

Transition to adult care of young people with congenital heart disease: impact of a service on knowledge and self-care skills and correlates of a successful transition

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Aims

Less than one-third of adolescents with congenital heart disease (CHD) successfully transition to adult care, missing out on education of their cardiac condition, and risking loss to follow-up. We assessed the efficacy of our transition clinic on patient education and empowerment and identified correlates of successful transition.

Methods and results

Overall, 592 patients were seen at least once in our transition service between 2015 and 2022 (age 15.2 ± 1.8 years, 47.5% female). Most adolescents (53%) had moderate CHD, followed by simple (27.9%) and severe (19.1%) CHD. Learning disability (LD) was present in 18.9% and physical disability (PD) in 4.7%. In patients without LD, knowledge of their cardiac condition improved significantly from the first to the second visit (naming their condition: from 20 to 52.3%, $P < 0.0001$; describing: 14.4–42.7%, $P < 0.0001$; understanding: 26.1–60.7%, $P < 0.0001$), and from the second to the third (naming: 67.4%, $P = 0.004$, describing: 61.4%, $P < 0.001$, understanding: 71.1%, $P = 0.02$). Patients with LD did not improve their disease knowledge over time (all $P > 0.05$). Treatment adherence and management involvement, self-reported anxiety, and dental care awareness did not change over time. Successful transition (attendance of ≥ 2 clinics) was achieved in 49.3%. Younger age at the first visit, simpler CHD, and absence of PD were associated with successful transition.

Conclusion

A transition service positively impacts on patient education and empowerment in most CHD adolescents transitioning to adult care. Strategies to promote a tailored support for patients with LD should be sought, and earlier engagement should be encouraged to minimize follow-up losses.

Keywords

Congenital heart disease • Transition • Adolescent medicine • Education • Learning disability

Introduction

Advances in the diagnosis and management of congenital heart disease (CHD) have led to vast expansion of the adult CHD population, with up to 97% of children affected reaching adulthood in the last few decades.¹ These patients, however, are at increased risk of

complications and require lifelong specialist adult CHD follow-up.² Guidelines recommend that healthcare transition starts during early adolescence in the paediatric setting and continues into adulthood.^{2–4} This process involves paediatric and adult CHD providers helping adolescents and young adults with CHD to develop specific knowledge and self-care skills, and ultimately gain independence and confidence

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All authors take responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

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with regards to their health. This is to prevent complications, minimize losses to specialist follow-up, and facilitate the transfer event, at which point patients are expected to take ownership of their healthcare.^{5,6} Children with more complex forms of CHD, who are at higher risk of neurodevelopmental deficits, may need further support during this transitional period.⁷ Patient education is at the centre of the transition process, however, data on the impact of transition service are limited. Currently, <50% of European ACHD centres have a structured transition programme and less than one-third of adolescents with cardiac conditions successfully transition to adult care, with a high rate of discontinuity of care during this period.^{8–10} Thus, there is a need to improve patient education in the transition process and develop a systematic and tailored program for paediatric hospitals and aligned adult CHD units.¹¹ This study assesses the impact of a nurse-led transition service on knowledge and self-care skills of adolescents and young adults with CHD, and identifies factors that are associated with a successful transition to adult care.

Methods

Study design and population

This is a retrospective, longitudinal study of patients with CHD seen at least once in our transition clinic between April 2015 and January 2022 at Royal Brompton Hospital (London, UK). Children over 12 years of age were referred to our transition service by paediatric cardiologists, paediatric cardiac nurse specialists, or other healthcare professionals. Patients with learning disability (LD) of any degree were included in the study. Learning disability was defined as the presence of impairment of cognitive, communication, and self-care skills.⁷ Physical disability was defined as a limitation of physical functioning due to mechanical or neurological causes.

This study was registered as a quality improvement project locally. The retrospective component of the study involved anonymized data collected for clinical purposes, and therefore individual consent was waived. To minimize the possibility of unintentionally sharing information that can be used to re-identify private information, patient-level data are not available for use outside of this study.

