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Anxiety and care experiences in adolescents with chronic health conditions: an international, longitudinal study across the transfer of care

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ABSTRACT

Objectives To evaluate changes in anxiety, care experiences and condition impact among adolescents with chronic health conditions in two countries as they transfer to adult healthcare and to assess factors influencing anxiety levels.

Design A longitudinal international study. Data was collected by questionnaires before (2017–2021) and a year after (2018–2022) transfer of care.

Setting Two specialist hospitals in Finland and Australia.

Participants 440 adolescents with chronic health conditions were recruited from Finland (FIN n=237; mean age 17.2) and Australia (AUS n=203; mean age 18.3) with the answering percentage FIN 68.8% and AUS 55.2% of the first time point.

Main outcome measures The validated State-Trait Anxiety Inventory short form (STAI) was used to measure care-related anxiety. Care experiences were measured using eight questions from the Adolescent-Friendly Hospital Survey. Self-reported condition impact was measured by a Visual Analogue Scale. Care experiences, condition impact, country and age were included in regression analyses as predictors of care-related anxiety.

Results At baseline, there were few clinically meaningful differences between participants at the two sites. Adolescents reported positive care experiences both before and after the transfer of care. In regression analyses after the transfer of care, adolescents with lower condition impact experienced lower anxiety levels than adolescents with higher condition impact (beta −9.00, 95% CI −13.85 to 4.16, p<0.001). After the transfer of care, adolescents who reported negative care experiences also reported higher anxiety (median STAI score 40.0 (IQR 30.0–50.0) versus 33.3 (IQR 23.3–41.6), p<0.001).

Conclusion Across two different healthcare systems, most adolescents with chronic health conditions reported low anxiety and positive care experiences before and after transfer to adult healthcare. Beyond efforts to generally enhance positive care experiences, focusing on adolescents with higher-impact chronic conditions may reduce disease-related anxiety.

Trial registration number ClinicalTrials.org NCT04631965, submitted 21 October 2020.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Adolescents who feel anxious and unprepared to transfer to adult health services may neglect their self-care, resulting in poorer health outcomes.
- ⇒ Little is known about the relationships between anxiety, healthcare experiences and the impact of a chronic health condition on daily living as adolescents transition to adult healthcare.

WHAT THIS STUDY ADDS

- ⇒ Negative care experiences and higher condition impact were associated with higher levels of anxiety.
- ⇒ Female adolescents reported higher anxiety levels than males.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ This international study highlights the common needs of adolescents during the transition of care suggesting that holistic transition support programmes may be indicated particularly for adolescents who report a greater impact of their condition.

INTRODUCTION

The incidence of anxiety increases across childhood and adolescence. Some groups are affected more than others including young people with chronic health conditions who have a higher likelihood of anxiety compared with their healthy peers.[1] Anxiety can negatively impact healthcare experiences, self-management, health outcomes and transition readiness in adolescents with chronic conditions.[2–5] Yet little is known about the relationships between anxiety, healthcare experiences and the impact of chronic health conditions on daily living as adolescents transition to adult healthcare.[6 7] Although transition programmes recommend addressing psychosocial needs, these have been inconsistently implemented and anxiety has rarely been a feature of these programmes.[2 8 9]

Adolescents with chronic health conditions undergo the gradual process of transition to adult healthcare in contrast to the transfer of care that signals when care is actually shifted from children's hospitals to adult facilities.[10] Transition is a complex process involving both child and adult health services. Adolescents have been reported to experience gaps in healthcare and unmet needs at this time as well as lacking information about future adult services.[5 11] Key factors such as age, health condition, access to developmentally appropriate holistic care and the availability of equivalent services shape the experience and outcomes of transition to adult healthcare.[1 9 12] The transition period may be a stressful process and can present challenges, both physical regarding health and psychosocial, for adolescents with a chronic health condition.[13] Previous research provides insight into the complexity of the transition process and the importance of addressing the multidimensional needs of adolescents with chronic health conditions[14–16] but knowledge of how to promote the most effective outcomes is still inconclusive.[17 18]

The healthcare needs of adolescents with chronic health conditions differ from those of young children and adults due to the complex interaction of physical, cognitive and psychosocial aspects of growing up.[9 14 19–21] A systematic review of the care experiences of adolescents shows that globally the healthcare needs of young people include continuity of care, patient-centredness, confidential and trustful care and the need to feel respected.[22] While the transfer of care for adolescents with chronic health conditions has been broadly studied, evidence on care experiences across the period in which adolescents transfer from paediatric to adult services remains limited.[9 23] Notwithstanding the value of exploring the experiences of adolescents in different health services in different countries, to our knowledge, international comparative studies are scarce.

