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Changes in health-related quality of life during transition to adult healthcare: an international prospective cohort study

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ABSTRACT

Objective To study changes in health-related quality of life (HRQoL) in adolescents and young adults (AYAs) with chronic medical conditions across the transfer to adult healthcare and associations of HRQoL with transition readiness and experience of care.

Methods Participants in this international (Finland, Australia) prospective cohort study were recruited in the year prior to transfer to adult health services and studied 12 months later. In addition to two HRQoL scales (Pediatric Quality of Life inventory (PedsQL), 16D), the Am I ON TRAC for Adult Care Questionnaire and Adolescent Friendly Hospital Survey measured transition readiness and experience of care and categorised by quartile. Data were compared before and after transfer to adult healthcare.

Results In total, 512 AYAs completed the first survey (0–12 months before transfer of care) and 336 AYAs completed it 1 year later (retention rate 66%, mean ages 17.8 and 18.9 years, respectively). Mean total PedsQL scores (76.5 vs 78.3) showed no significant change, although the social and educational subdomains improved after transfer of care. The mean single-index 16D score remained the same, but in Finland, distress increased and the ability to interact with friends decreased after transfer. AYAs within the best quartiles of experience of care and transition readiness had better HRQoL than AYAs within the worst quartiles.

Conclusions Overall HRQoL of AYAs remained unchanged across the transfer to adult healthcare. Recognising and supporting AYAs with unsatisfactory experience of care and poor transition readiness could improve overall HRQoL during the transition process.

Trial registration number NCT04631965.

INTRODUCTION

As they mature, adolescents and young adults (AYAs) with chronic medical conditions may encounter challenges with age-related and disease-related issues.^{1,2} This period of transition to adulthood is recognised as a risky time and can be associated with poor health outcomes.^{3,4}

Although patient-reported outcomes are considered important, studies measuring changes in health-related quality of life (HRQoL) during adolescence, especially across the transfer of care to adult health services, are limited.^{5–8} Existing research typically focuses on AYA with specific conditions and measures HRQoL either before or after transfer of care.⁹ In most existing longitudinal

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ The time around transfer to adult healthcare is considered a risky period for adolescents with chronic conditions in relation to adherence with treatment regimens and continuity of healthcare.
- ⇒ Despite increasing research on health-related quality of life during this period, factors affecting health-related quality of life during transition remain poorly understood.
- ⇒ More studies with validated inquiries, larger and more diverse populations are needed.

WHAT THIS STUDY ADDS

- ⇒ In a two-country international cohort, health-related quality of life remained largely unchanged across the year before and after transfer of care.
- ⇒ Good experiences of care and transition readiness were associated with acceptable health-related quality of life.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Our results reinforce the value of systematic measurement in clinical practice to recognise adolescents and young adults with unsatisfactory transition knowledge or who are dissatisfied with the treatment they received.
- ⇒ Patient education, holistic support and investments in good experience of care in this group of adolescents and young adults might lead to improved health-related quality of life.

studies, HRQoL has remained stable or improved across the transfer of care, both for those undergoing general transition processes as well as for those involved in specific transition programmes or interventions.^{5,8,10–14}

Healthcare-related factors impacting HRQoL in adolescents with chronic medical conditions remain largely unexplained. Some factors associated with HRQoL include satisfaction with transitional care, changes in adolescent-rated pain and disability, consultations that are independent of parents, physician-rated disease activity, self-medication and transition readiness.^{14–17}

We aimed to prospectively study changes in HRQoL of AYAs with various medical conditions in Finland and Australia as they transferred to adult

healthcare. Our second aim was to study possible associations of transition readiness and experience of care with HRQoL. We hypothesised that better transition readiness and positive experience of care would be associated with better HRQoL.

METHODS

Study design

This study is an international observational prospective cohort study undertaken in Finland and Australia. We compared data collected before and 1 year after the transfer of care.