Transition service

Transition care was provided through nurse-led clinics, overseen by a clinician with expertise in CHD transition. Additional support was accessible by patients via a dedicated telephone and email service. Due to the COVID-19 pandemic, the service was restructured, and face-to-face clinics were converted to virtual clinics using a web-based video conferencing tool.¹² According to the modified 'Ready, Steady, Go' model,¹³ the transition service consisted of three clinics for CHD patients from 12 to 21 years of age. The Pan-London Transition Consortium developed integrated care pathways that standardized transition visits to ensure high-quality, standardized care in all participating centres (Figure 1). The details of our transition model have been published previously.¹⁴ It was standard practice to discuss the patient's cardiac condition, previous procedures, comorbidities, medications, complications, and long-term outcomes. This was followed by completion of a transition checklist of competence in several areas, including the patient's ability to name, describe, and understand their CHD. The standard time lapse between two transition clinics was ~18 months, hence, our analysis cohort included all patients who had completed their second transition clinic visit at least 18 months from the end of the study period.

Collection of clinical variables

Information on demographic and clinical characteristics were collected from a dedicated clinical database. Congenital heart disease was categorized by anatomic severity using an established system of classification.¹⁵ Qualitative assessment of the following categories was undertaken by clinical nurse specialists during the appointment: ability to name, describe,

and understand their cardiac condition, treatment adherence, and involvement in medication management, self-reported anxiety, and dental care awareness. The ability to name and describe their cardiac condition was recorded as 'able', 'partially able', and 'unable', while the ability to understand the implications was classified as 'excellent', 'good', 'moderate', or 'poor'. In patients with severe LD, where questions could not be directed to the patients themselves, clinical nurse specialists addressed questions to accompanying family members/carers.

Transition service assessment questionnaire

To assess the efficacy of our transition service, we created a Transition Service Assessment Questionnaire (TSAQ), based on previously published questionnaires.^{16–19} Questionnaires were administered pre- and immediately post-consultation over a brief period of 3 months. Patients were verbally consented and able to complete questions (i.e. without significant LD). The TSAQ included topics about recognition of acute illness symptoms, awareness of importance of periodic specialist and dental follow-up, dental hygiene, contraception options, and pregnancy safety, and consisted of a mix of true or false and qualitative questions ('strongly agree', 'agree', 'undecided', 'disagree', 'strongly disagree'; Supplementary material online, Figure S1).

Statistical analysis

Numerical data were presented as mean \pm standard deviation, while categorical data were reported as absolute number and percentage. Binomial, paired parameters were analysed using McNemar's test, whereas continuous, paired data with Wilcoxon's signed-rank test.

A successful transition service was defined as attendance of ≥ 2 transition clinics. A multivariate logistic regression model was used to identify parameters associated with transition success including age, time interval between the first consultation and the study end date, sex, CHD complexity, presence of learning and physical disability, and Index of Multiple Deprivation 2019 (most deprived decile vs. remainder).²⁰ The latter represents the patients' socioeconomic status based on geographical location, and was calculated using seven domains such as income, employment, education, health, crime, living environment, and barriers to housing and services. *P* values < 0.05 were considered statistically significant. Statistical analyses were performed using SPSS, version 28 (SPSS, Chicago, IL, USA, 2021).

Results

Health education

A total of 592 patients were included in this study. Mean age at first visit was 15.2 ± 1.8 years and 47.5% of patients were female. One half (49.3%) of the patients attended two transition consultations and 20.5% three consultations. Mean time interval between the first and second visits was 16 ± 9 months, while between the second and third visits was 14 ± 7 months. Most patients (53%) had moderate CHD, whereas 27.9% had simple and 19.1% greatly complex CHD. Physical disability was present in 4.7%, while one-fifth (18.9%) of patients had LD. Of patients with LD, 28.3% had an associated genetic syndrome (Table 1). There was no significant difference in the rates of CHD complexity in patients with and without LD (simple: 21.4% vs. 29.4%, *P* = 0.09; moderate: 58.9% vs. 51.7%, *P* = 0.2; great: 19.6% vs. 19%, *P* = 0.99).

