


Transition readiness and anxiety among adolescents with a chronic condition and their parents: A cross-sectional international study

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Abstract

Aims: To evaluate associations of age, transition readiness and anxiety in adolescents with chronic conditions and to compare perceptions of adolescents and their parents regarding health self-management and transition readiness.

Design: Cross-sectional international study, reported following STROBE guidelines.

Methods: Adolescents and young adults ($N = 512$, mean age 17.7) with a chronic medical condition and their parents ($N = 322$) from Finland and Australia. Data were collected through surveys (between September 2017 and December 2020).

Adolescents reported the duration of their condition. Age at survey was defined by the response date of the questionnaires. Validated questionnaires were used to measure transition readiness (Am I ON TRAC? for Adult Care) and anxiety related to transition of care (State-Trait Anxiety Inventory short form). Perceptions of health self-management and transition readiness were compared in adolescent/parent dyads. Associations were explored using Spearman's correlation.

Results: Duration of condition and age at survey correlated weakly with transition readiness knowledge and behaviour. Higher transition readiness knowledge scores correlated with higher behaviour scores. Higher transition readiness behaviour scores were associated with lower levels of anxiety. Adolescents were less anxious than their parents and adolescents and parents mostly agreed about health self-management and transition readiness.

Conclusion: Transition readiness should be determined by an assessment of knowledge, self-management and psychosocial skills instead of age alone. Further research should address how well transition readiness predicts positive health outcomes after the transfer of care.

Implications for Patient Care: Transition readiness and self-management skills should be formally assessed because positive feedback may decrease the anxiety of both adolescents and their parents regarding the transfer of care.

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Reporting Method: We have adhered to the STROBE statement, using STROBE checklist for cross-sectional studies.

Patient or Public Involvement Statement: No patient or public involvement.

Trial and Protocol Registration: [ClinicalTrials.org](https://clinicaltrials.org) NCT04631965.

KEYWORDS

adolescent, anxiety, chronic disease, cross-sectional study, nursing, parents, transfer of care, transition readiness, transition to adult care

1 | INTRODUCTION

Advances in healthcare continue to improve the life expectancy of children with chronic health conditions (Sawyer et al., 2019). Over 10% of contemporary adolescents live with a chronic condition requiring some form of regular medical attention and follow-up as adults (Jin et al., 2017). During adolescence and young adulthood, the onus of responsibility for healthcare gradually shifts from parents to young people, which requires adolescents to have knowledge and skills for health self-management. During this period, the site of care coordination also commonly shifts from specialist paediatrics to specialist adult services. The timing of transfer to adult services differs between countries (Sawyer et al., 2019) and occurs simultaneously with other life transitions such as completing school, leaving home and entering employment (Hunt & Davis, 2017).

2 | BACKGROUND

Adolescents with a chronic condition benefit from comprehensive and coordinated transition programs where they acquired the necessary skills and knowledge that they need to self-manage their health. Unsuccessful transition of care can have adverse effects on disease outcomes, increase the need for emergency medical healthcare, and reduce independence and educational opportunities (Leeb et al., 2020; Patton et al., 2016).

Clinical guidelines recommend that healthcare providers commence the transition process when adolescents reach around 12 years of age (Leeb et al., 2020; McManus & White, 2017). Previous research suggests that, besides age, the transfer of care should consider other factors as well, especially among adolescents who have complex health conditions (Hunt & Davis, 2017). Age at transfer is still a controversial factor, often determined by institutional rules rather than through an evaluation of transition readiness (Kerr et al., 2017).

Transition readiness describes the knowledge, skills, responsibility and autonomy around self-management, such as the ability to manage medical appointments and the responsibility for medical care. Measures of transition readiness can be completed by adolescents, their parents and medical professionals (Schmidt et al., 2020).