Chronic conditions can diversely affect adolescents' lives.[1 20] Self-reported health status provides an estimate of the impact the chronic condition has on everyday life.[24–26] Gaining an understanding of how adolescents perceive the degree to which a chronic condition impacts their everyday life is important for promoting the health and well-being of adolescents and to understand their care experiences.[1 2 27]

The objective of this study was to assess changes in anxiety, care experiences and condition impact at two time points (before and after transfer of care) in two countries (Finland and Australia) in adolescents with chronic health conditions. We also set out to evaluate how care experiences, condition impact, age and country influence anxiety levels after the transfer of care.

METHODS

This study is part of an international prospective observational study (Bridge) which was conducted at the New Children's Hospital in Helsinki, Finland and the Royal Children's Hospital (RCH) in Melbourne, Australia.

Eligible participants were adolescents and young adults (aged 15–23 years) with a chronic health condition that was anticipated to need ongoing healthcare in young adulthood. Adolescents received both verbal and written information prior to providing written informed consent. In Finland, adolescents aged 15 or older may consent to participate in survey studies (which include no invasive interventions or treatments) autonomously without approval from their parents. For Australian adolescents aged under 18, the parents or carers also gave written consent.

Data were collected by questionnaire (either electronically or with pen and paper) at two time points, before and after the transfer from paediatric to adult health services. In Finland, pretransfer data were collected from October 2017 to May 2019 and post-transfer data were collected from September 2018 to October 2020, approximately 1 year later. The same approach took place in Australia with pretransfer data collected between November 2018 and March 2021 and follow-up from August 2019 to May 2022. In this study, to promote validity, we included those participants who completed questionnaires at both time points. For transparent reporting and to avoid bias we followed the STROBE (strengthening the reporting of observational studies in epidemiology) guidelines.[28]

Study sites

Helsinki, Finland, and Melbourne, Australia, differ in population and ethnicity but share similar, government-funded specialist healthcare services for adolescents with chronic conditions. In Melbourne, adolescents transfer to multiple adult hospitals depending on their condition while in Finland the majority transfer to a single adult hospital. Differences in administrative and medical record systems affect accessibility of patient data. Both children's hospitals have transition guidelines and the RCH also has a hospital-wide transition support service. Detailed methods are reported in the study protocol.[29]

Measurements

Anxiety

Anxiety was measured using the validated State-Trait Anxiety Inventory short form (STAI), a self-report instrument of six items scored on a four-point Likert scale.[30] The introductory text was adjusted so that questions assessed anxiety levels associated with health and transfer of care. The STAI yields scores between 20 and 80 with higher scores indicating higher anxiety. Previous research has defined a score of 34–36 as a cut-off for normal anxiety levels.[31]

Care experiences

Care experiences were assessed using eight questions from the Adolescent-Friendly Hospital Survey (AFHS).[32] The questionnaire was forward and backwards translated from English into Finnish and Swedish, the two official languages in Finland. Responses used a three-point Likert scale (1=true, 2=somewhat true, 3=false); lower points indicated more positive care experiences and higher points negative care experiences (minimum 8, maximum 24).

Condition impact

We defined condition impact as the extent to which a chronic condition affects daily life. In Finland, we asked participants 'How do you assess the activity of your illness or the intensity of symptoms during the last week?' while in Australia, we asked 'How much has your condition impacted you during the last week?' Responses were reported using a Visual Analogue Scale (VAS).[26 33] The VAS scale was modified due to the technical limitations of the electronic questionnaire. In Finland, the scale ranged from 1 (an extreme amount) to 7 (not at all). In Australia, it ranged from 0 (not at all) to 100 (an extreme amount). The Australian responses were reversed and scaled to match the Finnish scale. The responses were then categorised into three groups: High impact (1–2), medium impact (3–5) and low impact (6–7).