Participants

Participants were AYAs with different chronic medical conditions recruited between September 2017 and August 2020 from two study sites, the New Children's Hospital in Helsinki, Finland, and the Royal Children's Hospital (RCH) in Melbourne, Australia.¹⁸

Most Finnish AYAs transfer to the Helsinki University Hospital but transition services and the age at transfer vary between subspecialties. For example, AYAs with rheumatological conditions typically transfer to a transition clinic in the Department of Rheumatology at the Helsinki University Hospital, those with gastroenterological disease to adult specialist healthcare, while AYAs with diabetes mainly transfer to diabetes outpatient clinics within primary care. In contrast, AYAs in Australia transfer at age 18–19 years to a variety of adult specialist sites and/or primary care across the state of Victoria and to other states. The RCH offers a hospital-wide transition support service for patients with complex and chronic medical needs.

HRQoL measurements

Pediatric Quality of Life Inventory

Pediatric Quality of Life Inventory (PedsQL) is a validated generic instrument for AYAs 12–25 years old and includes 23 questions about physical, emotional, social and educational functioning during the past month.^{19–21} Questions are answered on a 5-point scale from 0 (never a problem) to 5 (always a problem), and reverse scored (0–100 scale). Total scores and subscale scores are calculated using the mean of each subdomain. Higher scores imply better HRQoL. Although PedsQL distinguishes between healthy children and children with chronic conditions,²⁰ no general definition of a meaningful change in scores is available. In our study, we used statistically significant differences between groups and statistically significant changes between time points and calculated a minimal clinically important difference (MCID).^{10 20 22}

16D

16D is a validated generic HRQoL measurement for adolescents 12–15 years old that is commonly used up to 18 years. Compared with the adult version 15D, 16D includes questions about school, hobbies and friends.^{23 24} The 16 questions cover different aspects of health and life, and every question has five response options. 16D can be used as a weighted profile or a single-index score from 0 (dead) to 1 (full HRQoL).²³ The minimum important change (MIC) over time for 15D has been estimated to be ± 0.015 .^{25 26}

Transition readiness

A validated generic tool, the Am I ON TRAC for Adult Care Questionnaire (ON TRAC) was used to measure transition readiness.^{27 28} ON TRAC has 14 questions that construct the knowledge indicator. Questions are answered on a 4-point scale from strongly disagree (1) to strongly agree (4). The total knowledge

score is the sum of item scores and ranges from 14 to 56 (if no use of medication, from 11 to 44) and higher scores indicate better knowledge. We calculated the mean scores of questions concerning medication in each participating country and imputed those mean scores for AYAs who did not use any medication to make all scores comparable (ie, score range 14–56 for all participants).

Experience of care

The inquiry based on the Adolescent Friendly Hospital Survey (AFH), developed by the RCH, was used to measure experience of care.²⁹ Participants answered eight questions by choosing true (1), somewhat true (2), false (3) or I don't know (blank). Scores were summed if at least seven questions were answered with options 1–3. Scores ranged between 8 and 24. Lower scores implied better experience of care. The mean scores remained stable during transfer of care (unpublished result), so we concentrated on the scores before transfer of care.

Statistical analysis

Statistical analyses were done using IBM SPSS Statistics V.25. We present categorical and ordinal data as frequencies and percentages (%). Means, ranges and SDs are used for continuous variables to describe the data better than with medians and IQRs notwithstanding that HRQoL, ON TRAC and AFH scores were slightly skewed. X^2 tests for independence were used to compare categorical variables. We used Wilcoxon signed-rank test to compare HRQoL before and after transfer of care. Mann-Whitney U and Kruskal-Wallis tests were used to compare continuous variables between groups. All tests were two tailed and $p < 0.05$ was considered significant.

To determine correlations between two continuous variables, the Spearman correlation coefficient was used. The strength of correlations was determined as high or moderate (± 0.50 to ± 1.00) and low or negligible (± 0.00 to ± 0.50).³⁰

We determined the MCID for PedsQL scores through calculating SE of measurement (SEM); changes in scores exceeding one SEM were evaluated as clinically important.^{10 20} SEM was derived by multiplying the SD by the square root of one minus Cronbach's alpha reliability coefficient separately for total scores and different subdomains.²²

We categorised the total scores of AFH and total scores of ON TRAC into quartiles and used these to compare AYAs with the best and worst experience of care and the highest and lowest transition readiness and their associations with HRQoL.