Adolescents with a chronic condition have an elevated risk of psychosocial and mental health problems, and they experience higher levels of anxiety than their healthy peers (Crowley et al., 2011; Ssewanyana et al., 2017). Anxiety can greatly affect the transition process and potentially lead to poor health management and loss to follow-up (Leeb et al., 2020). Parents have different beliefs than their children. For example, Peeters et al. (2014) showed that parents felt more anxious than the young people about their self-management capabilities (Peeters et al., 2014). Further research on transition of care for adolescents with a chronic condition across cultures and healthcare organizations is needed (Fegran et al., 2014).

3 | THE STUDY

3.1 | Aims

The aims of this study were to evaluate associations of age, transition readiness and levels of anxiety in adolescents with chronic conditions and to compare the perceptions of adolescents and their parents regarding health self-management and transition readiness. A secondary aim was to assess whether differences exist in associations of age, transition readiness and anxiety between Finnish and Australian cohorts of adolescents.

4 | METHODS

4.1 | Design

This cross-sectional study is part of an international, prospective observational study (Bridge, trial registration number NCT04631965 at [ClinicalTrials.org](https://clinicaltrials.org)) that is conducted in Finland and Australia. The study protocol has been published previously (Kosola et al., 2021).

4.2 | Sample and recruitment/participants

Study participants were adolescents and young adults (aged 15–23 years) with a chronic health condition who were recruited with

a parent or carer from children's units of two specialist services in the 6–12 months prior to their expected transfer to adult healthcare services.

In Finland, healthcare professionals in different subspecialty clinics at the New Children's Hospital, Helsinki identified adolescents who were expected to transfer to adult services within the next 6 months. A research nurse who was not involved in patient care met eligible adolescents face-to-face when they attended a routine outpatient appointment from September 2017 to August 2019.

In Australia, healthcare professionals from the Transition Support Service at the Royal Children's Hospital, Melbourne invited eligible adolescents to participate in the study when they attended routine transition appointments within 12 months prior to their expected transfer of care between October 2018 and August 2020. The study coordinator also identified eligible adolescents who did not have an upcoming transition appointment and contacted them by phone or email.

The parents or carers at both study sites were either recruited at the same visit, if they accompanied their adolescents, or through written information administered to them either through their child or by mail. In this study, we use the word parents to describe the carers, next of kin or responsible adults of the adolescents.

4.3 | Data collection

In Finland, 306 adolescents were approached, of whom 279 (91%) provided written informed consent and 253 (83%) completed the survey. In total 281 parents were approached of whom 214 (76%) granted written informed consent and 189 (67%) completed the survey. In Australia, 259 of 367 (71%) adolescents and 261 of 380 (69%) parents granted written informed consent and completed the survey.

Out of the 189 Finnish and 261 Australian parents who responded to the survey, we included those parents whose children participated in the study ($n=322$) to build dyads and to compare outcomes.

Despite differences in country size, population and ethnicity, the two hospitals are based in countries with similar healthcare settings and educational systems, as previously reported (Kosola et al., 2021). In both countries, adolescents living with chronic conditions are mostly treated in specialty care at the main hospitals.

4.4 | Measurement

4.4.1 | Age

We used self-reported age at diagnosis to determine the duration of each chronic health condition. Age at survey was calculated based on the response date and date of birth. In Finland the data on age

and duration of chronic condition was collected both from electronic patient records and as self-reports.

4.4.2 | Transition readiness

The 'Am I ON TRAC? For Adult Care Questionnaire' (ON TRAC) was used to measure transition readiness (Moynihan et al., 2015; Paone et al., 2006). This validated measure includes a knowledge scale of 14 items and a behaviour scale of 9 items. The knowledge scale scores range from 14 to 56 (11–44 if the adolescents indicate they are not taking any medications). The behaviour scale scores range from 9 to 45 (8–40 if adolescents are not using medications). Higher scores imply greater transition readiness. The questionnaire was available in Finnish, Swedish and English. The Finnish and Swedish versions were forward and backward translated to maintain equivalence of the test questionnaire in each language.