Statistical analyses

Statistical analyses were undertaken using the SAS System, V.9.4 for Windows (SAS Institute, Cary, North Carolina, USA). For the attrition analyses, we compared the characteristics of the participants before and after the transfer of care. Descriptive statistics of categorical data are presented as frequencies (with percentages) and continuous variables with medians and IQR. Age is presented both as the mean and range for descriptive purposes. Due to the skewed distribution, change in care experiences was tested using Wilcoxon signed-rank test. Anxiety, care experience and condition impact at both time points (before and after transfer of care) were compared between males and females separately in both countries using the Kruskal-Wallis test.

A linear regression model was used to study the association of anxiety levels after transfer of care (dependent variable) and age, condition impact, care experiences and country. Self-reported condition impact and country were categorical independent variables and age and care experiences were included in the model as continuous independent variables.

The anxiety and care experience scores were split into three groups: The lowest quartile, the two middle quartiles and the highest quartile. This division aimed to facilitate comparison between the lowest and highest quartiles given that adolescents with higher anxiety levels and more negative care experiences are anticipated to be in greatest need of support. Based on the distribution of responses on the STAI, we defined low anxiety as 20–27 points, medium anxiety as 28–46 points and high anxiety as 47–80 points. Positive care experiences were defined as 8 points, neutral as 9–11 points and negative care experiences as 12–24 points on the AFHS. Participants in the lower and upper quartiles were compared using the Mann-Whitney U test and two-sample t-test.

All tests were performed as two-sided with a significance level set at 0.05.

Patient or public involvement

15 adolescents with chronic health conditions were involved in developing the study questionnaires.

RESULTS

The characteristics of the participants completing the surveys at each wave from each country are presented in table 1. The Finnish participants were younger than the Australian participants when they transferred to adult care (17.2 vs 18.3 years). In both countries, the time span between waves was one year (table 1).

Change in anxiety, care experiences and condition impact before and after transfer of care

We found no significant changes in the total median scores on anxiety levels, care experiences and condition impact measured before and after the transfer of care. Some changes among female participants in the levels of anxiety were detected; Finnish female participants exhibited comparatively lower anxiety levels prior to the transfer of care and their levels decreased after the transfer. Conversely, Australian female participants experienced an increase in the levels of anxiety after the transfer of care. The anxiety levels for males remained constant across the two time points. Participants mostly reported positive care experiences both before and after the transfer of care (table 2).

The median scores on anxiety, care experiences and self-reported condition impact remained almost unchanged before and after the transfer of care (see online supplemental table 1). Consistent with the aims of the study, we focused primarily on analysing the data after the transfer of care to examine any associations with anxiety.

Levels of anxiety after transfer of care

Australian participants reported higher anxiety levels after transfer of care than Finnish participants (FIN median 33.3 vs AUS median 40.0 p=0.001) as shown in figure 1.

Comparison of anxiety by clinical conditions showed that Australian participants reported slightly higher levels of anxiety than Finnish participants after transfer of care (see online supplemental table 2). Some variations were detected; adolescents with diabetes reported similar anxiety levels (FIN median 33.3, IQR 26.7 to 43.3 (n=75) vs AUS median 33.3, IQR 23.3 to 46.7 (n=23)) as shown in figure 2.

Table 1 Characteristics of participants before and after transition of care

Country	W1 FIN n=237	W1 AUS n=203	W2 FIN n=163	W2 AUS n=112
Sex	n (%)	n (%)	n (%)	n (%)
Male	111 (46.8)	133 (51.4)	72 (44.2)	48 (42.8)
Female	124 (52.3)	126 (48.6)	89 (54.6)	64 (57.1)
Other	2 (0.8)	0 (0)	2 (1.2)	0 (0)
Clinical condition				
Diabetes	87 (36.7)	59 (22.8)	70 (42.9)	18 (16.7)
Cardiology	18 (7.6)	24 (9.3)	6 (3.7)	10 (8.9)
Gastroenterology	44 (18.6)	27 (10.4)	31 (19.2)	15 (13.4)
Kidney, liver or Tx	12 (5.1)	27 (10.4)	5 (3.1)	12 (10.7)
Neurology	18 (7.1)	62 (23.9)	8 (4.9)	32 (28.6)
Rheumatology	60 (25.3)	4 (1.5)	43 (26.3)	2 (1.8)
Other*	0 (0.0)	56 (21.6)	0 (0.0)	26 (20.8)
	Mean (range)	Mean (range)	Mean (range)	Mean (range)
Age, 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)

*Other = adolescents with anorexia nervosa, cystic fibrosis and some other rare syndromes.
AUS, Australia; FIN, Finland; Tx, solid organ transplant; W1, wave one, before transfer of care; W2, wave two, after transfer of care.