RESULTS

Before transfer to adult care, 512 AYAs (253 from Finland and 259 from Australia) completed the survey at a mean age of 17.8 years (SD 1.2, range 15.3–22.8) (table 1 and online supplemental file 1). A total of 336 (66%) AYAs completed the second survey approximately 1.2 years (SD 0.4, range 0.3–3.2) later. Finnish AYAs were younger than Australian AYAs ($p < 0.001$) (table 1).

AYAs who did not respond to the second survey were younger at diagnosis (mean ages 6.2 vs 7.8 years, $p = 0.003$), and more often male ($p = 0.002$) and Australian ($p < 0.001$). HRQoL, transition readiness, experience of care and age at first survey were similar between AYAs who responded or did not respond to the second survey.

The PedsQL total scores remained unchanged after transfer of care ($p = 0.084$). In subdomains, the psychosocial health scores improved after transfer ($p = 0.017$) (table 2). The 16D single-index scores showed no difference before and after

Table 1 Demographic and clinical characteristics of adolescents before and after the transfer of care to adult healthcare

	Before transfer of care			After transfer of care		
	Total	FIN	AUS	Total	FIN	AUS
N (%)	512 (100)	253 (49.4)	259 (50.6)	336 (65.6)	199 (78.7)	137 (52.9)
Male	250 (48.8)	118 (46.6)	132 (51.0)	147 (43.9)	85 (42.7)	62 (45.3)
Female	258 (50.4)	132 (52.2)	126 (48.6)	186 (55.5)	112 (56.3)	74 (54.0)
Other/missing	4 (0.8)	3 (1.2)	1 (0.4)	3 (0.6)	2 (1.0)	1 (0.7)
Mean age (SD) at survey completion	17.8 (1.2)	17.2 (1.2)	18.4 (0.7)	18.9 (1.2)	18.3 (1.1)	19.8 (0.8)
Diabetes	17.4 (0.9)	16.9 (0.7)	18.2 (0.6)	18.5 (1.0)	18.1 (0.7)	19.6 (0.6)
Neurology	17.9 (1.1)	16.6 (0.7)	18.3 (0.8)	19.3 (1.2)	17.7 (0.7)	19.9 (0.7)
GI disease	18.7 (0.8)	18.8 (0.9)	18.6 (0.7)	19.8 (0.7)	19.8 (0.5)	19.9 (0.8)
Rheumatology	16.3 (0.7)	16.1 (0.5)	18.1 (0.4)	17.3 (0.7)	17.3 (0.6)	19.2 (0.4)
Other	18.5 (0.8)	–	18.5 (0.8)	19.9 (1.0)	–	19.9 (1.0)
Cardiovascular	18.2 (0.8)	17.8 (0.7)	18.6 (0.7)	19.3 (1.0)	18.7 (0.7)	20.0 (1.0)
Nephrology	18.5 (0.8)	19.2 (0.6)	18.2 (0.6)	19.7 (0.6)	20.3 (0.5)	19.3 (0.4)
Mean age (SD) at diagnosis	7.3 (5.7)					

AUS, Australia; FIN, Finland; GI, gastrointestinal.

transfer ($p=0.27$). After transfer of care, 127 (39.1%) adolescents reported a clinically meaningful increase in PedsQL total scores and 114 (36.1%) in 16D single-index scores, while clinically meaningful decreases were reported by 107 (32.9%) and 125 (39.6%) adolescents, respectively (online supplemental

file 2). Groups with decreased, increased and unchanged HRQoL scores showed no differences in age, age at diagnosis, experience of care or transition readiness, but significant differences were found between diagnostic groups in PedsQL ($p=0.028$) and between countries in 16D ($p=0.016$). Online

Table 2 Mean health-related quality of life scores of Finnish and Australian adolescents before and after the transfer of care; higher scores mean better quality of life