4.4.3 | Anxiety

The State-Trait Anxiety Inventory short form (STAI) was used to measure anxiety. The introductory text to the questionnaire was modified to assess feelings of anxiety 'regarding transfer of care'. This validated self-report instrument consists of six items that are scored on a 4-point Likert scale (Marteau & Bekker, 1992). The STAI yields scores between 20 and 80, with higher scores indicating higher anxiety levels. Previously, a score of 34–36 has been defined as an estimate for normal (Bekker et al., 2003). In this study, we used a cut-off of 40 (<40, low anxiety, ≥40 high anxiety) to avoid overestimation of anxiety. The questionnaire was available in Finnish, Swedish and English. Both adolescents and their parents completed the same questionnaire, with parents asked to estimate their child's anxiety in relation to the transition of care (Al-Yateem & Brenner, 2017).

4.4.4 | Readiness statement

One additional item followed the STAI statements. This item read 'I am ready' and response options followed the same Likert scale as the STAI. Inclusion of an overall transition readiness question can help gain understanding of the perceived transition readiness (Zhang et al., 2014). Response options ('strongly disagree', 'disagree', 'agree' and 'strongly agree') were also dichotomized into categories of 'not ready' (first two responses) and 'ready' (last two response options).

4.4.5 | Health self-management

Health self-management questions focused on the administration of medications, booking doctors' appointments, and understanding of

the medical condition. There were 11 questions, answered both by adolescents and their parents, and scored on a Likert scale from one to four.

4.5 | Ethical considerations

The Bridge study was approved by the Ethics Committee for Women's and Children's Health and Psychiatry at the Helsinki University Hospital (HUS/1547/2017) and the RCH Human Research Ethics Committee (38035). Participants provided informed consent after receiving both oral and written information explaining the purpose of the study. The time that adolescents spent completing surveys was financially acknowledged (voucher valued 10 EUR/10 AUD). The parents were not reimbursed.

4.6 | Data analysis

Age was used as a continuous variable and reported as mean (with range for greater descriptive value). When measuring the difference of duration of condition the cut-off point age above or below 12 years was used as a categorical variable, using Mann-Whitney *U*-test.

The transition readiness knowledge and behaviour scores and STAI scores are presented as means (with standard deviations). The associations between duration of condition and age at survey, anxiety and transition readiness were assessed using Spearman's correlation and 95% confidence intervals (CI).

To estimate the extent to which adolescents and parents agreed with one another on the health self-management of adolescents, levels of anxiety (STAI) and readiness statement scores were used in analyses as categorical variables. The agreement and differences between high or low anxiety, health management and dichotomous readiness statements ('not ready' vs. 'ready') are presented as frequencies (percentages). Differences in answers between the adolescent/parent dyads were tested using Wilcoxon signed rank test, using the original scale (1–4 points, 1 strongly disagree, 2 disagree, 3 agree, 4 strongly agree). The *p* value < .05 was considered statistically significant. Data were analysed using R 4.0.2 version.

Attrition analyses on age, country, sex, diagnoses, and items for all questionnaires were conducted. The frequency of missing data was low and did not reduce statistical power. Data frequencies are reported for all questionnaires and tables.

4.7 | Validity and reliability

The data were collected from two countries and across several different diagnostic groups, and adolescents were recruited consecutively. The generalizability and validity of the results are

further supported by the government-funded healthcare systems in Finland and Australia, as this reduces the effect of private insurance and other financial barriers that could affect access to healthcare.

The trial was registered to [ClinicalTrials.gov](https://clinicaltrials.gov) to avoid citation bias, and participant data was pseudonymized. For reliability and to prevent outcome bias, we used validated measures and conducted attrition analyses. Frequencies are reported for all questionnaires and tables, with inconsistencies reflecting missing data. The usage of electronic patient records in Finland for data collection on the clinical conditions and age lessens the likelihood of recollection bias. To ensure transparent reporting and rigour, we followed the STROBE guideline (von Elm et al., 2007).