Associations of care experience, self-reported condition impact, country and age with anxiety after transfer of care

The overall regression model was statistically significant (R^2=14.0 %, F=8.6, p<0.0001). Participants with low condition impact experienced lower levels of anxiety (beta −9.00, p<0.001) than participants with high condition impact. Finnish participants experienced lower levels of anxiety (beta −4.8, p<0.01) compared with Australian participants after the transfer of care. Anxiety showed a significant association with care experience (p=0.01) and low condition impact versus high condition impact (< 0.001) (table 3).

We compared the lowest and highest quartiles of anxiety and care experiences after the transfer of care. Participants who reported negative care experiences reported higher anxiety levels than participants who reported positive care experiences (40.0 (IQR 30.0–50.0) versus 33.3 (IQR 23.3–41.6), p<0.001) (table 4).

Table 2 Total median scores and change with comparison of countries and gender before and after transfer of care on anxiety, care experience and condition impact

	Total Before transfer of care median (IQR)	Total After transfer of care median (IQR)	Total Change, median (IQR)		FIN Before transfer of care median (IQR)	FIN After transfer of care median (IQR)	AUS Before transfer of care median (IQR)	AUS After transfer of care median (IQR)
Anxiety	33.3 (26.7–76.7)	33.3 (26.7–80.0)	0.0 (–6.7–6,7)	m.	30.0 (26.7–40.0)*	30.0 (23.3–36.7)†	33.3 (26.7–46.7)*	33.3 (23.3–46.7)*
				f.	36.7 (30.0–43.3)	33.3 (26.7–40.0)	40.0 (30.0–50.0)	43.3 (30.0–53.3)
Care experience	9.0 (8.0–11.0)	9.0 (8.0–11.0)	0.0 (–1.0, 1.0)	m.	9.0 (8.0, 11.0)	9.0 (8.0, 11.0)	9.0 (9.0, 10.0)	9.0 (8.0, 11,0)
				f.	10.0 (9.0,11.0)	9.0 (8.0, 11.0)	10.0 (8.0, 11.0)	10.0 (8.0, 12.0)
Condition impact	6.0 (4.0, 7.0)	6.0 (4.0, 7.0)	0.0 (–1.0, 1.0)	m.	6.0 (4.0, 7.0)	6.0 (4.0, 7.0)	6.0 (4.0, 7.0)	6.0 (4.0, 7.0)
				f.	6.0 (4.0, 7.0)	5.0 (4.0, 6.0)	5.0 (3.0, 7.0)	5.0 (3.0, 7.0)

Anxiety: total STAI scores between 20 and 80. Higher scores indicate higher anxiety.
Care experience: total scores between 8 and 24. Higher scores indicate more negative care experiences.
Condition impact: scores between 1 and 7. Lower scores indicate higher condition impact.
Before transfer anxiety total n=486, after transfer anxiety total n=323.
Before the transfer of care experience total n=477, after the transfer of care experience total n=291.
Before transfer condition impact total n=479, after transfer condition impact total n=327.
FIN before transfer, male n=113–117, female n=124–132. AUS before the transfer male n=109–120, female n=115–119.
FIN after transfer, male n=73–85, female n=89–112. AUS after transfer, male n=57–58, female n=69–70.
*p=<0.05.
†p=<0.01.
AUS, Australia; f, female; FIN, Finland; m, male.