	Before transfer of care, mean			One year after transfer of care, mean		
	All	FIN	AUS	All	FIN	AUS
PedsQL (N)	(487–488)	(252)	(235–236)	(334–335)	(199)	(135–136)
Total	76.5	80.6	72.2	78.3	80.1	75.7*
Physical	79.5	85.1	73.4	79.9	84.3	73.5
Psychosocial	74.9	78.2	71.4	77.5*	77.9	76.8*†
Emotional	71.2	74.1	68	72.6	72.4	72.8
Social	83.8	88	79.4	86.8*	88.9	83.7*
School	69.5	72.3	66.6	73.0*	72.4	73.9*
16D (N)	(486–493)	–251	(235–242)	(329–336)	–199	(130–137)
Total	0.866	0.905	0.825	0.868	0.894	0.829
Vitality	0.779	0.811	0.745	0.763‡	0.774‡	0.748
Vision	0.927	0.935	0.919	0.931	0.941	0.915
Breathing	0.85	0.941	0.756	0.868‡	0.949	0.75
Distress	0.717	0.792	0.639	0.712	0.751‡§	0.656‡
Hearing	0.969	0.976	0.961	0.966	0.97	0.96
Sleeping	0.762	0.816	0.706	0.764	0.801‡	0.71
Eating	0.981	0.995	0.967	0.985	0.996	0.969
Discomfort and symptoms	0.795	0.827	0.761	0.798	0.826	0.758
Speech	0.928	0.951	0.903	0.943‡	0.963	0.915
Physical appearance	0.774	0.862	0.683	0.771	0.846‡	0.661‡
School and hobbies	0.814	0.855	0.771	0.82	0.846	0.782
Mobility	0.972	0.989	0.953	0.967	0.985	0.941
Friends	0.877	0.949	0.801	0.883	0.924‡§	0.824‡
Mental function	0.918	0.947	0.888	0.914	0.928‡	0.893
Excretion	0.896	0.911	0.88	0.879‡	0.897	0.852‡
Depression	0.806	0.832	0.778	0.791‡	0.812‡	0.761‡

*Statistically significant change for better ($p<0.05$, Wilcoxon signed-rank test).

†Change is more than the minimal clinically important difference (online supplemental file 2).^{10 22}

‡Change is more than the minimum important change, that is, at least ± 0.015 .²⁵

§Statistically significant change for worse ($p<0.05$, Wilcoxon signed-rank test).

AUS, Australia; FIN, Finland; PedsQL, Pediatric Quality of Life Inventory.

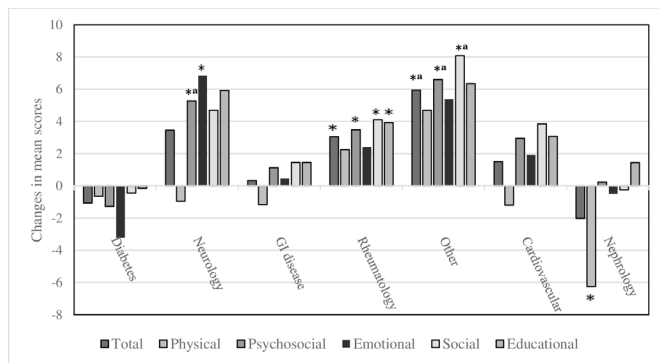


Figure 1 Changes in mean Pediatric Quality of Life Inventory total and subdomain scores across the transfer of care by diagnostic groups. Positive change means better scores after transfer of care. Number of adolescents and young adults in diagnostic subgroups: diabetes 99, neurology 49, GI disease 55, rheumatology 50, other 26, cardiovascular 26, and nephrology and/or organ transplants 20. The 'other' group included participants from Australia whose condition did not readily fit the other subgroups (for example, cystic fibrosis, eating disorders, or a syndrome or metabolic condition affecting multiple organs). *Statistically significant change in scores, $p < 0.05$ (Wilcoxon signed-rank test). ^aChange is more than the minimal clinically important difference. GI, gastrointestinal.

supplemental file 3 summarises the changes in 16D according to MIC groups.