Amongst the 480 patients without LD, only a minority were able to fully name (20%), fully describe (14.4%), and well or excellently understand the implications (26.1%) of their cardiac condition at the first visit (Table 2). There was a significant increase in their ability to fully name their cardiac condition from the first to the second (52.3%, *P* > 0.0001) and from the second to the third consultation (67.4%, *P* = 0.004). The ability to fully describe their cardiac condition improved significantly to 42.7% (*P* < 0.0001) by the second and to

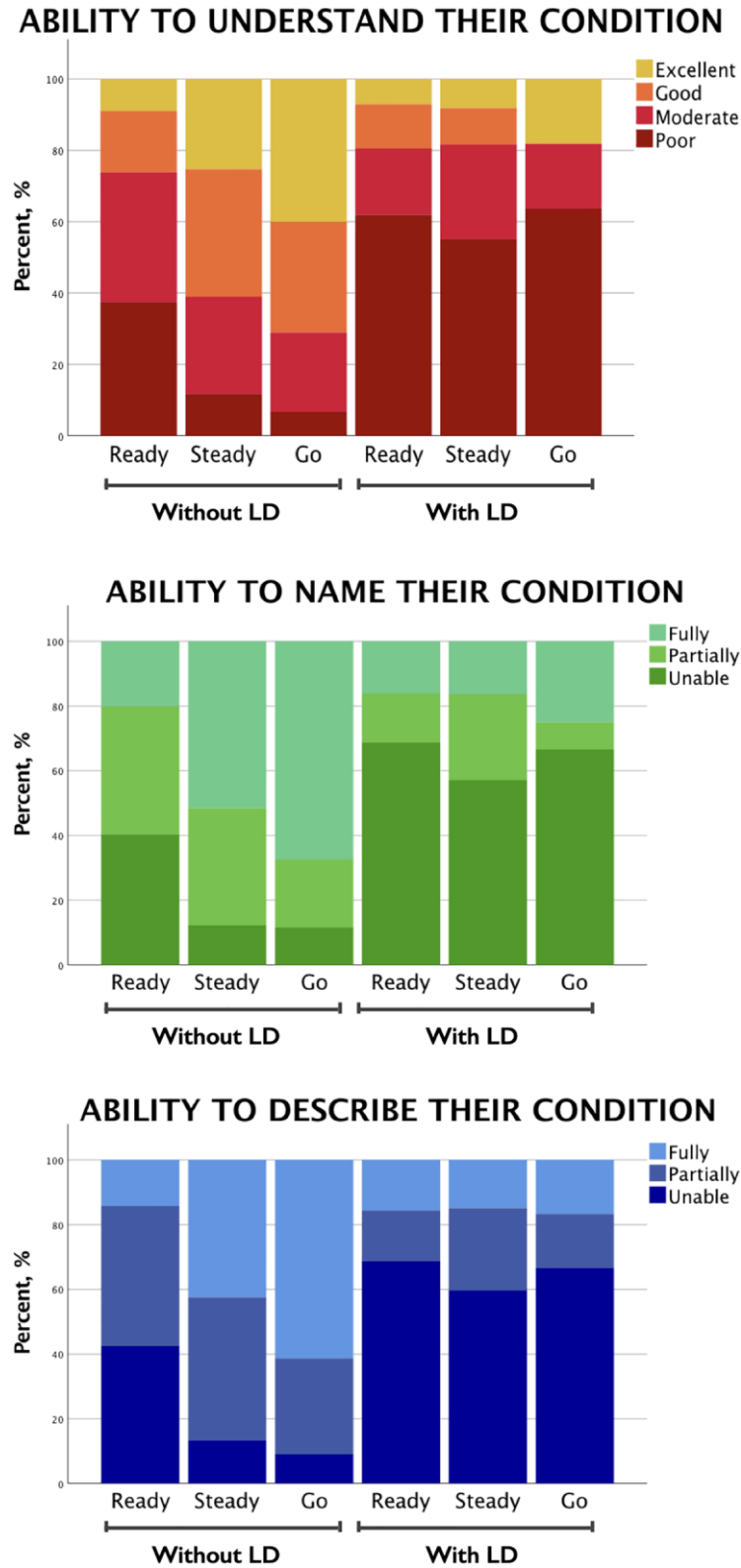


Figure 1 'Ready, Steady, and Go' (1st, 2nd, and 3rd clinic) model by categories (ability to understand, name, and describe their cardiac condition) in patients with and without learning disability (LD).

