1). This study assesses transition readiness as a means to determine the healthcare needs of adolescents with chronic health conditions at transfer of care.

Table 1. Transition readiness tools.

Tool	Country	Age	Goal	Target
TRAQ (Sawicki et al., 2011)	USA	14-21	Transition readiness skills	Adolescents
Am I on TRAC (Moynihan et al., 2015)	Canada	12-19	Knowledge and self-management for transition readiness	Adolescents
Transition-Q (Klassen et al., 2015)	Canada	12-18	Health self- management & self- advocacy	Adolescents
Ready Steady Go (Nagra et al., 2015)	UK	over 11 years	Knowledge and skills for health self-management	Adolescents
ParTNerSTEPs Program (Thomsen et al., 2022)	Denmark	16-18	Adolescents and parents needs during transition	Parents
UNC TRxANSITION (Ferris et al., 2012)	USA	15-21	Self-management	Adolescents
Good2Go (Mellerio et al., 2020)	France	14-18	Health self-advocacy, knowledge, self-management	Adolescents

TRAQ = Transition Readiness Assessment Questionnaire. Am I on TRAC = Am I on TRAC (Taking Responsibility for Adolescent/Adult Care) for adult care questionnaire, TRANSITION-Q = Transition Questionnaire, ParTNerSTEPs = Parents in Transition- a Nurseled Support and Transfer Education Program, UNC TRxANSITION = University of North Carolina Transition scale, Good 2 Go = Good to Go program.

2.2.2 Transition and person-centred care

Healthcare has developed from being traditional provider-driven care towards person-centred care, where individual needs and engagement are central (D. Allen et al., 2022; Phillips et al., 2023). Person-centred care has been shown to improve health outcomes across a range of conditions and may benefit individuals with chronic conditions. Person-centred care supports the individual in health self-management and considers psychosocial and mental aspects of care (Fernandes et al., 2022; Suris & Akre, 2015; Svamo et al., 2024). By highlighting active involvement and addressing individual needs, person-centred care may support adolescents in receiving psychosocial care. Adolescents with chronic health conditions need to develop their skills for health self-management and decision making at the transfer of care. Decisions taken early in life, regarding the management of chronic health conditions, may have long-lasting effects (D. Allen et al., 2022). Previous research shows that adolescents have a great need for information but are reluctant to raise questions regarding personal issues, such as poor adherence or educational- and socio-emotional problems (Beresford & Sloper, 2003). Information and communication are essential in the transitional care of adolescents and health professionals need to address both practical, but also attitudinal and behavioural issues to support person-centred care (Ammerlaan et al., 2017; Fegran et al., 2023; Hanghøj et al., 2020; Varty et al., 2020). Person-centred care may empower adolescents to greater treatment adherence and health self-management.

2.3 Adolescents with chronic health conditions and support

2.3.1 Psychosocial support

Psychosocial support can be defined as support provided by another person and is an important part of healthcare delivery and an efficient tool for promoting behaviour change (Matsayi Aji et al., 2024). However, support from health professionals and/or peers may only be useful if the support is age-appropriate and answers to the needs of the adolescent (Fegran et al., 2023).

Adolescents with chronic health conditions strive to live as ordinary a life as their healthy peers. Despite having a diagnosis, they have common fundamental needs, that have to be addressed for comprehensive psychosocial support. These needs include: importance of friends; relationships; family support; experiences in school, education and overall life situation (Berkelbach van der Sprenkel et al., 2022; Goldering & Cohen, 1988; Klein et al., 2015). While adolescents are gradually

gaining independence and competence in health self-management, they are still dependent on the support of their closest network and the continuity in care (Rasalingam et al., 2021; Thomsen et al., 2022). Adolescents with chronic health conditions wish for peer support (Smith et al., 2021), although they may often feel difficulties in peer relations and social participation (Taylor et al., 2008).

The psychosocial support that adolescents get from healthcare personnel is an integral part of adolescent-friendly care (Rasalingam et al., 2021; Sawyer et al., 2014). Psychosocial support needs to be combined with appropriately tailored health communication to achieve health behaviour change and health self-management (Bol et al., 2020; Van der Stege et al., 2014; Van Staa & Sattoe, 2014). Confidentiality is one of the most important elements in the care of young persons (Chung et al., 2024), and it has to be explained to be understood (Matsayi Aji et al., 2024). For the young person to receive support in discussing sensitive issues with healthcare personnel, there needs to be an understanding of the confidentiality of the discussions. Parents or carers need to give space to the young person so that they can build a confidential relationship, form trust and develop emotional safety, resulting in open communication with healthcare professionals (Kim & White, 2018). Time alone at medical appointments and privacy is one of the cornerstones in the shift of health self-management from the parents to the young persons (Chung et al., 2024; Mehus et al., 2023).

Research has identified: a lack of support and communication; insufficient means to manage stigma; and lack of access to educational material as fundamental issues that need addressing for adolescents with chronic health conditions during the transition of care (Colver et al., 2017; Varty et al., 2020). Psychosocial support and health coaching may help to increase the self-management of chronic health conditions and provide important social and emotional support (Marren et al., 2025).

In this study, data on the psychosocial aspects of care were explored to define how adolescents experience and assess the received psychosocial support of healthcare professionals across the transfer of care.

Health Coaching

Health coaching is based upon behavioural change theory and strives for person-centeredness involving goal setting and changes in health behaviour (Olsen & Nesbitt, 2010; Wolever et al., 2013). Health coaching is defined as, “a goal-oriented, client-centred partnership that is health-focused and occurs through a process of client enlightenment and empowerment“ (Olsen, 2014). As health coaching aims to be person-centred, includes personal goal setting, and encourages self-discovery, it could support adolescents to reach increased independence (Fazel, 2013; Kivelä et al., 2014; Marren et al., 2025; Obro et al., 2021).

Coaching can be used by healthcare professionals as an additional strategy for motivating and addressing health self-management and integrating psychosocial support (Barr & Tsai, 2021; Wright et al., 2018). Integrating health coaching into healthcare can improve goal orientation, person-centredness, and health education and confirm the behavioural aspects of care (Fazel, 2013; Kivela et al., 2014; Marren et al., 2025; Obro et al., 2021). Both coaching in person, and online methods have been proven beneficial for improving health outcomes (Kivelä et al., 2014; Stinson et al., 2016), and a combination of these may be beneficial for adolescents with chronic health conditions (Obro et al., 2021).

2.3.2 Digital health services

The World Health Organisation (WHO) has launched a Global strategy on digital health 2020-2025 which targets to promote easily accessible health and well-being for everybody globally. As part of the global strategy, the WHO states that digital health initiatives need to be strategically guided and have to integrate financial, organisational, human and technological means. (WHO, 2021). Digital health services create many possibilities, such as health promotion, disease prevention, cost-effectiveness and patient engagement. However, risks that need to be taken into consideration are data privacy and ethical aspects such as integrity, confidentiality and availability. Also, health literacy and internet availability are of global concern (Bol et al., 2020; Li et al., 2024; WHO, 2021). The European Commission states that digital health services need to benefit everyone and that innovative solutions are needed to promote accessible and effective personalised care (EUC, 2018).

Digital health solutions are a growing field, and many innovations strive for health promotion, patient engagement and affordability. To create new and advanced digital health solutions, policies and regulations are needed to secure the integration and sustainability of new services (WHO, 2021). The effectiveness of digital health solutions, despite the available global and regional strategies, remains varied and *undefined in usefulness* and delivery (Li et al., 2024; Mumtaz et al., 2023). There are still many obstacles to implementing digital services despite the many benefits new technology can bring to the healthcare sector (Guo et al., 2020; Mumtaz et al., 2023).

In this study, the term digital health services indicates digital tools and services that use information and communication to increase the availability of and access to healthcare provided by healthcare professionals.

2.3.3 Digital transition health services

The rapid growth of digital healthcare is transforming the care of people with chronic health conditions. Digital health services have been proven helpful for adults with

chronic health conditions, but there is still limited evidence on the effectiveness of digital health interventions for adolescents with chronic health conditions (de Sousa et al., 2022; Domhardt et al., 2021; Li et al., 2024). Challenges during the transition from child to adult healthcare services may arise from several stakeholders (school, home, healthcare team, peers) and require multifaceted approaches. A comprehensive approach is needed for digital interventions and services to be effective and helpful for adolescents in transition (Berkanish et al., 2022; Stinson et al., 2016). Also, identifying factors that contribute to person-centred care that promotes positive healthcare outcomes for adolescents is needed (Domhardt et al., 2021). Considering adolescents' familiarity with digital platforms, utilising digital health services has the potential to develop person-centred and empowering healthcare services (Allen et al., 2008; Domhardt et al., 2021; Li et al., 2024).

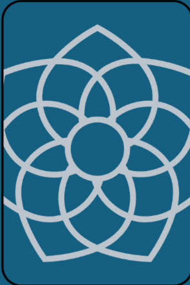
Several digital health interventions, models and guidelines have been developed, with some grounded in theoretical frameworks and some based on practical guidelines (Morrison, 2015). However, meta-analyses examining the effectiveness of theoretical frameworks for digital health interventions have yielded contradictory results. While some studies demonstrate the positive impact of theory-based interventions (Fishbein & Yzer, 2003; Lycett et al., 2018; Webb et al., 2010), others suggest that theory does not enhance the effectiveness of interventions (Prestwich, 2014). The efficacy of theory-based digital interventions might be undermined by inadequate utilisation of theoretical frameworks during the development and implementation phases or by insufficient integration of these frameworks into the interventions themselves (Prestwich, 2014; Webb et al., 2010).

Health coaching in digital health services

In a scoping review by Obro et al., 2021, health coaching interventions and digital health services were found to benefit from one another, even though the coaching methods were varied and somewhat undefined (Obro et al., 2021). Coaching methods can facilitate the tailoring process and personal learning (Wolever et al., 2013), and tailored digital interventions have been proven more effective in influencing health behavioural change (Obro et al., 2021). Despite the many possibilities digital health services can provide in self-monitoring, such as: potential anonymity; accessible communication; data tracking; easy adaptation and scaling, evidence indicates that people still prefer interpersonal support and consistent relationships for effective communication and positive health outcomes (Bol et al., 2020). In conclusion, digital health services may support coaching, and coaching, in turn, may support the use of digital health services (Obro et al., 2021; Wolever et al., 2013).

In this study, digital transition health services with coaching elements were defined as digital transition services incorporating elements of social interaction, whether through human support or interactive features.

Summary of key findings:



Chronic conditions in adolescence can impact developmental processes and may affect life course and health behaviour.

Further research is needed on healthcare needs and psychosocial factors to support adolescents with chronic health conditions.

Transition is a complex process and may be challenging; it is associated with poorer health outcomes and a lack of continuity of care.

Further research is needed to understand the factors affecting transition readiness and the care experiences of adolescents during transition.

Digital health services pose many opportunities for person-centred care and empowering health behaviour.

There is still limited evidence on the use of digital health-interventions and to identify factors that contribute to person-centred care and acknowledge adolescents' preferences

3 Aim

The overall aim of the study was to evaluate the healthcare needs and support of adolescents with chronic health conditions across the transfer of care

The research questions for the study were:

RQ 1: What are the **healthcare needs** of adolescents with chronic health conditions going through transition?

- What are the health self-management needs that should be addressed for adolescents across transfer? (study I, FIN/AUS, study III, FIN)

RQ 2: What are the background factors associated with healthcare needs across transfer?