Using PedsQL, Australian AYAs had better total and psychosocial scores after transfer of care (table 2). In 16D, single-index scores showed no significant changes in either Finnish or Australian AYAs. In Finland, AYAs reported more distress and a decreased ability to interact with friends ($p = 0.026$ and $p = 0.027$, respectively) after transfer of care.

Using PedsQL, males had better scores after transfer of care in social functioning and females in educational functioning ($p = 0.008$ and $p = 0.01$). In 16D, no difference between males and females was found.

PedsQL scores improved after the transfer of care among AYAs with rheumatological disease and AYAs in the 'other' diagnostic group ($p = 0.008$ and $p = 0.045$) (figure 1). In 16D, single-index scores decreased in AYAs with diabetes ($p = 0.006$), but no significant changes were found in other diagnostic groups.

The mean ON TRAC knowledge score was 47.2 (SD 6.0, range 27–56). Total scores between genders and countries were similar. AYAs with diabetes had the highest ON TRAC scores and AYAs with neurological conditions had the lowest (49.6 and 44.6, $p < 0.001$ between groups).

The mean score of experience of care was 10.1 (SD 2.3, range 8–24). Scores were similar between genders, countries and diagnostic groups. AYAs gave worst evaluations to the statements 'The hospital provided an age-appropriate environment for me' and 'I spent at least some of the consultation alone without my parents' (mean scores 1.5 for both, SD 0.7 and 0.8).

In the total study population, transition readiness or experience of care showed no correlation with HRQoL ($r < 0.3$). AYAs in the top quartile of experience of care had better HRQoL before and after transfer of care and better transition readiness than AYAs in the lowest quartile of experience of care (figure 2). HRQoL and transition readiness were also associated with most questions regarding experience of care (table 3).