Table 1 Demographic and clinical characteristics of patients undergoing transition.

	n = 592
Age at first transition clinic visit, years \pm SD	15.2 \pm 1.8
Female sex	281 (47.5%)
Transition clinic attendance	
• 2 consultations	292 (49.3%)
• 3 consultations	60 (20.5%)
Time interval, months \pm SD	
• between 1 st and 2 nd consultation	16 \pm 9
• between 2 nd and 3 rd consultation	14 \pm 7
CHD complexity	
• Simple	165 (27.9%)
• Moderate	314 (53%)
• Severe	113 (19.1%)
Physical disability	28 (4.7%)
Learning disability	112 (18.9%)
• associated with genetic syndromes:	
o Down syndrome	22 (19.4%)
o DiGeorge syndrome	10 (8.9%)

Values are given as mean \pm SD or n (%).

61.4% ($P < 0.001$) by the third visit. Patients with a good or excellent understanding of their cardiac condition increased from the first to the second (60.7%, $P < 0.0001$) and from the second to the third visit (71.1%, $P = 0.016$).

With regards to the 112 patients with LD, only a few were able to fully name (16.7%), fully describe (16.2%) and well or excellently understand their cardiac condition (20.2%) at the first visit. Their abilities did not improve from the first to the second (name: 15.6%; describe: 14%, understand: 17.8%; all $P > 0.05$) or from the second to the third clinic (name: 25%; describe: 16.7%; understand: 18.2%; all $P > 0.05$).

Most patients adequately adhered to medications in both groups (no LD: 1st clinic: 68.1%, 2nd:76.8%, 3rd:71.9%; LD: 1st: 83.3%, 2nd:80.6%, 3rd:62.5%; all $P > 0.05$, Table 2) since the first consultation with no significant change over time. Involvement in medication management was observed in a higher proportion of patients without LD (1st clinic: 77.5%, 2nd:84%, 3rd:80%, all $P > 0.05$) compared with those with LD (1st: 33.3%, 2nd:48.5%, 3rd:14.3%, all $P > 0.05$) throughout transition. Anxiety was reported in a minority of patients without LD (1st clinic: 21.8%, 2nd:23.5%, 3rd:16.7%, all $P > 0.05$), while a higher percentage was present in those with LD (1st: 38.4%, 2nd:46.2%, 3rd:37.5%, all $P > 0.05$) with no change over time. Almost all patients (>99%) showed good awareness of the importance of dental hygiene in both groups throughout transition (all $P > 0.05$).

Transition service assessment questionnaire

A subset of 27 patients completed the Transition Service Assessment Questionnaire (TSAQ) before and after the transition consultation. Age at questionnaire completion was 15.2 \pm 1.7 years and 10 (37%) were female. Two-thirds of questionnaires (18, 66.7%) were provided at the first transition clinic, while 7 (25.9%) at the second and 2 (7.4%) at the third consultation. Most patients (17, 63%) had moderate CHD, whereas 7 (25.9%) had simple, and 3 (11.1%) greatly complex CHD.

Almost all patients agreed or strongly agreed that they could name their heart condition and/or previous surgeries following the clinic visit [increased from 13 (48.1%) to 25 (92.6%), $P < 0.001$, Table 3]. The transition visit led to improvements in the perceived knowledge of when [from 18 (65.4%) to 24 (88.5%), $P = 0.03$] and how [from 15 (55.6%) to 26 (96.3%), $P < 0.001$] to seek medical help in the presence of acute health issues. The transition consultation significantly increased the proportion of patients aware of a lifelong CHD follow-up [from 14 (51.6%) to 23 (85.2%), $P = 0.004$].