- How are country, age, transition readiness, condition impact, care experiences and care-related anxiety associated during the transfer of care? (study I and II, FIN/AUS)
- What are the changes in perceived healthcare needs (condition impact, care experience and care-related anxiety) of adolescents with chronic health conditions across transfer of care? (study I and II, FIN/AUS and study III, FIN)?

RQ 3 What kind of **healthcare support** is there for adolescents with chronic health conditions across transfer?

- What psychosocial aspects of care have adolescents experienced across transfer? (study III, FIN)
- What are the use and expectations of digital health services among adolescents with chronic health conditions? (study III, FIN)
- What digital health transition services exist, and how are coaching elements used in these? (study IV)

4 Materials and Methods

Through analyses of health self-management, condition impact, care-related anxiety, care experiences and transition readiness, across two countries, the study explored the healthcare needs to be met for adolescents across the transfer of care. Data on the psychosocial aspects of care help to define the support adolescents received from healthcare professionals across the transfer of care. Furthermore, by analysing the health coaching elements in digital health services, the study aimed to define helpful digital health services for adolescents with chronic health conditions across the transfer of care. For this study, the methodological approach was both quantitative (studies I, II and III) and quantitative and qualitative (study IV), as the care of adolescents with chronic health conditions at transition is complex.

The needs of adolescents were assessed through data from three studies that had been carried out (study I, II, III) across the transfer of care. A cross-sectional international study (study I, FIN/AUS) was conducted at the children's hospitals to gain insight into the needs to be met regarding: health self-management; transition readiness; and levels of care-related anxiety regarding the transfer of care among adolescents with chronic health conditions and their parents. The longitudinal study (study II FIN/AUS) explored the changes and associations of perceived healthcare needs; care-related anxiety; care experiences; self-reported condition impact; and country context before and after the transfer of care. We assessed adolescents' reported time alone with doctors and the confidentiality aspect of care to further explore care experiences (study III).

The support of adolescents across the transfer of care was assessed through a longitudinal study (study III, FIN) and a systematic review (study IV). Study III explored the use of digital health services by adolescents with chronic health conditions and the received psychosocial aspects across the transfer of care at three time points (Finnish participants). The systematic review defined digital transition services with health coaching elements for adolescents with chronic health conditions. The insights resulted in a deeper understanding of the available support, psychosocial and digital support received during transition.

The following chapter includes the study design, settings, participants and ethical considerations of this study, along with the original publications that support it.

4.1 Study design

In this study, exploring various aspects of care transition was important to gain an understanding of the needs of and available support for adolescents across the transfer of care. The aim, study design and methods are presented in Table 2. The data for the survey studies were gathered at three time points through questionnaires across diagnoses in two countries (FIN/AUS). A systematic review was chosen to gather data on current digital transitional support services for chronically ill adolescents and to analyse the health coaching and transition elements in these. (Table 2)

Table 2. Aim, design and methods of studies I-IV.

RESEARCH	Aim	Study design	Methods
Adolescents' healthcare needs study I and II	To explore aspects of healthcare needs: country, age, transition readiness, care-related anxiety, care experience and condition impact across the transfer of care, in two countries (study I, II FIN/AUS). Changes in condition impact and care-related anxiety (Study III, FIN)	I. Cross-sectional study II. Longitudinal study III. Longitudinal study	A quantitative approach was used I. To identify associations of adolescents' transition readiness, age, care -related anxiety and health self-management in two countries T0. II. To evaluate changes in anxiety, care experiences, and condition impact among adolescents with chronic health conditions, in two countries T0, T1. III. Changes in condition impact and care-related anxiety T0, T1, T2
Healthcare support for adolescents study III and IV	To define received and available support assessing use of digital health services, and perceived experiences of psychosocial aspects of care (FIN) across the transfer of care and to describe existing digital transition services with health coaching- and transition elements.	III. Longitudinal study IV. Systematic Review	III. A quantitative approach was used to compare changes in the use of digital health services and experiences of psychosocial aspects of care collected longitudinally T0, T1, T2. IV. Both qualitative and quantitative design was used on data from peer reviewed articles to gather the results on existing digital health services. Qualitative design was used to extract through a narrative synthesis the transition and coaching elements used, and quantitative to evaluate the effectiveness of the outcomes.

FIN = Finland, AUS = Australia, T0 = at children's hospitals, at transfer, T1 = one year after transfer of care, T2 = two years after transfer of care

4.1.1 Study design of the survey study

Study I had a cross-sectional design, and **studies II** and **III** had longitudinal designs, encompassing quantitative measures. Study I is a cross-sectional survey study with data gathered before the transfer of care, at children's hospitals, in two countries (FIN/AUS). Study II is a longitudinal survey study with data gathered before and after the transfer of care (FIN/AUS). Study III, is a longitudinal study with data gathered at three time points across the transfer of care (FIN). These designs were used to assess: health self-management; condition impact; care-related anxiety; care experiences; and transition readiness; across two countries; to depict the healthcare needs of adolescents across the transfer of care.

Study I assesses the correlations between age, transition readiness and anxiety at the transfer of care. Transition readiness entails behaviour- and knowledge items (Moynihan et al., 2015) health self-management and the levels of anxiety regarding the transfer of care. It is important to assess adolescents' healthcare-related behaviour-, knowledge- and health self-management aspects to determine the transition readiness and healthcare needs before transfer to adult care (Moynihan et al., 2015; Zhang et al., 2014). In this study, the parents of the adolescents were included: both adolescents and parents assessed an item on readiness and items on health self-management. It is meaningful to incorporate the parents of the adolescents as they have taken care of the healthcare appointments and have had full responsibility for their child's care before adolescence (Thomsen et al., 2022).

Study II evaluated: changes in anxiety; care experiences; condition impact; age and country, across the transfer of care in two countries (FIN/AUS). Futhermore, it assessed what was associated with care-related anxiety.

Study III reported on how the Finnish participants used digital health services (Kanta, Omaolo, or other secure digital health services for youth) and on the received psychosocial aspects of care at three time points: before the transfer of care and one- and two years after the transfer of care. Any changes in levels of care-related anxiety and self-reported condition impact were also evaluated. The secure digital health services, available for all Finnish citizens (Kanta and Omaolo), are developed by public- and private organisations (DigiFinland, 2024; Kela, 2024). The other secure digital-health services referred to, were non-governmental organisations that provide youth-focused health services.

4.1.2 Study settings and participants for the survey study

Settings

The study was administered at two study centres: The New Children's Hospital (NCH) in Helsinki, Finland and the Royal Children's Hospital (RCH) in Melbourne, Australia. Despite differences between the sizes of the two countries, with Finland being a small country with a small population and Australia representing a vast country with a large population, the two countries have similarities. There are similarities regarding both healthcare- and educational systems. There is publicly funded healthcare in both countries, and severe chronic conditions are treated mainly in the main hospitals. Furthermore, both countries demonstrate a high participation rates in secondary education, making the conditions the adolescents grow up in more comparable.

The main differences between the two countries regarding care for adolescents with chronic health conditions are that Australia has a hospital-wide transition clinic, and Finland has general transition guidelines, differing by subspecialties. Also, the general upper age of care at paediatric hospitals differs, with the upper age in Finland being 16 and in Australia 19 years. Both children's hospitals adhere to transition guidelines, though in Australia the guidelines are more defined. Furthermore, in RCH, Melbourne, Australia, there is an expansive transition support service, a transition clinic, with several persons employed part-time (e.g., teachers and nurses). The employees coordinate the care by meeting the young person and their parents or carer several times and by contacting the adult facilities and helping with issues regarding education and social security. In RCH the transition support services are specially designed for adolescents with very complex health problems, therefore most of the adolescents transfer without special assistance according to the guidelines for their subspecialty. In Australia, adolescents transfer to different hospitals in the area of metropolitan Melbourne, but some will be transferred to regional and rural Victoria. In Finland, the Helsinki University Hospital is the main hospital where most of the adolescents will transfer. For the adolescents who have moved away from the metropolitan area, the care will be transferred to other main hospitals in Finland.

Participants

The study participants were adolescents and young adults aged 15-24 years, from Finland and Australia, with chronic health conditions who were expected to need ongoing healthcare into young adulthood. The participants were recruited from paediatric units approximately 6-12 months prior to their planned transfer to adult

healthcare in Finland and Australia. If the adolescents were under 18 years old, permission to attend the study was also received from their parents or carers.

In Finland, at the New Children's Hospital in Helsinki, healthcare professionals from different subspecialty clinics identified adolescents who were expected to transfer within the next six months to adult healthcare settings. A research nurse met suitable adolescents face-to-face when they attended regular appointments between September 2017 to August 2019. In Australia, at the Royal Children's Hospital in Melbourne, healthcare professionals from the Transition Support Service met eligible adolescents when they attended routine transition appointments within a year before their expected transfer of care between October 2018 and August 2020.

At both study sites, the parents or carers were recruited during the same routine appointment- if they accompanied their adolescents, or through written information delivered to them either by their child or by mail. In total, 512 adolescents (Finland n = 253, Australia n = 259) and 473 parents (Finland n = 214, and Australia n = 259) gave consent and answered the survey. In this study the data of the parents that formed a dyad with their adolescent were included (n = 322). When the participants had provided written informed consent, data were collected by questionnaires, either electronically or by pen and paper.

Study II used data collected by surveys at transfer, at the children's hospitals, and a year after transfer from Finland and Australia.

Study III used data from the Finnish participants and was collected at three time points: at the transfer of care; a year after; and two years after the transfer of care.

4.1.3 Data Collection for the survey study

The data collection for the survey study spanned several years at three time points: at the children´s hospitals (T0), one year after transfer (T1), and two years after transfer of care (T2), (Table 3).

Table 3. Flowchart and data of survey studies I, II and III FIN = Finland, AUS = Australia, T0 = At children´s hospitals at the transfer of care, T1 = A year after the transfer of care, T2 = Two years after the transfer of care.

	T0 **FIN** 09/2017-08/2019 **AUS** 10/2018-08/2020	**T1** **FIN** 09/2018-10/2020 **AUS** 08/2019-05/2022	**T2** **FIN** 09/2020-02/2021
STUDY I	Health self-management, Transition readiness, Anxiety, Age, "I am ready" Participants FIN n = 253 Participants AUS n = 259 Health self-management, "My adolescent is ready" Parents n = 322		
STUDY II	Anxiety, Care experiences, condition impact Participants FIN n = 237 Participants AUS n = 203	Anxiety, Care experiences, condition impact Participants FIN n = 163 Participants AUS n = 112	
STUDY III	Anxiety, condition impact, Use of digital health services, Psychosocial aspects of care Participants FIN n = 163	Anxiety, condition impact, Use of digital health services, Psychosocial aspects of care Participants FIN n = 163	Anxiety, condition impact, Use of digital health services, Psychosocial aspects of care Participants FIN n = 163

4.1.4 Data collection instruments for the survey study

Following data was collected: health self-management; condition impact; care-related anxiety; care experiences; and transition readiness; across two countries; to depict the healthcare needs to be met of adolescents across the transfer of care.

We assessed eleven **health self-management** questions about topics such as medication usage, understanding of the medical condition and booking appointments. These topics were asked of both the adolescents and their parents. These questions were also scored on a Likert-type scale from one to four (1= strongly disagree to 4= strongly agree).

Transition readiness was measured through the validated questionnaire "Am I ON TRAC? For Adult Care Questionnaire (ON TRAC) (Moynihan et al., 2015; Paone et al., 2006). This questionnaire consists of two scales: a knowledge scale of 14 items and a behaviour scale of 9 items. The knowledge scale scores range from 14-56 points (11- 44 if no medication is used). The behaviour scale ranges from 9-45 points (8- 40 pts. if no medications are used). Readiness was assessed by one

item, reading “I am ready”/ My adolescent is ready. This was evaluated with a Likert-type scale ranging from one to four (one = strongly disagree to four = strongly agree).