5 | RESULTS

The characteristics of the 512 adolescent participants are summarized in [Table 1](#). Finnish adolescents were younger than Australian adolescents (FIN mean 17.2 years vs. AUS mean 18.3 years, $p < .001$; [Table 1](#)).

5.1 | Transition readiness and anxiety

The mean transition readiness knowledge score reported by adolescents was 42.5/55 (SD 6.8, $n=465$) and the mean transition readiness behaviour score was 26.7/45 (SD 4.3, $n=460$), interpreted as high knowledge scores and medium behaviour scores. Only 10% of the participants reported no medication use. Adolescents who were diagnosed before 12 years of age scored slightly higher in transition readiness knowledge scores (median=44) than adolescents who were diagnosed in their teens (median=41, $p=.002$).

The mean anxiety score regarding transition of care for adolescents was 36.7/80 (SD 12.3, $n=487$) interpreted as normal anxiety. Adolescents who were diagnosed before 12 years of age yielded slightly lower STAI scores (median 33) than adolescents who were diagnosed in their teens (median=35, $p=.040$).

5.2 | Associations of duration of condition and age at survey with transition readiness and anxiety

Transition readiness knowledge scores and behaviour scores showed a moderate correlation (0.62, $p < .001$, $n=447$) ([Table 2](#)). The duration of condition and age at survey showed weak associations with transition readiness knowledge and behaviour scores as well as with levels of anxiety. Anxiety was negatively associated with both transition readiness behaviour and knowledge scores ([Table 2](#)). Comparisons between the Finnish and Australian cohorts on the association of age, transition readiness knowledge and behaviour

TABLE 1 Demographic and clinical characteristics of Finnish and Australian cohorts.

	Finnish cohort		Australian cohort	
	<i>n</i>	%	<i>n</i>	%
Gender				
Male	118	46.6	133	51.4
Female	132	52.2	126	48.6
Other	3	1.2	0	0
Clinical condition				
Diabetes	92	35.5	59	22.8
Cardiological	19	7.3	24	9.3
Gastroenterological	45	17.4	27	10.4
Kidney, liver/organ transplant	13	5.0	27	10.4
Neurological	18	6.9	62	23.9
Rheumatological	66	25.5	4	1.5
Anorexia nervosa and cystic fibrosis*	0	0	56	21.6
Age	Mean	Range	Mean	Range
Age at diagnosis	9.0	0–17.5	5.4	0–17.0
Age at survey	17.2	15.3–22.8	18.3	16.0–21.1

*This group consisted mainly of adolescents with anorexia nervosa or cystic fibroses including some other rare conditions.

TABLE 2 Correlations between duration of condition, age at survey, transition readiness knowledge, transition readiness behaviour and anxiety.

	Duration of condition		Age at survey		Transition readiness knowledge		Transition readiness behaviour	
	<i>r</i> (95% CI)	<i>n</i>	<i>r</i> (95% CI)	<i>n</i>	<i>r</i> (95% CI)	<i>n</i>	<i>r</i> (95% CI)	<i>n</i>
Transition readiness knowledge	.19* (.10, .28)	437	.29* (.20, .37)	464	–	–	–	–
Transition readiness behaviour	.01 (–.08, .10)	430	.13** (.03, .21)	459	.62* (.56, .68)	447	–	–
Anxiety	–.01 (–.11, .08)	465	.06 (–.03, .16)	486	–.16* (–.25, –.07)	449	–.28* (–.37, –.19)	444

Abbreviations: CI, confidence interval; *r*, Spearman's correlation coefficient.

p* < .001.; *p* < .01.

scores and anxiety levels yielded no statistically significant differences (Table S1).

5.3 | Adolescent and parent agreement regarding transition readiness and anxiety

Evaluation of the readiness statement ('I am ready'/ 'My adolescent is ready') indicated that only half of the adolescent/parent dyads felt ready for the transfer of care (Table 3). The adolescent and parent dyads showed strong agreement on transition readiness but nearly half of adolescent/parent dyads disagreed about the level of anxiety regarding transfer of care. Overall, the adolescents reported less anxiety and a stronger sense of readiness than did their parents (Table S2).