Most patients were already aware of the importance of regular medical [from 22 (81.5%) to 26 (96%), $P = 0.1$] and dental follow-up [from 25 (92.3%) to 27 (100%), $P = 0.99$] before the visit, which further increased to include almost all cases after the consultation. Fewer patients were aware of current practice guidelines regarding the use of antibiotic prophylaxis [from 10 (37.5%) to 17 (62.5%), $P = 0.1$]. Their perceived knowledge about which exercise or sports to perform increased after the consultation [22 (80%) to 26 (96%), $P = 0.1$]. A single patient was aware of issues regarding health insurance (3.7%), but this rose remarkably to 14 (52.2%) post-consultation ($P < 0.001$). Female patients notably improved their knowledge regarding fertility [from 2 (18.2%) to 7 (72.7%), $P = 0.03$], pregnancy-related complications [from 1 (10%) to 8 (80%), $P = 0.02$] and pregnancy safe medications [from 2 (16.7%) to 5 (50%), $P = 0.5$]. Most of them were aware of contraception options (from 79.6% to 84.6%, $P = 0.99$) both prior and post consultation.

All patients knew that they could access higher education ($P = 0.99$) and the vast majority were aware that they could access employment [26 (96%) to 23 (84%), $P = 0.99$] despite their cardiac condition. The transition consultation clarified doubts about limitations for certain jobs because of their cardiac condition, with a significant reduction of the proportion of those who were unsure [from 8 (30.8%) to 2 (7.7%), $P = 0.03$]. Almost all patients were aware that they could have children [from 22 (81.8%) to 25 (90.9%), $P = 0.5$].

Factors associated with transition success

We found that 49.3% of adolescents with CHD met our criteria of transition success. Older age at the first appointment (OR 1.64, 95% CI 1.48–1.85, $P < 0.001$), greater CHD complexity (OR 1.54, 95% CI 1.04–2.27, $P = 0.03$), and physical disability (OR 3.85, 95% CI 1.56–10, $P = 0.006$, Table 4) were less likely to succeed in attending ≥ 2 transition clinics. Neither sex, LD, time interval between the first visit and the study end date nor socioeconomic status remained in the multivariable model.

Discussion

This study showed a positive impact of a structured transition on the empowerment of most adolescents and young adults with CHD, by equipping them with knowledge about their cardiac condition and self-care skills. Patients who are introduced to the transition service at a younger age, with simpler CHD, and without physically disability, appear more likely to transition successfully to adult care. The transition process was effective in addressing additional topics, such as recognition of symptoms of acute illness, acknowledgement of the importance of periodic specialist CHD and dental follow-up, maintenance of dental hygiene, and awareness of contraception options and pregnancy safety. This broad range of subjects covered is relevant to most adults with a chronic cardiac condition and is aimed at reducing long-term complications and loss to follow-up.

Studies to date have demonstrated that only one-third of adolescents with cardiac conditions successfully transition to adult care, and transition knowledge deficits are commonly associated with a

Table 2 Patients with and without learning disability (LD) at the first, second, and third transition clinic.

		Patients without LD n = 480		Patients with LD n = 112		
Ability to fully name their condition	95 (20%)	125 (52.3%) P < 0.0001 ^a	29 (6.7%) P = 0.004 ^b	18 (16.7%)	7 (15.6%) P = 0.2 ^a	2 (2.5%) P = 0.6 ^b
Ability to fully describe their condition	68 (14.4%)	99 (42.7%) P < 0.0001 ^a	27 (6.4%) P < 0.001 ^b	17 (16.2%)	6 (14%) P = 0.3 ^a	2 (16.7%) P = 0.7 ^b
Good or excellent understanding of their condition	124 (26.1%)	147 (60.7%) P < 0.0001 ^a	32 (7.1%) P = 0.016 ^b	22 (20.2%)	8 (17.8%) P = 0.6 ^a	2 (18.2%) P = 0.7 ^b
Adherence to medications	168 (68.1%)	119 (76.8%) P = 0.4 ^a	23 (7.9%) P = 0.4 ^b	60 (83.3%)	25 (80.6%) P = 0.99 ^a	5 (62.5%) P = 0.5 ^b
Involvement in medication management	193 (77.5%)	131 (84%) P = 0.3 ^a	28 (80%) P = 0.99 ^b	25 (33.3%)	16 (48.5%) P = 0.4 ^a	1 (14.3%) P = 0.5 ^b
Self-reported anxiety	87 (21.8%)	53 (23.5%) P = 0.7 ^a	7 (16.7%) P = 0.1 ^b	33 (38.4%)	18 (46.2%) P = 0.6 ^a	3 (37.5%) P = 0.99 ^b
Awareness of the importance of dental hygiene	465 (99.4%)	242 (99.2%) P = 0.99 ^a	46 (100%) P = 0.99 ^b	110 (110%)	44 (100%) P = 0.99 ^a	11 (100%) P = 0.99 ^b