Care experience was measured by eight questions drawn from the Adolescent Friendly Hospital Survey (AFHS) (Ambresin et al., 2013; Sawyer et al., 2014). A three-point Likert-type scale was used: 1 = true, 2 = somewhat true and 3 = false. The points ranged from 8 to 24, with lower scores expressing more positive care experiences.

Condition impact was assessed in Finland by a question framed as, ‘How do you assess the activity of your illness or the intensity of symptoms during the last week?’. In Australia, the question was framed as, ‘How much has your condition impacted you during the last week?’. In Finland, the options to answer were 1 = an extreme amount to 7 = not at all, but in Australia, due to limitations of the electronic questionnaire, the scale ranged from 0 = not at all to 100 = an extreme amount. The Australian answers were reversed and modified to match the Finnish scale. Self-reported condition impact is a simple way to detect adolescents that feel a burden of their health condition and may be in need for support (Puolanne et al., 2017).

Anxiety was measured by the validated self-report instrument: State-Trait Anxiety Inventory short form (STAI-6). The introductory text to the survey was altered to assess feelings of care-related anxiety. The instrument consists of six items that are rated on a 4-point Likert-type scale (Marteau & Bekker, 1992). The scores range from 20- 80, and a score of 34-36 points has been defined as normal anxiety levels (Bekker et al., 2003).

The following data was collected that explored the available and received healthcare support: psychosocial aspects of care and digital health service use across the transfer of care.

The HEADSS structured psychosocial interview guide was used for evaluating the **psychosocial aspects** of care. HEADSS is a developmentally suitable guide to assess the psychosocial surroundings of young people in healthcare facilities (Goldering & Cohen, 1988). The acronym signifies: Home; Education/employment; peer group Activities; Drugs; Sexuality; and Suicide/depression. The acronym has developed by 2004 into HEEADSSS to involve Eating and Safety issues, and by 2014, to further include questions on the use of social media under the heading Activities (Goldering & Cohen, 1988; Klein et al., 2014). We asked the participants to determine with whom (“physician”, “nurse”, “other”, and “no one”) for the past year, they have had discussions with addressing the HEEADSSS topics at the main hospital. We also asked about discussions held outside the hospital (“at other healthcare sites, such as regional hospitals or healthcare centres”, “educational or occupational healthcare services”, “virtually through a reliable internet health service”, and “nowhere”).

The following three questions assessed **the use of digital health services**; First; “Do you use secure digital health services (Kanta, Omaolo or similar)?” with response choices yes/no. Second; “Do you know how to find reliable health information online (Kanta, Omaolo or similar)?” Thirdly; “Are you active in social media or online groups?” The options to answer the two last questions were “1= strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree”. Additionally, one open question was presented “What would you wish from digital health services?”

4.1.5 Statistics of the survey study

Categorical data are presented as frequencies (with percentages) and continuous variables with means and standard deviations (SD) or with median and interquartile range (IQR). Age is presented both as the mean and the range for descriptive purposes. For study I, the statistical analyses were done using R (version 4.0.2) and study II, the SAS System, version 9.4 for Windows (SAS Institute Inc., Cary, NC, US). For study III, data analyses were done using IBM SPSS Statistics V.25. A p-value of <0.05 was considered significant.

Study I. Both age at diagnosis and age at transfer were calculated to understand if the duration of the condition and the age of the participants at the children’s hospitals, at the transfer of care would have an impact on the results. When comparing the duration of the condition, the participants were categorised into two groups using a cut-off point of 12 years, and the differences between these groups were analysed using the Mann-Whitney U-test. The transition readiness entailed both knowledge- and behaviour items. The scores on anxiety and transition readiness were presented as means. Spearman’s correlation with 95% confidence intervals (CI) was used to establish the associations between duration of condition, age at transition, anxiety and transition readiness. Adolescents’ and parents' agreement with each other on health self-management, anxiety and the transition readiness statement “I am ready/ My adolescent is ready” were used as categorical variables. The agreement and disagreement on statements “I am ready/ I am not ready”, High anxiety/ Low anxiety were presented as frequencies with percentages. Wilcoxon signed rank test was used to test variations in answers between adult/ parent dyads.

Study II. Paired T-tests were used to test changes in anxiety levels and to assess changes between countries. The changes in care experiences due to the skewed distribution were evaluated with the Wilcoxon signed rank test, and to compare the changes between countries, the Kruskall-Wallis test was utilised.

To test the associations between levels of anxiety with age, condition impact, care experiences, and country, a linear regression model was applied. To ease the comparison between the lowest and highest quartiles, the anxiety and care

experience scores were divided into three groups: 1) the lowest quartile, 2) the two middle quartiles and 3) the highest quartile.

Study III Descriptive statistics contained frequencies (with percentages) and means with standard deviation (SD). Chi-Square tests were used to compare the categorised condition impact and anxiety with gender and psychosocial assessments. To compare anxiety levels with the use of digital services and gender The Mann-Whitney U test was performed.

4.1.6 Study sampling and data collection of the systematic review

The systematic review conducted on randomised controlled trials examined health coaching and transition elements of digital interventions for adolescents with chronic health conditions. Systematic methods minimise bias and provide reliable findings, and they provide a comprehensive process of searching published research, appraising study quality and giving an overview of the findings (Shaheen et al., 2023). The review was carried out with the support of the Cochrane Handbook for Systematic Reviews of Interventions and drafted following the PRISMA statement (Preferred Reporting for Systematic Review and Meta-analyses) (Moher et al., 2009).

The data collection for the systematic review was assembled through a search process guided by the Preferred Reporting for Systematic Review and meta-analysis statements (Moher et al., 2009). Medline (Ovid), Scopus, CINAHL, and PubMed were searched on the 28th of May 2018 regarding adolescents, health coaching and transition published between 2008-2018. The time frame of ten years was chosen to reflect the most relevant data aligned with the rapid development of digital health tools. A wide-ranging list of medical subject headings (MESH terms) and closely encompassed words linked to coaching or equivalents for this were used for the search, (see Study IV). Following the systematic web search, the search was completed manually (snowballing), using the reference lists of the included studies. Google and Google Scholar were explored with combined search terms to ensure comprehensive results. The search was done with an information specialist. Screening of the studies by titles and abstracts was done primarily by one researcher (AA), and the results were discussed with the second researcher (OT). Finally, through the electronic databases and the manual search, 422 screened records were detected. After checking for eligibility, 12 randomised controlled trials that covered digital health interventions for adolescents with chronic health conditions, were included. Two researchers (AA & OT) read the full-scale versions of the texts. The Cochrane Collaboration's tool for assessing the risk of bias in randomised controlled trials was employed to perform a risk of bias assessment of the included studies. The assessment was performed independently by two researchers (AA & OT) (Higgins

et al., 2011). The included studies were published between 2010- 2017. See Prisma flowchart Figure 1 in Study IV.

The systematic review included studies if they addressed Population: adolescents with chronic health conditions; had participants who were between the ages of 10-25; Intervention: Studies were digital internet-based interventions (digital-, online-, internet-, mobile-, interventions, programs or tools). The included interventions could also entail non-digital items; Control: included a control group without coaching elements; Outcomes: information on both transition and coaching elements: HRQoL; care motivation; self-care; health self-management; self-efficacy; social support; coping; transition readiness; effectiveness or impact; mentor; counsel; or coach.

Data extraction and synthesis

Data extraction was carried out primarily by the first reviewer (AA) but conversed with the second reviewer (OT). The extraction of the data complied with the Template for Intervention Description and Replication (TIDieR) (Hoffmann et al., 2014). The data extraction was completed in four phases: first, the features of the included studies were identified. This was followed by extraction of the features of the interventions (through analysing the features of the interventions, the transition elements were recognised). Thirdly, the statistical data on transition elements was drawn to get an understanding of the effects of the interventions. Lastly, a narrative synthesis was done to identify the coaching elements (Grant & Booth, 2009; Rodgers et al., 2009). For retrieving knowledge on the identified coaching elements, data was extracted in three phases. First, appropriate coaching synonyms and coaching actions were recognised. This was followed by grouping the synonyms and actions into themes. Thirdly, the themes were categorised. The Grade of Recommendations Assessments, Development and Evaluation criteria (GRADE) was employed to appraise the certainty of the transition outcomes (Guyatt et al., 2008).

4.2 Ethical considerations

Ethically accurate research needs to state sources of financing, conflicts of interest or other engagements (TENK, 2023). Sources of financing have been reported in each study, including grant numbers when available. There were no conflicts of interest to state for any of the studies. All authors made substantial contributions to all four manuscripts and have all sufficiently participated in the work to take public responsibility for sections of the content. They can be taken accountable for all features of the work and have followed the guidelines on research with human participants (TENK, 2019). No conflicts of interest have been stated by any of the

included authors. This study conforms with the EU General Data Protection Regulation and the Finnish Data Protection Act (European Parliament and Council, 2016; Finnish Ministry of Justice, 2018). The data collected by the surveys was coded by numbers to ensure the anonymity of the respondents.

Ethics of Survey Study

Research ethics was considered in each phase of the survey study and complied to the Declaration of Helsinki (WMA, 2024), and was conducted following good scientific protocol (TENK, 2023). Studies I, II and III are part of a larger international study, The Bridge Study. The Bridge Study was authorised by the Ethics Committee for Women's and Children's Health and Psychiatry at the Helsinki University Hospital (HUS/154/2017). It was also authorised by the RCH Human Research Ethics committee (38035). The Bridge Study trial was registered to ClinicalTrials.gov.

The studies were reported following the STROBE guideline for transparent reporting (Von Elm et al., 2008). All participants (both adolescents and adults) provided written informed consent after obtaining both written and oral information clarifying the objective of the study. The participants were reimbursed financially (with a voucher valued at 10 EUR/ 10 AUD: equal to a movie ticket) to acknowledge the time spent completing the surveys. The parents did not get reimbursed. Participation was voluntary, and the participants were able to interrupt their participation without any consequences on their care. The data was stored securely on the Helsinki University Hospital server, it was password-protected and only available to the research team. Results of the questionnaires were collected either through Webropol (Finland) or REDcap (Australia) or by pen and paper and transferred to Microsoft Excel sheets where the identity of the participants was coded with ID numbers for anonymity. All results are reported with no possibility of identification of the participants.

Ethics of the Systematic Review

A systematic review of the literature is a scientific method of exploring existing research through a systematic search and this permits an objective analysis of the included studies (Vergnes et al., 2010). All the included studies were randomised controlled trials. A risk of bias assessment (Higgins et al., 2011) was performed, separately by two reviewers (AA and OT) to critically appraise the methodological quality of the included interventions. The certainty of the evidence for transition outcomes of the included studies was estimated using the GRADE criteria (Grade of Recommendations, Assessment, Development and Evaluation) (Guyatt et al., 2008).

5 Results

The results of this study are presented in compliance with the study's aim: to evaluate the healthcare needs and support of adolescents with chronic health conditions across transfer of care The understanding was built by exploring: health self-management; the impact of chronic health conditions; health-related anxiety; care experiences; and transition readiness, to identify the healthcare needs of adolescents with chronic health conditions. Furthermore, the available and received healthcare support was explored: (psychosocial; digital health; and health coaching support) across the transfer of care.