5.4 | Adolescent and parent agreement on health self-management

Adolescent and parent dyads showed strong overall agreement on the medical and health self-management of the adolescents. Both felt that the self-care skills of the adolescents were good and agreed about understanding the risks and benefits of treatments and medication use. Both adolescents and parents reported that one third (29.8%) of the adolescents did not meet the doctor alone, and around half (52.1%) of the adolescents did not know how to contact the hospital independently. The greatest disagreement in responses involved the abilities of the adolescents to ask about health issues from the healthcare personnel as the adolescents rated these issues lower than their parents (Table 4; Table S3).

Items	Adolescents and parents agree on the items, both answering yes or both answering no		Adolescents and parents disagree on items, one answers yes, the other no	Dyad total
	Yes % (n)	No % (n)	Yes / No % (n)	N
Anxiety total (STAI)	21.9 (68)	32.4 (100)	45.8 (142)	310
I am ready	42.4 (135)	17.9 (57)	39.6 (126)	318

Note: The negative answer to anxiety (STAI) indicates less perceived anxiety. The positive answer to the I am ready statement indicates confidence in transition readiness. STAI total; yes ≥ 40 high anxiety, no < 40 low anxiety. I am ready yes = agree or strongly agree, no = disagree or strongly disagree.

Abbreviation: STAI, State-Trait Anxiety Inventory short form.

Items	Adolescents and parents agree on the items, both answering yes or both answering no		Adolescents and parents disagree on the items, one answers yes, the other no	Dyad Total
	Yes % (n)	No % (n)	Yes/No % (n)	N
My family supports me in managing my health	97.5 (307)	0.0 (0)	2.5 (8)	315
I understand the risks and benefits of treatments before consenting to them	89.4 (269)	0.3 (1)	10.3 (31)	301
I know why I use each medicine	92.5 (261)	0.4 (1)	7.1 (20)	282
I know the names of my medications/ treatments	91.6 (262)	1.4 (4)	7.0 (20)	286
I take my meds on my own	77.3 (214)	4.7 (13)	18.0 (50)	277
I know the side effects of my medication	64.4 (172)	8.6 (23)	30.0 (72)	267
I ask about my health from the healthcare personnel	63.2 (184)	9.6 (28)	27.2 (79)	291
I know how to explain my conditions to others	60.6 (188)	16.7 (52)	22.6 (70)	310
I can go to the hospital on my own	48.5 (147)	28.7 (87)	22.8 (69)	303
I meet the doctor on my own	39.8 (119)	29.8 (89)	30.4 (91)	299
I can contact the hospital on my own	17.8 (52)	52.1 (152)	30.1 (88)	292

6 | DISCUSSION

In this study, adolescents reported high transition readiness knowledge and medium behaviour scores. Adolescents reported normal anxiety levels regarding transition of care. Younger age at diagnosis was associated with higher transition readiness knowledge. Transition readiness knowledge and behaviour scores showed moderate correlation. Higher transition readiness associated with lower levels

of anxiety regarding transition of care. Adolescent and parent dyads reported a strong agreement on transition readiness, while adolescents felt less anxious than did their parents.

Younger age at diagnosis was associated with higher transition readiness knowledge and it could be argued that knowledge on health management has developed with time. Some adolescents, however, acquire skills necessary for a successful transition around age 18 years or in early adulthood (Stollon et al., 2017) and younger

TABLE 3 Agreement of adolescents and their parents on the feelings of anxiety regarding the transfer of care and the statement 'I am ready'/'My adolescent is ready'.

TABLE 4 Adolescent and parent agreement on health self-management.

age at transfer of care may be associated with less knowledge and interest (McPherson et al., 2009). This is closely related to brain maturation in adolescence since impulse control and postponing gratification are among the last skills to develop (Blakemore & Robbins, 2012). Our findings suggest that transition readiness is related to cognitive and psychosocial skills, and therefore these skills should be systematically assessed (Zhou et al., 2016).