*a: comparison between the first and second transition clinic; b: comparison between the second and third transition clinic. Values are presented as n (%).

decrease in self-efficacy and autonomy.^{8,17,21} Our service had a positive impact on patient education and empowerment in most cases, especially those without LD. Patients improved the knowledge of their cardiac disease and related complications and developed greater 'readiness skills', including better treatment adherence, involvement in medication management, and dental hygiene awareness.²² Knowledge of their cardiac condition (ability to name/describe/understand) continued to improve after the second and third visit, advocating for a 'process' of transition with repeated encounters that allow time and space for learning.

Many adolescents with CHD have limited self-management skills, as the responsibility for managing their health has been overseen by their parents. Developing health-related knowledge and self-management skills are associated with improved quality of life, and is essential for empowerment and independence in healthcare.^{8,23} The use of a pre- and post-transition clinic questionnaire in a subgroup of patients demonstrated a positive impact of a single visit, with a clear improvement in perceived knowledge and self-management skills, including recognition of acute illness symptoms, awareness of the importance of periodic specialistic follow-up, and dental hygiene. Perceived knowledge about fertility, contraception, and pregnancy increased considerably in almost all female patients over the transition period. Finally, the transition consultations addressed concerns regarding the impact of cardiac limitations on educational and employment opportunities. This process of education of young people with chronic heart conditions arms them with the tools to take responsibility in managing their health, adhere to medication and specialist follow-up, and recognise symptoms in a timely fashion, seeking help when appropriate.

We found that the majority of our population had a successful transition, similar to other studies, although their definition of success differed to ours.²⁴ While previous studies have investigated the transfer to adult care, we focused on engagement with transition services, which we defined as attendance of two or more specialist transition clinic visits. In this study, non-attendees were more likely to be older at their first transition visit, with greater complexity of CHD and physical disability. Hence, we have identified a high-risk category of patients, who were less likely to engage with the transition service.⁵ Several steps can be taken to target this group and improve transition success. Although older patients may possess greater maturity and

better understanding of their condition and potential complications, ensuring an earlier initial transition visit allows better patient involvement and more time for education before transfer to adult care. Previous studies have found that patients with simpler defects and no residual lesions who are asymptomatic after successful repair, are less likely to undergo a smooth transition; this was not the case in our population.¹⁰ All paediatric CHD patients and their families, regardless of the severity of their condition, should receive counselling to stress the role of the transition service in ensuring uninterrupted, lifelong specialist care, with the aim of minimising complications and improving outcomes. Patients with physical disability also had a lower attendance rate.²⁵ Hospital transport, an accessible hospital environment that meets the needs of physically disabled patients, and the use of web-based video conferencing tools, when appropriate, can help minimize non-attendance and loss to follow-up.

This study showed limited knowledge and self-care skills and higher levels of anxiety in adolescents and young adults with LD.^{26,27} This supports the need for a transition service tailored to patients with LD, with careful assessment of the severity of LD and a multidisciplinary approach. Patients with mild to moderate LD may benefit from additional or longer transition clinic appointments, with the use of dedicated learning material. An approach with close involvement of family and/or carers is more appropriate for those with severe LD, also involving a broader team of general practitioners, teachers, social workers, etc.

Limitations

The main limitation of this study is its retrospective nature, with data derived from clinical records. Grading patients' knowledge required individual judgment by multiple clinical nurse specialists experienced in the care of adolescents with CHD who were involved in transition clinic assessments. Service disruption throughout the COVID-19 pandemic was overcome by conversion to virtual (video or telephone) clinics, which helped to limit missed appointments. However, the pandemic did affect our ability to routinely use the TSAQ, which was completed by a small group of patients. The TSAQ was administered at the end of the consultation. Separating the consultation visit and survey administration would have provided additional useful information about retention of information and transition

Table 3 Results of the pre- and post-transition clinic questionnaire.