5.1 Characteristics of the participants

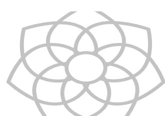
The mean age when diagnosed for all participants (child and adolescent) was 7.3 years, with children being a little older in Finland than in Australia (NCH 9 yrs vs RCH 5.4 yrs). At the New Children's Hospital in Helsinki, Finland, at transfer of care, the mean age was 17.2 years vs 18.3 years at the Royal Children's Hospital, Melbourne, Australia. The characteristics of the participants are summarized in Table 4. The clinical conditions represented across countries were similar apart from the group named "other". In Finland, there were no representatives of these conditions (some rare syndromes, anorexia nervosa and ADHD). (Table 4). For the Finnish participants, the care facilities were evaluated across transition, with most of the participants being treated at the main University Hospital for one and two years after transfer of care. Two years after the transfer of care around 30% of the participants were treated at other hospitals, and only a small percentage (up to 5%) at healthcare centres.

Table 4. Characteristics of participants of the survey studies I, II, and III.

Country	T0 FIN n = 253	T0 AUS n = 259	T1 FIN n = 195	T1 AUS n = 125	T2 FIN n = 166
Sex	n (%)	n (%)	n (%)	n (%)	n (%)
Male	118 (46.6)	133 (51.4)	83 (42.6)	59 (47.2)	97
Female	132 (52.2)	126 (48.6)	110 (56.4)	66 (52.8)	67
Other	3 (1.2)	0 (0)	2 (1.1)	0 (0)	2
Clinical condition					
Cardiology	19 (7.3)	24 (9.3)	15 (7.7)	10 (8.0)	8 (4.8)
Diabetes	92 (36.4)	59 (22.8)	74 (38.0)	22 (17.5)	61 (36.7)
Gastroenterology	45 (17.8)	27 (10.4)	35 (17.9)	18 (14.4)	31 (18.7)
Kidney, liver or Tx	13 (5.1)	27 (10.4)	10 (5.1)	11 (8.8)	15 (9.0)
Neurology	18 (7.1)	62 (23.9)	13 (6.7)	36 (28.8)	40 (24.1)
Rheumatology	66 (26.1)	4 (1.5)	48 (24.6)	2 (1.6)	11 (6.6)
Other *	0 (0.0)	56 (21.6)	0 (0.0)	26 (20.8)	0 (0)
Age at transfer	mean (range)	mean (range)	mean (range)	mean (range)	mean (range)
Years	17.2 (15.3–22.8)	18.3 (16.0–21.1)	18.3 (16.5–22.1)	19.7 (18.3–21.5)	19.8 (17.9–24.2)

FIN = Finland, AUS = Australia, T0 = at transfer of care, T1 one year after transfer of care, T2 = Two year after transfer of care. Tx = Transplant. *= “Other” consisted of some rare syndromes, anorexia nervosa and ADHD.

5.2 Health self-management skills at transfer of care



At both study centres participants' abilities for health self-management showed that around 50% of participants felt confident on issues regarding medication and treatment. Participants had a good understanding of the risks and benefits of treatment and of the use and naming of their medicines. Just under 50% felt confident in their ability to ask about health issues from healthcare personnel, and over 60% were unsure in how to contact the hospital. (study I, FIN/ AUS).

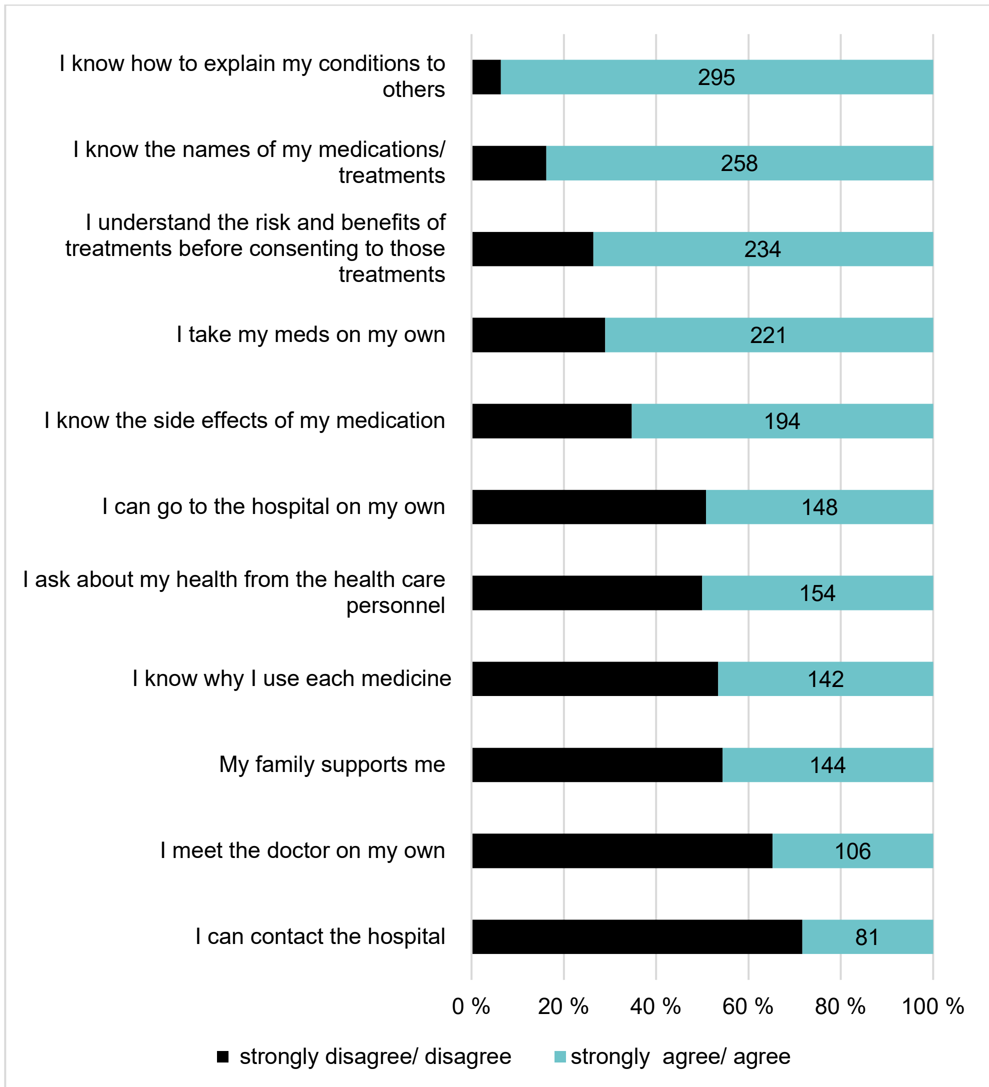


Figure 2. Adolescents' assessments on health self-management before transfer of care at children's hospitals in Finland and Australia. n = 314-321

Around 35% of the participants reported meeting a doctor alone at the children's hospitals, (Figure 2). During the year leading up to the transfer of care, under 50% of the Finnish participants had had discussions on confidentiality aspects of care. Discussions on selfcare stayed at a good level during the transfer of care, (Figure 3).

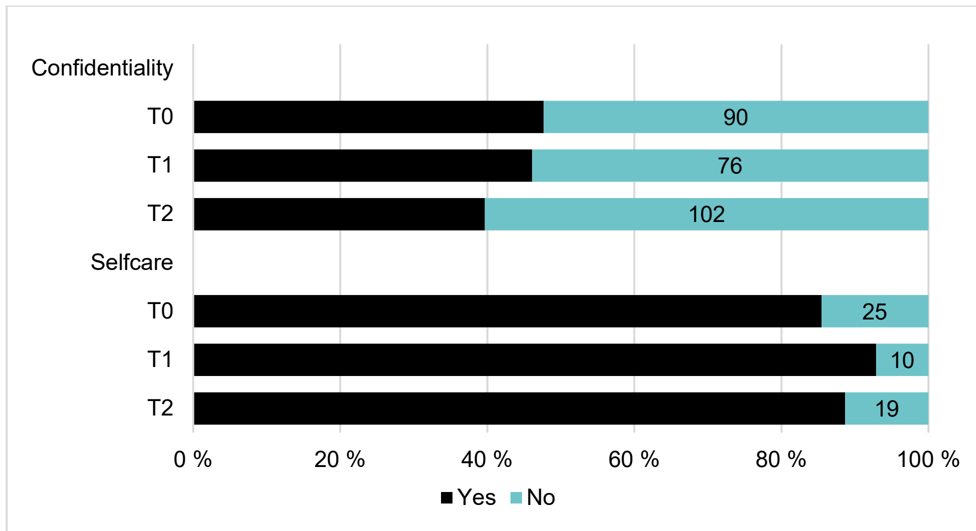


Figure 3. Discussions with healthcare professionals at the main hospital on confidentiality and self-care. T0 = at Children's Hospital, T1 = one year after transfer to adult hospitals, T2 = two years after transfer (Finnish participants n = 163).

5.3 Factors affecting transition readiness

At the children's hospitals around, 65% of the participants answered strongly agree/ agree with the "I am ready" statement, with no statistically significant differences comparing countries. The average mean score for the Am I on TRAC for adult care was 47.2 points (min. 14–max. 56 pts.), with higher scores indicating better transition readiness. The mean transition readiness behaviour scores were high (42.5/55 points, SD 6.8) and at a medium level for transition readiness behaviour (26.7/45 points, SD 4.3). There were no significant differences in average transition readiness mean scores between country and gender. The attributes that supported participants in feeling less anxious for the transfer of care were good health-related knowledge and behaviour, see Figure 5. Participants who had been diagnosed before the age of 12 showed stronger transition readiness knowledge (median= 44, IQR= 9) than participants diagnosed at a higher age (median= 41, IQR= 11) $p < .001$. (study I, FIN/AUS).

Adolescent and parent dyads agreement on transition readiness

The results of the "I am ready statement/My adolescent is ready" showed 42.2% of parent/adolescent dyads answering yes, 17.9% answering no, and 39.6% of adolescents and their parents disagreeing (one answering "yes" and the other " no"). On health self-management questions, the biggest disagreements between

adolescent/parent dyads were on explaining the condition to others, reaching and contacting the hospital independently and meeting the doctor alone (for more information see study I). Regarding anxiety, the disagreement between adolescent/parent dyads reached 45.8%, with parents feeling more anxious and less prepared for the transfer of their adolescent. (Study I, FIN/AUS)

Associations on transition elements

Study I, FIN / AUS measured associations between transition readiness behaviour and knowledge, care-related anxiety, age at diagnosis and age at transfer. The results show that age at diagnosis and age at transfer were only weakly associated with care-related anxiety. At transfer, participants with lower health knowledge- and behaviour skills showed higher care-related anxiety, (Figure 5).

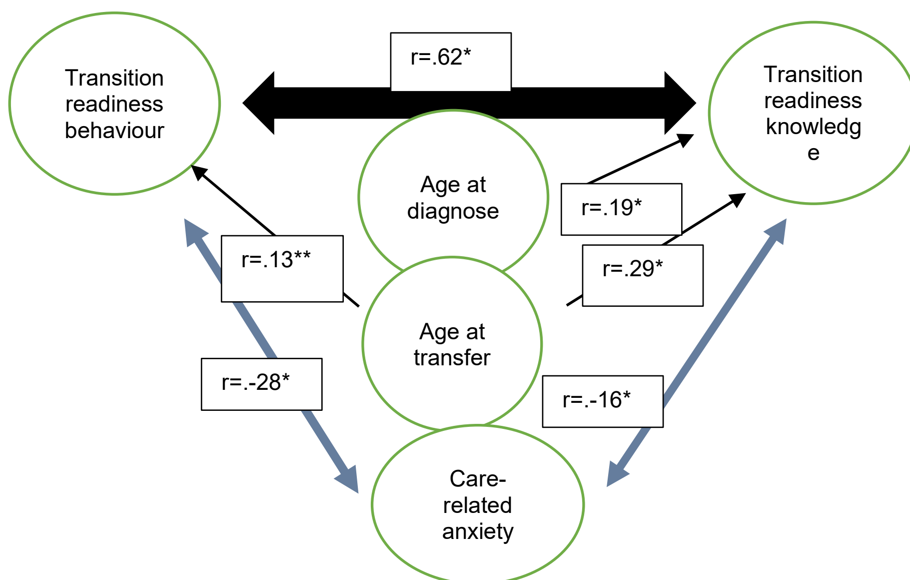


Figure 4. Associations on age at diagnose, age at transfer, transition readiness knowledge and behaviour and anxiety n = 465-430, r = Spearman's correlation coefficient. *p<.001, **p<.01.