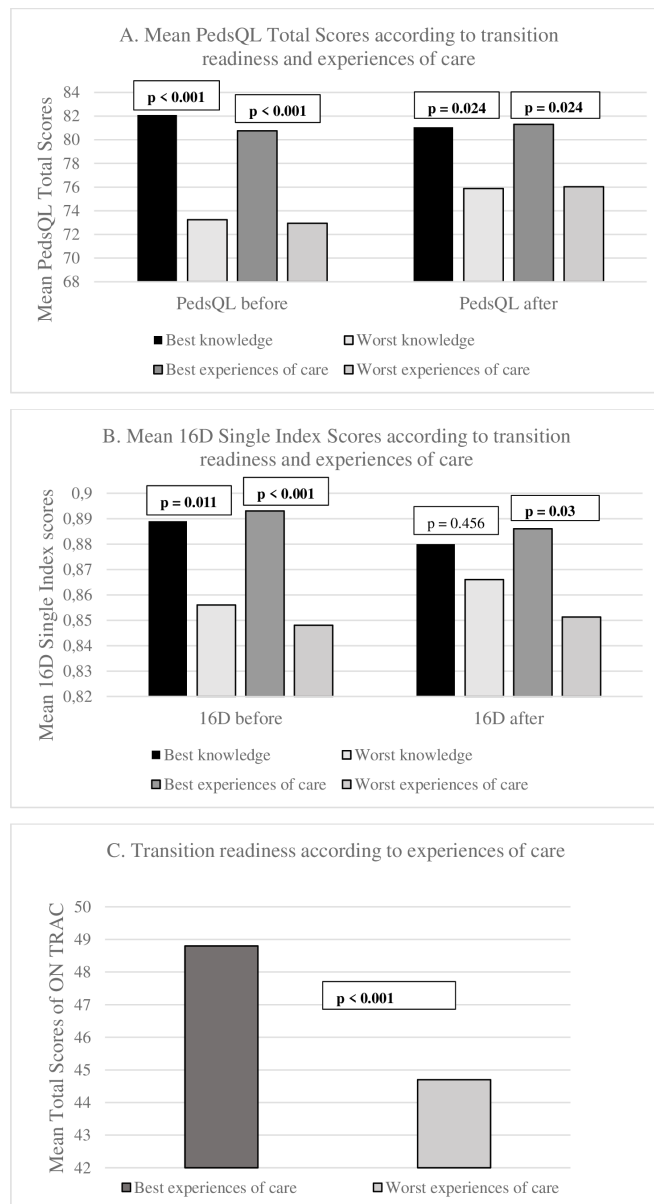


Figure 2 Health-related quality of life ((A) PedsQL; (B) 16D) among the highest and lowest quartiles of transition readiness and experience of care before and after transfer of care. (C) Transition readiness among the highest and lowest quartiles of experience of care before transfer of care. Number of adolescents in different groups: best experience of care (8 points) 137, worst experience of care (11–24 points) 150, best transition knowledge (≥ 52 points) 117 and worst transition knowledge (≤ 43 points) 116. $P < 0.05$ is considered statistically significant between best and worst knowledge and best and worst experience of care groups (Mann-Whitney U test). ON TRAC, Am I ON TRAC for Adult Care Questionnaire; PedsQL, Pediatric Quality of Life Inventory.

DISCUSSION

In this study, the mean HRQoL from two validated measures remained unchanged during transfer of care from paediatric to adult services. Better experience of care and better transition readiness before the transfer of care were associated with better HRQoL.

While our finding of similar HRQoL during transition is consistent with previous longitudinal studies of AYAs with chronic conditions,¹⁰ about one-third reported a decrease in HRQoL after transfer of care. Although our results are encouraging and

Table 3 Experience of care according to the modified Adolescent Friendly Hospital Survey and the associations of individual questions with health-related quality of life (PedsQL and 16D) and transition readiness before transfer of care

Adolescent Friendly Hospital Survey questions	The number of responses of the two alternatives True/somewhat true or false	PedsQL Mean total scores in the groups responding true/somewhat true or false (p value)	16D Mean single-index scores in the groups responding true/somewhat true or false (p value)	ON TRAC Mean total scores in the groups responding true/somewhat true or false (p value)
I felt welcome in the hospital.	459 (91%)/46	76.9/72.7 (0.115)	0.87/0.83 (0.024)*	47.3/45.8 (0.203)
The hospital provided an age-appropriate environment for me.	293 (58%)/209	76.7/76.7 (0.600)	0.87/0.87 (0.739)	47.6/46.6 (0.095)
I felt respected as a person by my treating team.	451 (89%)/55	77.1/71.3 (0.037)*	0.87/0.84 (0.072)	47.3/46.4 (0.503)
I fully understood the health information provided.	402 (80%)/103	78.0/70.9 (<0.001)*	0.87/0.84 (0.005)*	48.3/42.8 (<0.001)*
I received enough information about my medical problems.	435 (86%)/70	78.0/70.9 (0.001)*	0.87/0.84 (0.003)*	47.8/43.1 (<0.001)*
I was sufficiently involved in decisions about my care and/or treatment.	391 (80%)/101	77.3/73.5 (0.013)*	0.87/0.85 (0.074)	48.1/44.3 (<0.001)*
I felt comfortable to ask questions about my health and well-being.	426 (84%)/79	77.5/71.0 (0.001)*	0.87/0.84 (0.026)*	47.8/43.6 (<0.001)*
I spent at least some of the consultation alone without my parents	328 (65%)/177	77.8/73.8 (0.004)*	0.88/0.84 (<0.001)*	48.1/45.5 (<0.001)*

In PedsQL (maximum score 100), 16D (maximum score 1.00) and ON TRAC (maximum score 56), higher scores indicate better health-related quality of life and better transition readiness.

*Statistically significant difference, $p < 0.05$ (Mann-Whitney U) between groups according to true and somewhat true or false answers in Adolescent Friendly Hospital Survey questions and health-related quality of life and transition readiness.