Population characteristics	N = 27		
Age, years ± SD	15.2 ± 1.7		
Female sex, n (%)	10 (37%)		
Consultation tested, n (%)			
- first	18(66.7%)		
- second	7 (25.9%)		
- third	2 (7.4%)		
CHD complexity, n (%)			
- mild	7 (25.9%)		
- moderate	17 (63%)		
- severe	3 (11.1%)		
Questions:			
Agree or strongly agree with following statements, n (%)	Pre-clinic	Post-clinic	P value
1. I know the name of my heart condition/previous surgery	13 (48.1%) ^a	25 (92.6%) ^a	<0.001
2a. I know the name of my heart medication	6 (60%) ^b	9 (90%) ^b	0.3
2b. I know what my medicines are for	8 (80%) ^b	8 (80%) ^b	0.99
2c. I know how to get more medication when I run out	8 (80%) ^b	8 (80%) ^b	0.99
3. I know when to make my doctor aware of symptoms or other problems	17 (65.4%) ^c	23 (88.5%) ^c	0.03
4. I know how to contact my doctor	15 (55.6%) ^a	26 (96.3%) ^a	0.001
5. I know how often I need to see a heart doctor	22 (81.5%) ^a	26 (96.3%) ^a	0.1
6. I will need to see a heart doctor periodically for the rest of my life	14 (51.9%) ^a	23 (85.2%) ^a	0.004
7a. I know how often to see my dentist	24 (92.3%) ^c	26 (100%) ^c	0.99
7b. I know whether I need antibiotics when visiting my dentist	9 (37.5%) ^d	15 (62.5%) ^d	0.1
8. I know which exercise/sports activities I should and should not do	20 (80%) ^e	24 (96%) ^e	0.1
9. I know how to get health insurance	1 (4.3%) ^f	11 (52.2%) ^f	0.001
10. I know whether my heart condition could affect my ability to get pregnant	2 (18.2%) ^g	8 (72.7%) ^g	0.03
11. I know whether my heart condition could get worse if I got pregnant	1 (10%) ^b	8 (80%) ^b	0.02
12. I know whether my medication could be harmful to an unborn baby	1 (16.7%) ^h	3 (50%) ^h	0.5
13. I know what I can do to avoid an unplanned pregnancy	10 (79.6%) ⁱ	11 (84.6%) ⁱ	0.99
Because of my heart condition:			
14a. I can't go to college/University (false)	25 (100%) ^e	25 (100%) ^e	0.99
14b. I can't get a job (false)	24 (96%) ^e	21 (84%) ^e	0.3
14c. I can't have certain jobs (don't know)	8 (30.8%) ^c	2 (7.7%) ^c	0.03
14d. I can't have kids (false)	18 (81.8%) ^l	20 (90.9%) ^l	0.5

Number of answers analysed (denominators): a:27, b:10, c:26, d:24, e:25, f:23, g:11, h:6, i:13, l:22 values are given as mean ± SD or n (%).

Table 4 Predictors of attendance to at least two transition clinics based on multivariate logistic regression.

Characteristics	Odds ratio	95% confidence interval	P value
Age at the first clinic*	0.61	0.54–0.68	<0.001
Time interval between first visit and study end date	1.01	1.00–1.02	0.1
Sex (female)	1.13	0.79–1.62	0.5
Complexity of cardiac disease (moderate/severe)	0.65	0.44–0.96	0.03
Learning disability	1.48	0.91–2.40	0.1
Physical disability	0.26	0.10–0.64	0.006
Index of Multiple Deprivation (most deprived decile)	1.3	0.45–3.85	0.6

*Refers to 1 year increase.

consultation success. Further prospective studies are needed to examine the various components of the transition process and its efficacy, including variability of transition rates across specialist centres according to their size and region.

Conclusions

A structured transition service can have a positive impact on patient empowerment, with improvements in knowledge and self-care skills for most adolescents and young adults with CHD. The transition team should be able to accommodate patients with LD and their families. Transition cannot be completed in a single clinic visit, but is a multi-year process of education and preparation for adult life with CHD.

Supplementary material

Supplementary material is available at [European Heart Journal—Quality of Care and Clinical Outcomes](#) online.

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Data availability

To minimize the possibility of unintentionally sharing information that can be used to re-identify private information, patient-level data are not available for use outside of this study.

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