Care-related anxiety

At transfer of care, the care-related anxiety levels were normal for all participants in the study (n= 487, mean 36.7/80 SD 12.3, study I, FIN/ AUS). Participants who were diagnosed in their teens reported slightly higher anxiety levels than participants diagnosed before 12 years of age (median 35 vs 33, p= .04). Australian participants had somewhat higher levels of care-related anxiety than the Finnish participants

across transfer (AUS T0 median 36.7, IQR 26.7-50.0/T1 40.0, IQR 26.7-40.0 vs FIN T0 33.3 IQR 26.7-40.0/T1 33.3 IQR 26.7-40.0). Overall, the female participants experienced higher care-related anxiety than males. Furthermore, Australian females reported higher care-related anxiety than Finnish females after the transfer of care (median AUS 43.3, IQR 30.0-53.3 vs FIN 33.3, IQR 26.7-40.0), (Figure 5).

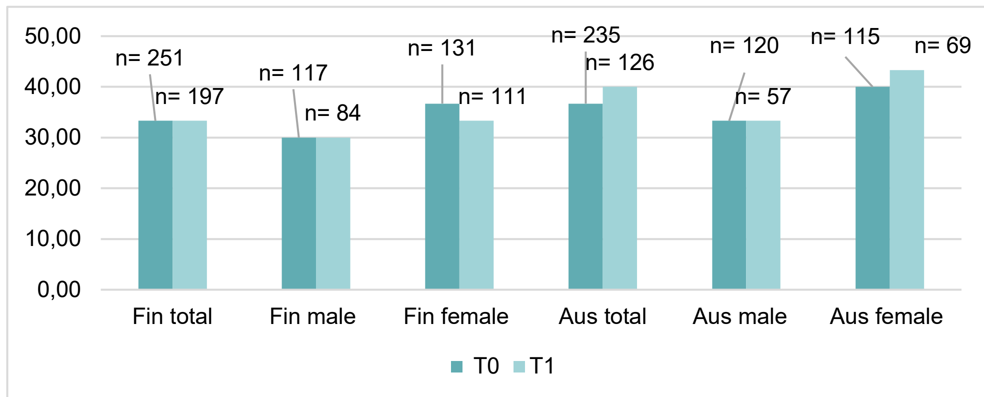


Figure 5. Care-related anxiety levels across transfer of care and countries (median) T0 = at children's hospitals, T1, one year after transfer. Fin = Finland, Aus = Australia, scale 20-80, (the higher the points, the higher anxiety).

For the Finnish participants (n = 163) the care-related anxiety levels for females were higher than for males across the transfer of care (T1 p = .02, T2 p = .003), (Figure 7).

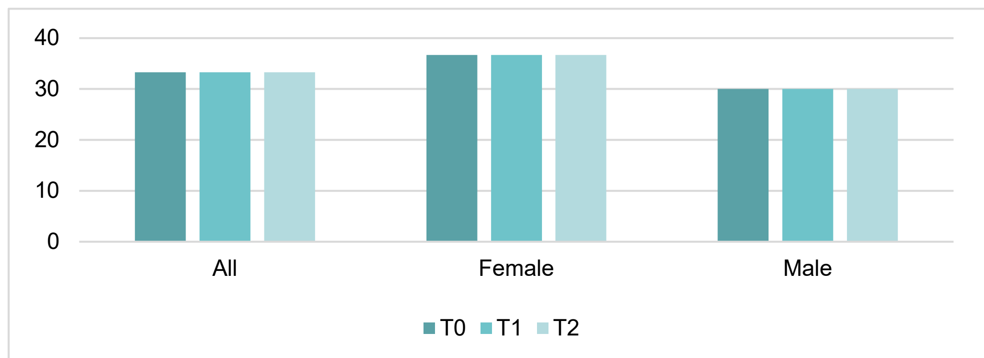


Figure 6. Comparison of median levels of care-related anxiety across transfer of care, Finnish participants. T0 = at children's hospital, at transfer, T1= one year after transfer, T2 Two years after transfer of care. Fin= Finland.

Associations of levels of care-related anxiety after transfer of care

In multiple linear regression model, the results indicate that after transfer of care, low condition impact was associated with lower levels of care-related anxiety (beta -9.00, $p < .001$) than that experienced by participants with high condition impact. The association with anxiety on care experience ($p = .01$) and on low condition impact vs high condition impact ($p < .001$) was statistically significant. Finnish participants experienced lower levels of anxiety than Australian participants (beta -4.8, $p < .001$). The regression model was statistically significant and indicates that care experiences, condition impact, country, and age explain 14 % of the care-related anxiety ($R^2 = 14.0$ %, $F = 8.6$, $p < .0001$), (Table 5).

Table 5. Multiple linear regression model on associations with levels of anxiety after transfer of care.

Independent variable	beta	std.err	Lower 95% CI	Upper 95% CI	p
Care experience	.76	.25	.26	1.26	.01
Condition impact neutral vs high	-3.84	2.46	-8.78	1.1	-
Condition impact low vs high	-9.00	2.51	-13.81	-4.16	.001
FIN vs AUS	-4.82	1.82	-8.41	-1.24	.001
Age after transfer of care	-.26	.75	-1.73	1.21	-

R^2 = 14 %, FIN = Finland, AUS = Australia, St. Err. = standard error, CI = Confidence interval

Changes in care-related anxiety, care experiences and condition impact

In both countries, the differences and median changes in care-related anxiety (FIN T0 = 35.3-T1 = 34.1 / AUS T0 = 38.6-T1 = 40.0), care experiences (FIN T0 = 10.1-T1 = 10.0/AUS T0 = 10.0-T1 = 10.5) and self-reported condition impact (FIN T0 = 5.2 -T1 = 5.1/AUS T0 = 5.1-T1 = 5.0) were largely unchanged across the transfer of care. Also, the impact of the condition on the everyday life of the participants stayed mostly unchanged across transfer of care.

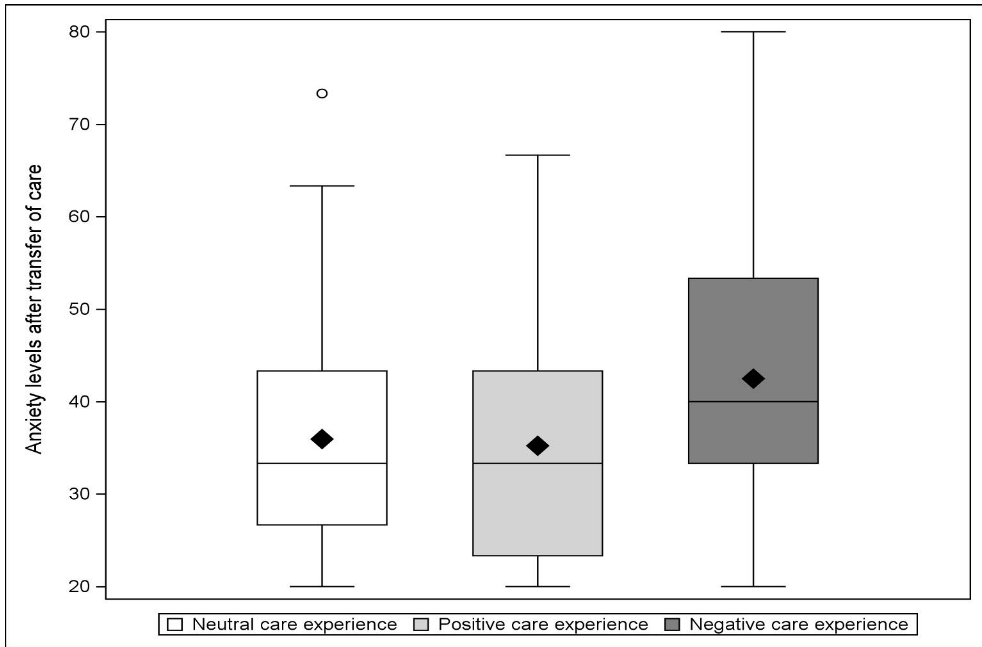


Figure 7. Associations on care-related anxiety and care experiences after transfer of care.

Negative care experiences were associated with higher anxiety levels (median 40.00 IQR 33.3-53.3) compared to positive care experiences (median 33.3 IQR 23.3-43.3) after transfer of care (Figure 7).

In study II (FIN/AUS) assessments by clinical condition, the care experience and care-related anxiety levels after the transfer of care found similarities across countries, (Figure 8). These findings, despite different chronic health conditions and care cultures, indicate that adolescents with chronic health conditions have fundamental common needs. For the Australian group "other" (n = 24-26), the level for care-related anxiety was is a bit higher than for the remaining diagnosis groups but care experience was 9 points, which is in line with the remaining diagnosis groups.

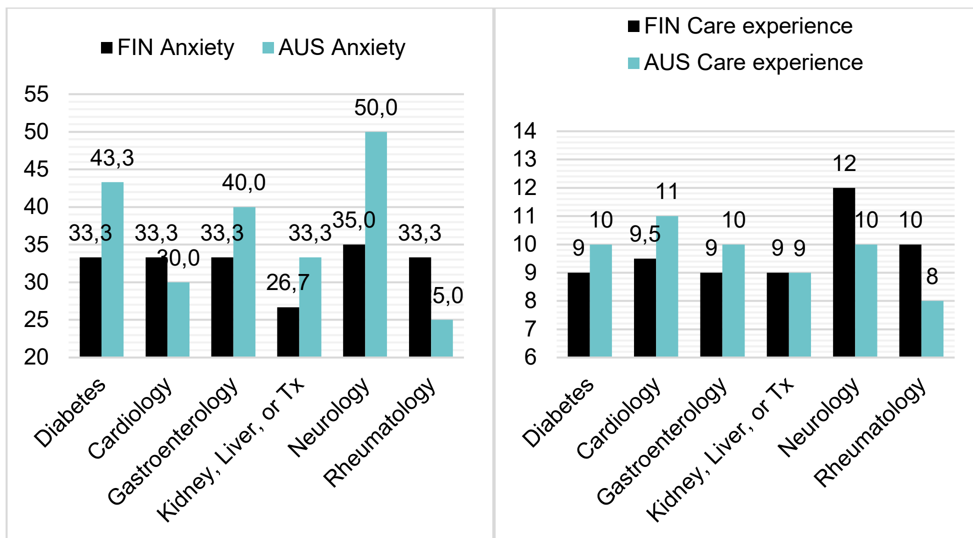


Figure 8. Care experience and care-related anxiety levels after transfer of care by diagnosis and country. Care experiences (scale 8-24), lower points describe positive care experiences. Care-related anxiety levels (scale 20-80) lower points describe lower anxiety levels. FIN = Finland, AUS = Australia. **Care experience**; FIN Diabetes n = 92, Cardiology n =19, Gastroenterology n = 45, Kidney, liver, TX n = 13, Rheumatology n = 66, Neurology n = 18, AUS Diabetes n =59, Cardiology n =24, Gastroenterology n = 27, Kidney, liver, TX = 27, Rheumatology n = 4, Neurology n = 62. **Anxiety;** FIN Diabetes n =75, Cardiology n =16, Gastroenterology n = 35, Kidney, liver, TX n = 9, Rheumatology n = 49, Neurology n = 13, AUS Diabetes n=23, Cardiology n =10, Gastroenterology n = 19, Kidney, liver, TX n = 13, Rheumatology 2 = Neurology n = 33.