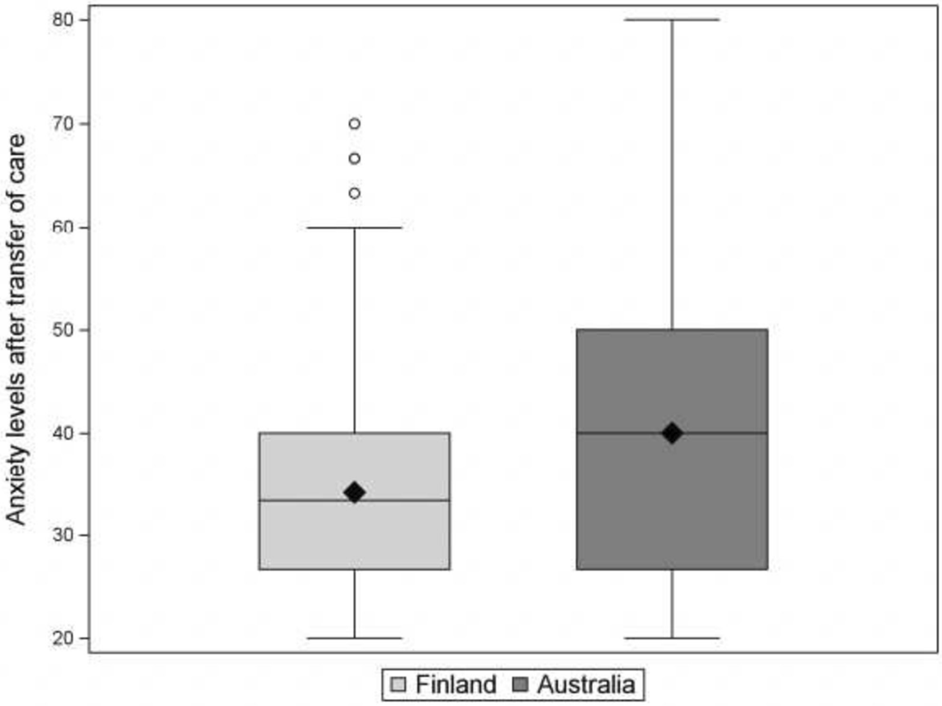

Figure 1 Levels of anxiety by clinical condition and country after transfer of care.

DISCUSSION

This study found that both Finnish and Australian participants reported largely positive care experiences before and after the transfer of care and that care experiences and condition impact remained largely unchanged at both study sites in the year after transfer to adult services. Participants who reported higher condition impact and negative care experiences expressed higher care-related anxiety. Australian adolescents experienced slightly higher anxiety levels than Finnish adolescents before the transfer of care and anxiety levels changed after transfer of care among females in both countries.

Although adolescents often report feeling unprepared for the transfer of care,[9 34] adolescents have also noted the benefits of adult care following transfer to adult services.[5] Our mainly positive findings about care experiences and

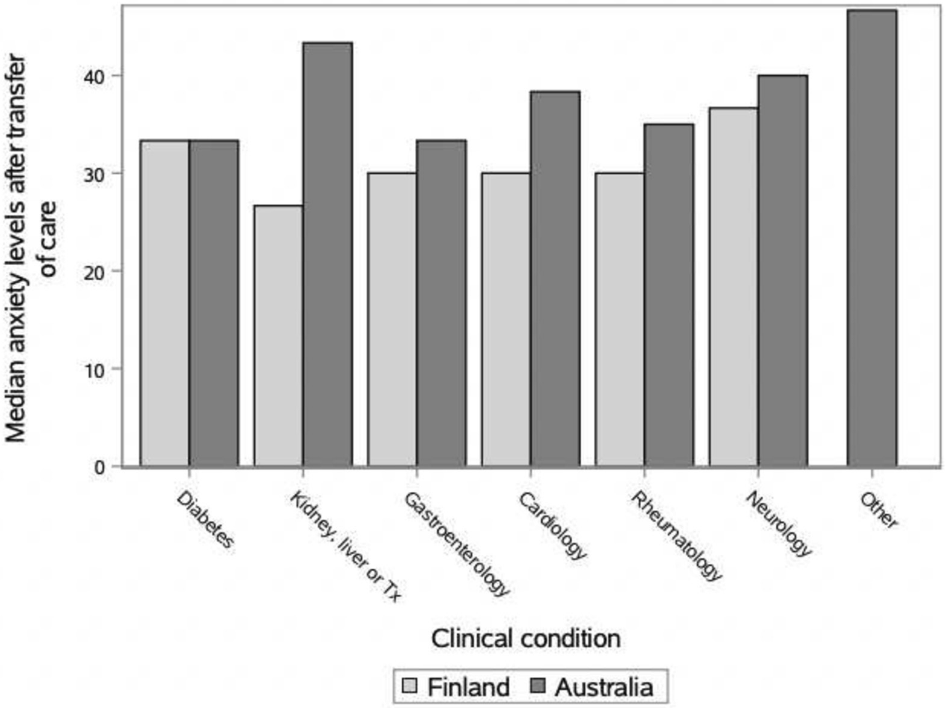

Figure 2 Anxiety levels by selected clinical conditions and country after the transfer of care.