ON TRAC, Am I ON TRAC for Adult Care Questionnaire; PedsQL, Pediatric Quality of Life Inventory.

show that transfer of care does not necessarily lead to deteriorating outcomes, AYAs with decreasing HRQoL could benefit from more intensive support during transition. Our finding that AYAs with rheumatological disease transferring via transition clinic had better HRQoL after transfer of care reinforces this notion. Based on our results, experiences of care and transition readiness could also be used to recognise AYAs in need of additional support, allowing for targeted transition interventions to promote positive outcomes.^{5 11 13 31}

Among Australian AYAs, psychosocial HRQoL scores increased after transfer of care in contrast to the subdomain scores of Finnish AYAs which all remained unchanged. The transition processes at these two study sites are different. The RCH provides a hospital-wide transition support service which might partly explain this improvement of scores. Beyond health systems, differences in the two countries' school systems and housing cultures may also contribute to these findings resulting in socioeconomic explanations of the differences in HRQoL. Lower HRQoL scores before transfer of care in Australian AYAs may also indicate that there was less room for improvement among Finnish AYAs (ie, ceiling effect).

We had anticipated differences in transition readiness and experience of care across the study sites, as we knew that transition processes differed between the two countries. Yet, we found no differences by country or gender. Although neither transition readiness nor experience of care showed an association with HRQoL in the total population, the top and bottom quartiles differed significantly. In previous studies, better transition readiness has been associated with better HRQoL and less anxiety and improved transition readiness with improved psychosocial quality of life.^{14 32 33} In our study, AYAs with diabetes had the best transition readiness. AYAs with diabetes must often take more responsibility for their condition at an early age to manage

their care at school. In addition, regular and frequent clinic visits may support learning which facilitates transition. For clinicians, recognising AYAs with poor transition readiness is important. Concentrating on education and self-management skill training could improve transitional care and reduce these differences seen in HRQoL as transition readiness can be improved with interventions and structured programmes.^{13 31}

Based on our study, poor experience of care was associated with poor HRQoL and poor transition readiness. It is concerning that so many AYAs spend their consultation visits together with their parents when meeting with adolescents alone for at least part of the consultation is considered a key element of successful transition.³⁴ Specifically, independent clinic visits and appropriate parental involvement are associated with improved HRQoL and other transition outcomes.^{16 35} AYAs themselves also appreciate the opportunity to talk to their doctor alone.³⁶ Ensuring that AYAs understand the information provided and directly involving AYAs in treatment are more likely the result of independent consultations, providing a strategy to improve experience of care, HRQoL and transition readiness.

As a strength of this study, participants were recruited from two different countries and represented many different diagnostic groups. We collected data prospectively and analysed changes in HRQoL between two time points and used two different HRQoL instruments. As a limitation, only 66% of the AYAs responded to the follow-up survey. Response rates were especially low among males and AYAs from Australia and the age at diagnosis was also different when comparing respondents and non-respondents. However, the retention rate was similar or better than in many related studies in this field (31–65%).^{14 15 37 38} Besides the medical condition, many other factors including body mass index and socioeconomic status can influence HRQoL.^{39 40} Because of the study design and limited

possibility to consider these potential confounding factors, our results should be interpreted with caution. As the transition process was not standardised, these results describe the changes in HRQoL of AYAs undergoing transition at the participating two hospitals. The 1-year follow-up time might also be too brief to capture all relevant changes in HRQoL.

Our findings suggest important avenues to pursue in future research, such as concentrating on factors affecting experience of care and transition readiness, as these are likely to enhance transitional care and the HRQoL of AYAs with chronic conditions. Studies explaining the reasons behind the deteriorating HRQoL during transfer of care would also provide additional information on how to support these AYAs.

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Contributors MMK collected data, carried out initial analyses, drafted the initial manuscript and reviewed and revised the manuscript. AT and HL collected data and reviewed and revised the manuscript. K-LK, EC and SMS participated in designing the study and reviewed and revised the manuscript. SK designed the study, coordinated and supervised data collection and critically reviewed the manuscript for important intellectual content. SK is responsible for the overall content as the guarantor. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and 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) in Australia as a part of a study called 'The Bridge'. All participants gave written informed consent.

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