5.4 Assessment of psychosocial aspects across transfer of care

After transfer from the Children's Hospital (Finland), the care continued for the large majority at the main University Hospital (T0 n = 158, T1 and T2 n = 99). For some participants, care was transferred to other hospitals in Finland (T1 n = 32 and T2 n = 50). Transfer of care to Healthcare Centres remained very low (max T2 n = 8). Assessments of received psychosocial discussions with healthcare professionals during the previous year were at a suboptimal level across transfer of care (the Finnish cohort, n = 163).

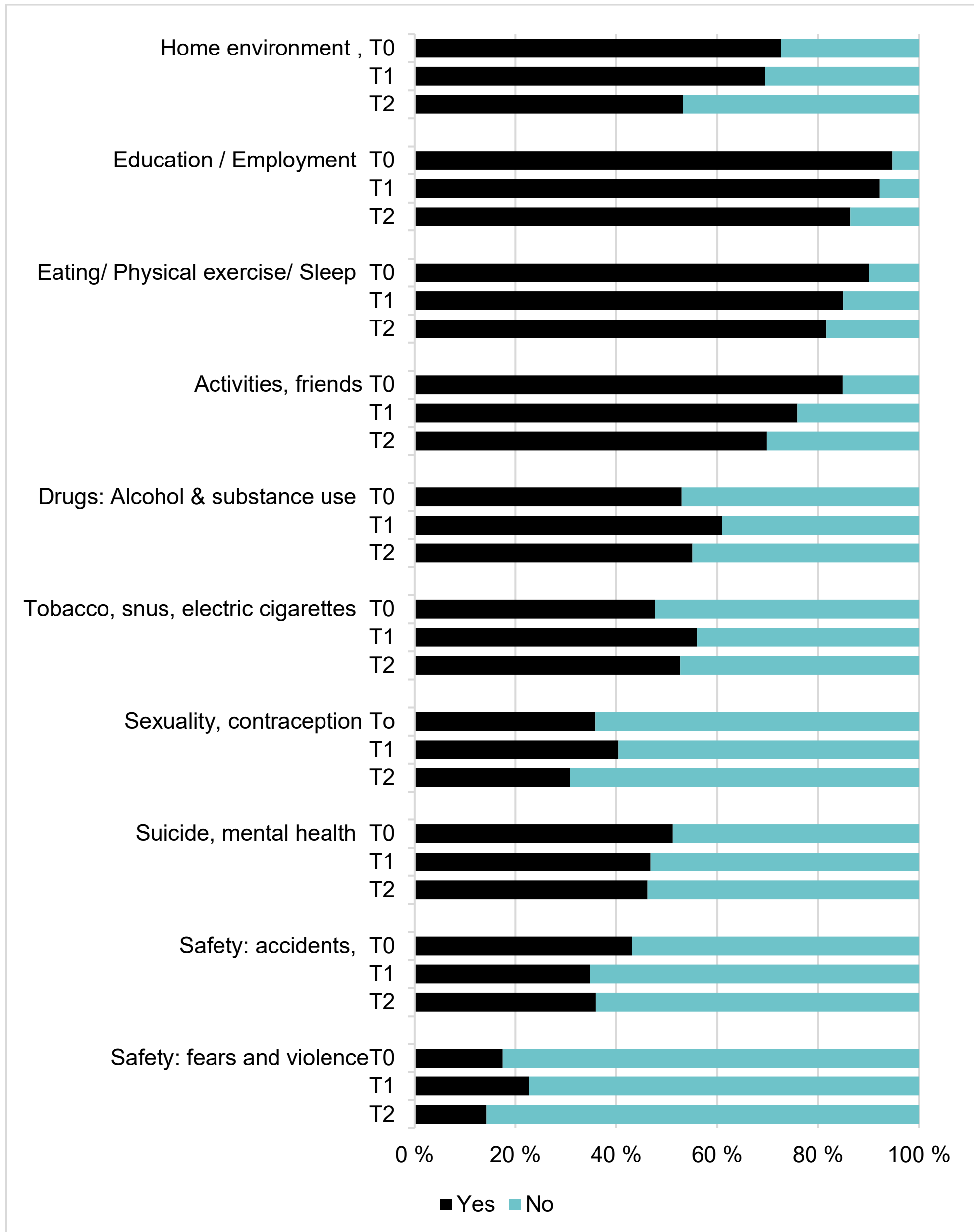


Figure 9. Evaluation of received discussions on HEEADSSS topics during transition at the main hospital. T0 = at transfer of care, T1 = one year after transfer of care, T2 = Two years after transfer of care.

At the main hospital, there were only slight differences in activity on discussing psychosocial aspects by health profession (physician, nurse, other). When asking the participants about the received discussions with healthcare professionals outside the

main hospital (other hospital, healthcare centre, educational/vocational health, online), the most active discussions on psychosocial aspects were at the educational/ vocational healthcare services. The participants reported next to no online discussions during transition with healthcare professionals, (See study III, Finnish cohort). Furthermore, less complex psychosocial issues such as home, life habits, friends and activities were quite well addressed, while more difficult subjects (sexuality, safety and fears) received less attention. The most active discussions were held at the children's hospital, with a constantly declining trend one and two years after transfer, (Figure 9).

5.5 Use of digital health services

At the New Children's Hospital, in Helsinki (Finland), the participants' had a low usage of digital health services, but the use rose one and two years after transfer to over 60% utilisation. Participants believed they knew how to find trustworthy health information online, and they reported being active on social media (study III, FIN, T0, TI, TII), (Figure 10). Participants did not have any particular wishes for digital health services other than they wanted them to be safe, confidential and easy to use.

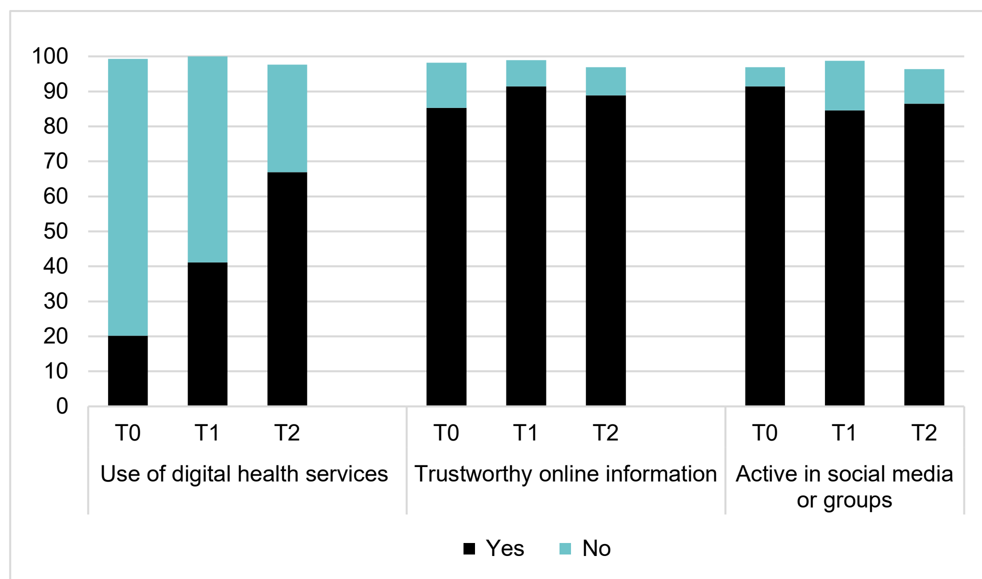


Figure 10. Use of digital health services and social media across transfer of care. T0 = At children's hospital, T1 = One year after transfer of care, T2 = Two years after transfer of care. Percentages.

5.6 Exploring digital transition health interventions

The systematic review gathered data on digital services for adolescents with a chronic health condition and on the health coaching elements used during the transition of care. The review explored the coaching and the transition elements included in the services (see study IV, table 3). All digital interventions had: elements of human support; some form of interactive features (messaging, phone calls, online meets); and social support provided by healthcare professionals. An educational element that targeted health outcomes was present in all of the interventions. The coaching elements in the included interventions were partly undefined, and they had many differences. Furthermore, the transition elements varied greatly.

The coaching elements identified were human support, interactive means and social support. Most of the interventions were built using a theoretical base on either psychoeducational, behavioural- or cognitive theories. The coaching element was often designed to both help motivate and support the adolescent users and also to enable the interactivity of the interventions (Figure 11).

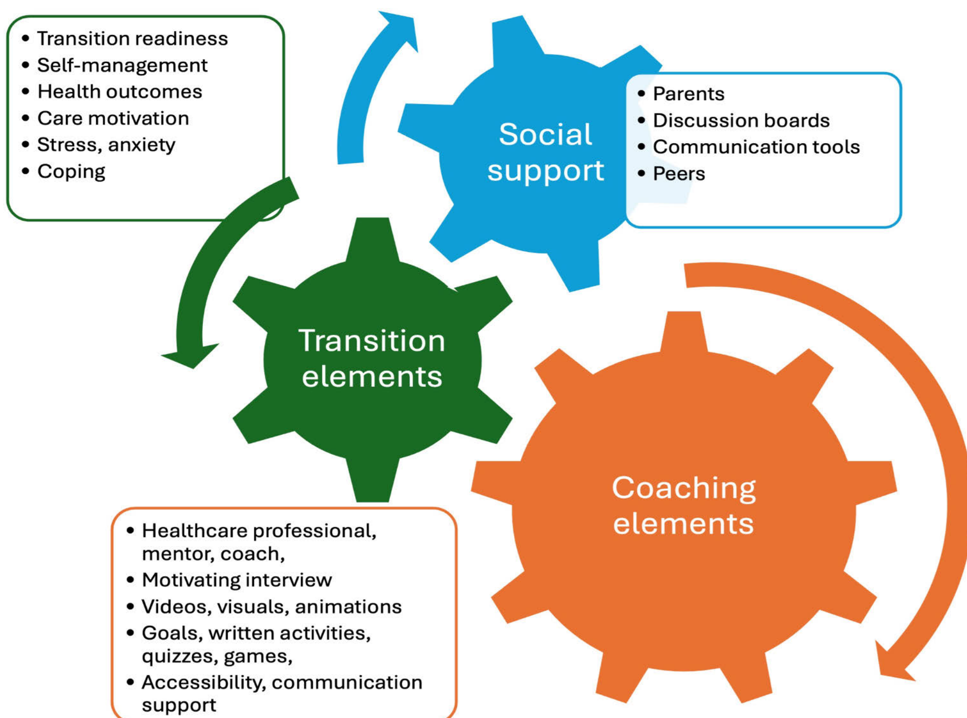


Figure 11. Identified coaching and transition elements in digital health services.

Summary of key results

Results on **healthcare needs** of adolescents with chronic health conditions during transition.