Table 3 Multiple linear regression model associations on levels of anxiety after transfer of care

	Levels of anxiety			
Independent variable	Beta	SE	95% CI	P value
Care experience	0.76	0.25	0.26 to 1.26	*
Condition impact neutral versus high	−3.84	2.46	−8.78 to 1.10	
Condition impact low versus high	−9.00	2.51	−13.85 to −4.16	†
FIN versus AUS	−4.82	1.82	−8.41 to −1.24	†
Age after transfer of care	−0.26	0.75	−1.73 to 1.21	

*p=0.01, R^2=14%.
†p=0.01.
AUS, Australia; FIN, Finland.

stable anxiety levels across this period of transfer align with these findings as do our findings that female participants reported higher anxiety levels than males.[6 35] These sex differences are consistent with reported differences in the prevalence of common mental disorders by sex in adolescents without chronic health conditions.[35] It was, however, noteworthy that the anxiety levels among Australian female participants increased while anxiety in Finnish female participants decreased after the transfer of care. Although the clinical relevance of this difference is uncertain, one possible explanation is that Australian adolescents overall experienced higher anxiety levels and were older than Finnish adolescents at the time they transferred to adult healthcare. As adolescents mature, they face increasing responsibilities and greater educational and vocational demands which may contribute to anxiety.[36 37] In the Australian sample, we also noted that the 'other' diagnostic group (which was not included in the Finnish cohort) reported higher anxiety levels. At least some conditions in this group have no equivalent service in the adult healthcare which may complicate the transfer process in addition to adolescents with this condition having higher comorbid rates of anxiety.[38 39] Other explanations are financial barriers that can limit access to healthcare which can also contribute to anxiety and differ by country.[39]

A strength of this study is the inclusion of participants with a variety of chronic conditions. Additional strengths are the longitudinal data collection spanning the transfer of care and the collection of data from two large children's hospitals in two countries. Previous research has emphasised that culturally responsive care for adolescents with chronic health conditions should be person-centred and assess biological, psychological and sociocultural factors.[1] Despite the differences in culture and healthcare systems in Finland and Australia, the consistent results of this study add to the body of evidence that adolescents with chronic conditions have largely common needs.[14 21 22 40] The two study sites also present some limitations. Systemic and administrative differences between the two healthcare systems and variances in electronic patient records presented challenges in data collection post-transfer. While the overall sample size was reasonable for studies of this type, different response rates in the follow-up survey may influence results. For validity and to avoid measurement bias, we only included the participants who responded at both time points and reported frequencies illustrating missing data. The responses to the surveys are self-evaluated and reflect a subjective view. In this study, we asked about care-related anxiety but this can be difficult to separate from anxiety related to other aspects of life. The personal views of adolescents and their coping mechanisms are important to consider as they are decisive in terms of treatment results.[27 37] Previously, self-reported condition impact has been associated with clinical disease activity which is why we used a VAS to assess the impact of the condition.[24–26 33] To our knowledge, there is no consensus about the best

Table 4 Comparisons of the lowest and highest quartiles of anxiety and care experience after the transfer of care

	Low anxiety n=95	High anxiety n=67		Positive care experience n=111	Negative care experience n=70
	Median (IQR)	Median (IQR)		Median (IQR)	Median (IQR)
Care experience n=80	9.0 (8.0–10.0)	9.0 (8.0–13.0)	Anxiety n=104	33.3 (23.3–41.6)	40.0 (30.0–50.0)
P value	<0.05*		P value	<0.001†	

Low anxiety 20–27 points, high anxiety 48–80 points.
Positive care experience 8 points, negative care experience 12–24 points.
*Kruskal-Wallis.
†Two sampled t-test.

approach to measuring healthcare experiences and no validated measures are available.[22 32] Finally, some of the data after the transfer of care were collected during the COVID-19 pandemic. We did not evaluate the subjective effects of the pandemic on levels of anxiety but appreciate that isolation and quarantine measures in Australia were more severe than in Finland.

CONCLUSION

In conclusion, holistic assessment is important in the provision of care to adolescents with chronic conditions. The consistent finding across Finland and Australia that participants who reported higher condition impact and less positive care experiences also reported higher anxiety suggests opportunities for enhancing adolescent care. The findings highlight the common needs of adolescents with chronic health conditions across different cultures and contribute to knowledge of how to improve adolescent-friendly care.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval The Bridge study was granted ethical approval 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 gave informed consent to participate in the study before taking part.

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