Since higher transition readiness was associated with less perceived anxiety, more structured care could advance both transition readiness and mental well-being. Structured educational transition programs yield positive results (Syverson et al., 2016) because they prepare the adolescents with chronic conditions to reach autonomy in managing their health (Schmidt et al., 2020). Contemporarily, institutional rules regarding the care of adolescents may need to be revised to overcome barriers to personalized care (Patton et al., 2016).

Parents reported somewhat higher anxiety regarding the readiness to transfer than did adolescents themselves. This is in line with previous findings where parent estimates of health-related quality of life were poorer than the evaluations of children (Mutanen et al., 2015) and where parents felt more anxious than their children (Peeters et al., 2014). Given the extent of support many parents have received from the paediatric healthcare professionals over the years, it is only natural that even the most prepared parents would feel some anxiety. Supporting parents to hand over responsibilities to their adolescents and a gradual building of trust may ease parental anxieties (Colver et al., 2018; Thomsen et al., 2022).

The abilities of adolescents to independently access medical appointments, contact hospitals, meet the doctor alone and discuss health and medical issues with healthcare personnel showed room for improvement. The confidentiality of healthcare influences the experiences of adolescents and their willingness to participate in care. Healthcare confidentiality evolves when adolescents have opportunities to meet the doctor alone (Britto et al., 2010). Shortcomings or gaps in knowledge or health behaviour will not be disclosed if there is no mutual perception of privacy and confidentiality. Also interestingly, when adolescent/parent dyads rated the item 'I am ready/My adolescent is ready' only half of the dyads felt ready for transition of care. Considering our results, an increased focus on confidentiality and strengthening the autonomy of adolescents could potentially improve transition readiness.

As adolescents reported similar average transition readiness regardless of the country they reside in, common challenges promote common responses to be developed in healthcare, focusing on educational and behavioural aspects and on the confidentiality of care.

7 | STRENGTHS AND LIMITATIONS

The strengths of this study include data collected from two countries and across several different diagnostic groups, and

the inclusion of information from the parents. The two study sites induce some limitations as there are systemic and administrative differences between the healthcare systems. Due to differences in electronic patient records and legal frameworks, we only had access to electronic patient records in Finland. The number of adolescent/parent dyads was smaller than the number of participating adolescents because all adolescents and parents made the choice regarding participation independently. Despite the smaller sample in analyses of adolescent/parent dyads, the results are valuable since the perspectives of both adolescents and parents may in turn affect transition success.

8 | CONCLUSION

Transition readiness should be defined through an assessment of knowledge and psychosocial skills instead of age alone. The general aim of transferring care around the age of legal maturity may only yield improved results if the extended time in paediatric care is used to increase the knowledge of adolescents and to support their self-management skills. More research is needed about how to coach and guide adolescents with chronic conditions to achieve long-term positive health outcomes.

AUTHOR CONTRIBUTIONS

Anna Tornivuori: conceptualization, data curation, formal analysis, methodology, writing original draft, reviewing and editing the manuscript. **Mira Kallio:** participated in data curation, reviewed and edited manuscript. **Miko Pasanen:** participated in data curation. **Sanna Salanterä:** participated in conceptualization and methodology, reviewed and edited the manuscript. **Evelyn Culnane:** participated data curation and reviewed and edited the manuscript. **Susan Sawyer:** participated in conceptualization and reviewed and edited the manuscript. **Silja Kosola:** participated in conceptualization, data curation, formal analysis, methodology, funding acquisition and recourses, supervision and validation, reviewing and edited the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

PEER REVIEW

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.15860>.

DATA AVAILABILITY STATEMENT

Research data are not shared. There is no plan to share individual participant data because only collated data may be shared according to EU and Commonwealth data protection requirements. Patient data gathered through questionnaires, for patient security and privacy reasons cannot be shared.

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