- ❖ Adolescents need support when discussing health self-management issues with healthcare professionals
- ❖ Time alone with doctors and discussions on confidentiality were at a suboptimal level
- ❖ Good health knowledge and behaviour was associated with better transition readiness
- ❖ High condition impact and negative care experiences were associated with higher care-related anxiety

Results on the **support** of adolescents with chronic health conditions during transition

- ❖ Adolescents reported low levels of psychosocial discussion throughout transition of care, with a declining trend one and two years after transfer.
- ❖ Use of digital health services was low at the transfer, even though online activity was common, there was next to no contact through online services with healthcare professionals
- ❖ Transition and health coaching elements are used with wide diversity, length of interventions, dose and outcome measurement differed greatly
- ❖ Digital interventions with health coaching elements were effective
- ❖ The most effective digital health interventions for adolescents are still partially undefined

6 Discussion

6.1 Chronically ill adolescents' needs during transition

The largely positive results of this study at two study sites, despite different care cultures, show that adolescents across different chronic health conditions have universal generic needs across transfer. A generic approach focuses on factors that are important for the everyday life of adolescents, such as psychosocial, psychological and social functioning (Bomba et al., 2017; Schmidt et al., 2020, 2016). The Finnish and Australian health systems have some basic similarities such as the publicly funded healthcare systems and that chronic diseases are mostly taken care of at the main hospitals. While there are differences such as the general upper age of paediatric care (FIN 16 / AUS 19) and the transition support services available, the positive results at both study centres across transfer of care suggest potential adaptability of effective care practices. Chronically ill adolescents (12-25 years) require comprehensive transition programs that take into consideration physical, psychological and social development along with continuity in care (Schmidt et al., 2020; Varty et al., 2020).

The results of this study showed that participants felt confident in understanding their condition and treatment decisions, also they knew the names of the medications and were able to independently take medications. However, they needed support in raising health issues with healthcare professionals. Furthermore, they were unsure of the reasons why each medicine was prescribed and of any possible side effects. They also felt they needed support in reaching and contacting the hospital independently. Previous research shows that disease-related skills and knowledge are often understood by adolescents with chronic conditions but are not always transferred into daily life practices (Grabowski & Rasmussen, 2014). Therefore, communication at an age-appropriate level is important to make certain that the information presented is understood (Mehus et al., 2023). Furthermore, the results suggest that parents felt confident about the health self-management abilities of their child. Reviews on health self-management highlight the importance of patient engagement and collaborative care for a positive impact on health self-management. However, there are gaps in research on adolescent health self-management (Lozano et al.,

2018; Smith et al., 2021). The long-term health outcomes of chronic diseases rely on disease awareness, and the capacity of the individual to pursue self-care and self-management (Ghasemiardekani et al., 2024; Smith et al., 2021). In line with previous research this study suggest that adolescents need encouragement to raise questions that are important to them (T. Allen et al., 2022; Bomba et al., 2017; J.-C. Suris & Michaud, 2004).

At both study centres adolescents reported positive care experiences both before and after the transfer of care. However, after the transfer of care, the results indicate that participants who reported a high impact of chronic health conditions also reported negative care experiences. Physical health metrics for chronic conditions traditionally guide care plans and guidelines for care (Nardini et al., 2021). Still, less frequently the adolescent's personal care experiences and the impact a condition has on their everyday life are used to guide care plans and support positive health outcomes (Ghasemiardekani et al., 2024; Puolanne et al., 2017; Van Staa & Sattoe, 2014). Furthermore, the subjective experience of the impact of chronic health conditions on everyday life is central for providing personalised care that forms the base for health self-management (Lozano et al., 2018; Puolanne et al., 2017).

Over half of the participants reported not meeting the doctor alone (FIN/ AUS) and not having discussions on the confidentiality aspects of care across transfer (FIN). When a child is under the age of reaching maturity (18 years), the confidentiality aspect of care needs special attention as healthcare professionals must navigate communication both between the parent and the youth (Chung et al., 2024).

Confidentiality is an important element of high-quality care and impacts care experiences and health outcomes (Chung et al., 2024; Ford et al., 2004). Meeting adolescents alone and enabling confidential discussions are important factors in gaining the trust of adolescents and in addressing personal concerns and sensitive information (Ford et al., 2004; Mehus et al., 2023). Adolescent-friendly care presents opportunities to ensure confidentiality and conduct psychosocial assessments (Crossen, 2017; Waller et al., 2023). Strong consistent adolescent-centred communication is important to support adolescents during the transition of care and strengthen their care experiences (Leung et al., 2021). For fruitful conversations with healthcare professionals, adolescents want to be active participants and feel respected and heard (Ambresin et al., 2013; Hanghøj et al., 2020). Healthcare professionals may need support in talking with adolescents to reach a better understanding of the adolescents situation and to provide adolescent-friendly care (Leung et al., 2021).

In this study, the parents of the participants were less confident in their adolescents being ready for transfer. Previous research indicates that parents have concerns regarding the growing independence of their adolescents, their health, self-management skills and readiness. Therefore, the parents need to be supported to hand

over the responsibility and respect the confidentiality aspect of care of their child (Colver et al., 2017; Thomsen et al., 2022). Parents wish for greater involvement in the transition process, and voice a need for inclusive communication, to help move the responsibilities to the adolescent and influence a successful transition (Coyne et al., 2017; Thomsen et al., 2022).

Care-related anxiety

Previous research shows that adolescents with chronic health conditions have an increased risk for higher levels of anxiety than their healthy peers (Cobham et al., 2020). In this study, the participants who experienced: feeling unprepared for transfer of care; having negative care experiences; and having a higher impact on their condition; reported higher care-related anxiety levels. Adolescent girls showed higher care-related anxiety levels than boys, both in Australia and Finland. Higher anxiety levels for adolescent females than males comply with previous research (McLean et al., 2011). A lack of psychosocial support may lead to feelings of anxiety, and anxiety may have a negative influence on transition readiness (Rutishauser et al., 2011; Traino et al., 2022). Parents reported slightly higher anxiety levels than their adolescents, as is consistent with previous findings (Peeters et al., 2014).

Transition readiness

The findings of this study suggest that participants reported feeling prepared for the transfer of care, and the transition readiness scores were at a good level (mean 47.2/ 56 points) at the children's hospitals at both study centres. The transition readiness knowledge scores were high, while the behaviour scores were at a medium level at the children's hospitals. Prior literature indicates that educational aspects are strongly connected with: the process of reaching autonomy; health self-management; and transition readiness (McManus & White, 2017). Systematic transition programs, good communication, disease awareness, and the ability to engage in selfcare, all promote transition readiness of adolescents with chronic health conditions (Chapados et al., 2024; Kim & White, 2018; Mehus et al., 2023).

In this study the participants who had been diagnosed before the age of 12 scored slightly better transition readiness knowledge scores. According to clinical guidelines, the transition process is recommended to commence when children reach 12 years of age (Leeb et al., 2020; McManus & White, 2017). The results indicates that readiness need to be evaluated through assessments on knowledge and behaviour, rather than on age alone- especially for adolescents with a condition that has high impact on everyday life or who have high levels of care-related anxiety. For adolescents with complex health conditions, the transfer of care should also consider

multiple care factors (Chapados et al., 2024; Hunt & Davis, 2017; Moynihan et al., 2015; Zhang et al., 2014). Previous research shows that stronger psychosocial functioning (Chapados et al., 2024) and greater transition knowledge and health self-management skills were associated with better transition readiness (Uzark et al., 2015; Van Staa & Sattoe, 2014).

6.2 Chronically ill adolescents received support

Psychosocial aspects of care

The results showed that lighter topics (such as home, education and activities) from the psychosocial HEEADSSS interview guide were fairly well addressed at the New Children's Hospital (Finland). However, there was a declining trend in the activity of discussions with healthcare personnel, both one and two years after the transfer. Furthermore, discussions on more complex subjects (risky behaviour, sexual identity, alcohol and drug use) were at a suboptimal level across the transfer.

Research shows that both adolescents, their parents and healthcare professionals voice a need for support to confidential discussions on complex issues; mental health, substance use, reproductive and sexual health (Bogart et al., 2024; Engelen et al., 2020). To reach an understanding of the environment the adolescents live in, and to understand the health-behaviour and views of adolescents, the psychosocial aspects of their lives need to be taken into consideration (Berkelbach van der Sprenkel et al., 2022; Leung et al., 2021). Previous research shows that adolescents who report stronger social and emotional well-being were more likely to master health self-management skills (Chapados et al., 2024). Adolescents expect emotional aspects and anxieties to be acknowledged in care, as well as social relationships and family issues (Bonanno et al., 2019). Adolescents' psychosocial skills need to be assessed early (Chapados et al., 2024; Korell et al., 2024), and continuously through the transfer by starting at the age of 12 at the children's hospital and leading up to early adulthood at around 25 years of age at adult healthcare facilities (American Academy of Pediatrics et al., 2002).

Psychosocial skills (considering physical, psychological and social factors) may be regularly measured through self-reported assessments. Research shows that chronic health conditions may have a negative impact on psychosocial well-being of individuals and thus, result in lower quality of life (Berkelbach van der Sprenkel et al., 2022; WHO, 2023). Therefore, by integrating psychosocial support into healthcare, adolescents who are in higher need of support can be recognised. This could yield positive results on their health outcomes and care experiences.

Use of digital health tools

The participants reported very low levels of use of digital health services at the New Children's Hospital (Finland). However, the usage did rise slowly, reaching 60 % two years after the transfer of care. Adolescents did not have any particular requirements for digital health services other than for them to be secure and easy to use. Furthermore, the participants, in line with current research, were very active on social media (Lupton, 2021).

The results of the systematic review showed that for adolescents, digital interventions with coaching elements had a positive impact on communication, motivation and support for health self-management. Furthermore, active participation and peer support showed a positive effect on transition outcomes.

Psycho-educational digital interventions have demonstrated advancements in the health behaviour, problem-solving and health self-management of adolescents with chronic health conditions (Grey et al., 2014; Palermo et al., 2016; Whittemore et al., 2016). The results of this study indicate, that the health behaviour and the psychoeducational aspects of care were improved by the coaching elements of the digital health interventions. The role of the online coach is to increase the educational features of the digital health services, by for example emphasising information, notifications and reminders of postings. Furthermore, digital health coaching services need to address the psychological adjustment to a chronic illness, be comprehensive and meet the individual needs of adolescents with chronic health conditions.

Digital interventions as part of usual care may provide chronically ill adolescents with efficient and accessible care. Still, there is restricted evidence on the efficiency of digital health interventions for youth with chronic health conditions (Domhardt et al., 2021; Li et al., 2024). Digital interventions are to be tailored to the adolescents' needs, and should include a coaching element to improve health outcomes and provide personal and motivating health services. Health coaching shows positive results and may be an integral part of future digital healthcare.

The complex process of gaining independence; changes in educational or vocational settings; peer support; and social environment are important factors that affect health for adolescents in transition. Health self-management interventions for adolescents with chronic health conditions are shown to have beneficial effects on well-being, by increasing health knowledge and self-management behaviour. Educational, skill-based interventions that assess the psychological well-being of adolescents have shown some positive outcomes(Sansom-Daly et al., 2012; Santos et al., 2016).

Validity and Reliability of the study

The relevancy and validity of the results of the cross-sectional and longitudinal studies were supported by the similarities of the publicly subsidized healthcare systems in Finland and Australia. Public funding reduces financial barriers that could affect care accessibility. Data were collected in two countries by validated- and self-reported measures across different chronic conditions and spanning over the transfer of care. The Am I ON TRAC for Adult Care (ON TRAC) survey is a validated psychometrically sound measure that was used to assess transition readiness (Moynihan et al., 2015) and the validated State-Trait Anxiety Inventory short form (STAI-6) (Marteau & Bekker, 1992) were chosen for reliability and validity. The used surveys were forward and backward translated for validity, apart from the STAI 6 and the HEEADSSS interview guide as the validated versions (Finnish and Swedish) already exist. The introductory question to the STAI-6 form was altered to imply how adolescents and their parents assessed care-related anxiety during the transition. It is noted the introductory text varied, at transfer, it read, "How anxious are you about the transfer of care?" and after the transfer, "How anxious are you about your care?" We have no means to decipher if the variation of the introductory text affected the reliability of the answers. Self-reported measures were used to make certain the individual experiences of the adolescents in transition were present (Puolanne et al., 2017; Van Der Lee et al., 2007). Furthermore, the younger age of the participants at the children's hospital may contribute to the low use of digital health services, and affect the validity of the result. For transparent reporting, we followed the STROBE guideline for the cross-sectional and longitudinal studies (Von Elm et al., 2008).

The validity of the systematic review was supported by following the Cochrane Handbook for Systematic Reviews of Interventions. Due to resource limitations, the selection process (titles and abstracts) was done only by one researcher (AA), which may contribute to selection bias. Furthermore, the time frame of ten years for the included studies may have excluded some relevant earlier research. The Preferred Reporting Items for Systematic Reviews and Meta-analyses Statement (PRISMA) was used for transparent reporting (Moher et al., 2009). The assessment of the risk of bias in the included studies focused on the internal validity of the studies and strived to achieve reliable conclusions of the results (Higgins et al., 2011). The risk of bias assessment resulted in a low or unclear risk of bias. Furthermore, the GRADE tool was used to systematically assess the certainty of the evidence for transition outcomes of the included studies resulted in evidence being moderate to low (for more information, see study IV. Table 1).

Strengths and limitations of the study

The strengths of this study were that it consisted of longitudinal data from two countries and that it covered participants across different chronic health conditions. To reach an understanding of the youth's views at transition, assessments of self-evaluated care experiences and condition impact were conducted (Puolanne et al., 2017; Van Der Lee et al., 2007). Adolescents with chronic health conditions were included to participate in the evaluation of the surveys. To our knowledge, international longitudinal transition research is scarce. Research that has been carried out on digital health interventions in transitional care shows wide-ranging interventions that often have small sample sizes (Domhardt et al., 2021). Digital health interventions for adolescents with chronic health conditions that include health coaching elements, are still scarce, and the studies which were included for the systematic review resulted in highly varied interventions.

The two study centres pose some limitations due to differences in their systemic and administrative systems. For example, variances in electronic health records displayed some difficulties in the data collection, as there was only access to the Finnish electronic patient record system. The Ethics Committee for Women's and Children's Health and Psychiatry at the Helsinki University Hospital in Finland required an alternation to the ON TRAC questionnaire, which changed the scoring and the designated cut-off scores of the questionnaire could not be used. This may have led to a decrease in differentiation between groups. Furthermore, the self-reported measures might be prone to recollection bias as the participants were asked to assess if the HEEADSSS topics had been addressed throughout the previous year. There was some loss of participants, especially two years after the transfer of care was completed (FIN T0 n = 253, T1 n = 195, T2 n = 166/ AUS T0 n = 259, T1 n= 125, T2 n = 0). Data collection during COVID-19 exposed challenges and may have contributed to data loss; Study III only assessed the Finnish participants as the Australian participants was too small to include. Also, there were no means to explain the differences in health-related anxiety between the countries. It must be noted that the COVID-19 restrictions were more severe in Australia and also, that the Australian adolescents were older at transfer. Both of these circumstances may lead to higher anxiety levels as they experience more responsibilities in their lives.

As the included studies of the systematic review were of small samples, varied measurements and dose, it was not possible to reach extensive conclusions nor to carry out a meta-analysis. The GRADE criteria help to support transparency, consistency and accuracy in evaluating the certainty of evidence (Guyatt et al., 2008; Prasad, 2024). However, using the GRADE tool on the coaching outcomes was not viable due to the variability of the methods used.

6.3 Suggestions for future research and practical implications

Suggestions for future research:

This study increased awareness on adolescents' needs and support during transition. There is still a need for further research on these topics, and the following recommendations are identified:

- The demonstrated results on associations between age, transition readiness, care-related anxiety, care experiences and condition impact were based on one quantitative cross-sectional and one longitudinal study. Further research confirming the associations on measurements of adolescents' needs and support is called for to strengthen and define person-centred care during transition.
- The most effective way of introducing psychosocial support into care needs to be further explored, with research including interventions with psychosocial support available at an early age, enabled by time alone with doctors and having a confidential aspect in care. Research, including parents and peers is essential, as they provide important support for adolescents with chronic conditions in transition.
- Further research is needed to assess adolescents' use and views on digital health tools and to explore the benefits of digital health interventions for adolescents with chronic health conditions who are going through transition.
- The digital health coaching elements that were presented were recognised through the systematic qualitative analysis of data gathered from the systematic review. The results showed positive outcomes from interventions with coaching elements for patient engagement and health self-management. Further research is needed to define the most effective coaching elements. Coaching elements need to be integrated into transitional care both at appointments and through digital services. Therefore, research defining the most effective health coaching elements is called for.

Practical implications:

The results of this study yield the following practical implications for promoting transitional care for adolescents with chronic health conditions, (Figure 12):

- Tailored transition interventions, starting by the age of 12 years, encompassing psychosocial aspects and goal-driven care, may improve transitional care.
- Person-centred care can be reached by measures on: self-reported condition impact; care experiences; care-related anxiety; transition readiness; and psychosocial aspects in care. Furthermore, an increased focus on confidentiality and person-centred care helps identify adolescents who have the highest need of support and promotes health-related quality of life.
- Healthcare professionals need support in communicating with adolescents and in raising difficult topics. Discussions on psychosocial aspects need to be started early, making it easier and more natural to discuss difficult topics. Furthermore, the confidentiality of care needs to be evident for the adolescents to build trust and to have respectful communication with their healthcare professionals.
- Digital interventions as part of usual care may provide chronically ill adolescents with efficient and accessible care. Digital health interventions are to be tailored to the adolescents' needs, and should include coaching elements to improve health outcomes, provide personal support and motivating health services. Health coaching shows positive results and may be an integral part of future digital healthcare.

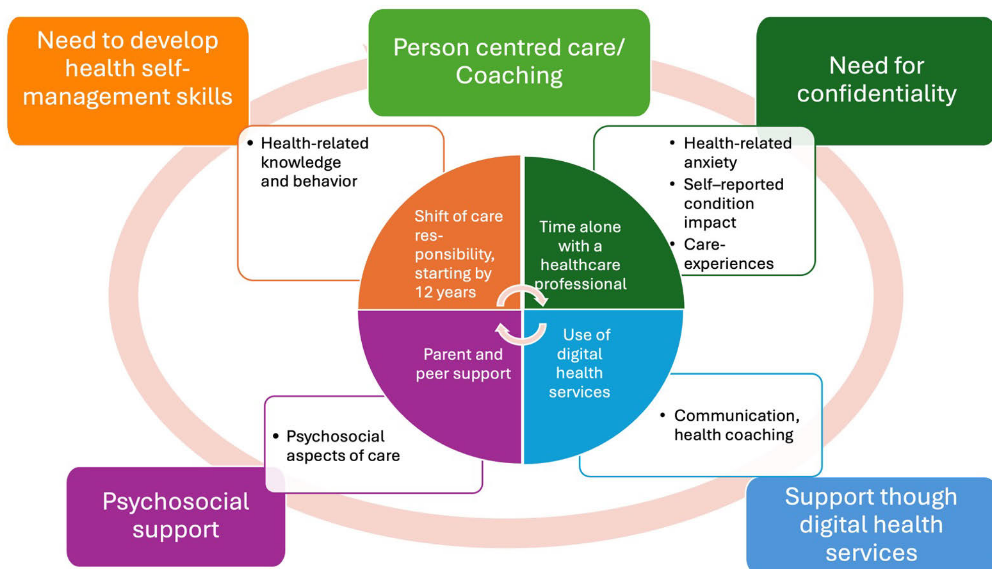


Figure 12. Practical implications for providing person-centred care with health coaching based on the healthcare needs and support for adolescents with chronic health conditions during transition of care.

7 Conclusions

This study shows that transition support for adolescents with chronic health conditions needs to be carefully tailored and timed, and should be integrated into both the paediatric and adult healthcare systems. For these adolescents who experience care transition, the complex process of gaining independence, along with changes in educational or vocational settings and social environment, are important factors that affect health. Therefore, holistic health self-management interventions, based on the healthcare needs, to support increased health knowledge and improve health behaviour, are needed.

The results of this study show that good health knowledge and positive health behaviour were associated with lower levels of care-related anxiety at the children's hospital. Adolescents who had been diagnosed before the age of 12, showed slightly higher health-related knowledge, than adolescents being diagnosed at an older age. Therefore, the transition process is to be started at an early age for the adolescents to leverage the acquired knowledge and benefit from it. Transferring disease-related skills and knowledge into everyday life practice is challenging, and adolescents need support to discuss health-related issues with healthcare professionals. Time alone with doctors and discussions on confidentiality were at a suboptimal level during transition. Consequently, well-timed and carefully tailored transition support for adolescents with chronic health conditions is needed

The results suggest that high condition impact and negative care experiences were associated with higher care-related anxiety during transition. Hence, an increased focus on confidentiality and person-centred care helps identify adolescents who have the highest need of support. Furthermore, individualised goal setting may be a significant element for improving transition support and health outcomes. Coaching elements may increase the possibilities of individual goal setting and personal care during transition. Thus, coaching elements need to be integrated into transitional care both at appointments and through digital services.

As many different digital platforms compete for adolescents' attention, digital health interventions need to be well-integrated into care, be easy to use, be personalised and need to show potential to engage and to motivate health self-management among adolescents. However, exclusively youth-focused interventions

are insufficient for improving health self-management. Therefore, to reach more efficient transitional care, further research on digital health solutions, psychosocial care collaborative personalised care, peer support, and health coaching elements is needed.

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Helsinki, May 8th, 2025
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List of Figures, Tables and Appendices

Figures

Figure 1. Transition of care. 18
Figure 2. Adolescents' assessments on health self-management before transfer of care at children's hospitals in Finland and Australia 40
Figure 3. Discussions with healthcare professionals at the main hospital on confidentiality and self-care 41
Figure 4. Associations on age at diagnose, age at transfer, transition readiness knowledge and behaviour and anxiety 42
Figure 5. Care-related anxiety levels across transfer of care and countries 43
Figure 6. Comparison of median levels of care-related anxiety across transfer of care, Finnish participants.......................43
Figure 7. Associations on care-related anxiety and care experiences after transfer of care. 45
Figure 8. Care experience and care-related anxiety levels after transfer of care by diagnosis and country 46
Figure 9. Evaluation of received discussions on HEEADSSS topics during transition at the main hospital. 47
Figure 10. Use of digital health services and social media across transfer of care 48
Figure 11. Identified coaching and transition elements in digital health services 49
Figure 12. Practical implications for providing person-centred care with health coaching based on the healthcare needs and support for adolescents with chronic health conditions during transition of care 59

Tables

Table 1. Transition readiness tools. 20
Table 2. Aim, design and methods of studies I-IV. 28
Table 3. Flowchart and data of survey studies I, II and III 32
Table 4. Characteristics of participants of the survey studies I, II, and III. 39
Table 5. Multiple linear regression model on associations with levels of anxiety after transfer of care. 44

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