The Turkish Journal of Pediatrics 2026; 68: 401-415
https://doi.org/10.24953/turkjpediatr.2026.6723

Original Article

Bridging the gap: knowledge deficits and adherence challenges in adolescents with congenital heart disease

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ABSTRACT

Background. Although approximately 90% of children with congenital heart disease (CHD) survive into adulthood, many lack sufficient knowledge about their condition and the need for life-long care. This leads to gaps in follow-up, especially during transition to adulthood, nonadherence to treatment, and increased risk of complications. This study aimed to assess CHD-related knowledge and adherence among adolescents.

Method. The Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD) was translated and validated into Turkish to evaluate CHD-related knowledge, including treatments, endocarditis, pregnancy risks, appropriate contraceptive methods, and the risk of recurrence. Adequate disease knowledge was defined as answering ≥80% of questions correctly. The Medication Adherence Reporting Scale (MARS) was used to assess medication adherence.

Results. Among 118 adolescents, only two had adequate knowledge (≥80% correct), with a mean LKQCHD score of 51.09/100. Older adolescents and those with higher adherence had significantly better knowledge. The poorest knowledge areas were endocarditis and reproductive health.

Conclusion. The insufficient disease knowledge among CHD patients may lead to poor adherence and increased comorbidities, and higher mortality in adulthood. We recommend implementing a structured education and transition program focused on improving health literacy, adherence, and continuity of care, developed collaboratively by cardiologists and adolescent medicine specialists.

Key words: adolescent, congenital heart disease, disease knowledge, treatment adherence, transitional care.

Congenital heart disease (CHD) is the most common congenital defect, with an estimated prevalence of nearly 8 per 1000 live births.[1] Due to advances in diagnosis and treatment, around 90% of children with CHD now reach adulthood.[2] Lifelong follow-up of these patients are necessary due to long term complications of CHD such as heart failure, endocarditis, arrhythmia and pulmonary hypertension.[3] Despite its importance, many patients

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Received 28th Jul 2025, revised 31st Jan 2026, accepted 27th Feb 2026.

The study was prepared as a thesis, it was presented at the 23rd IAAH European Regional Conference “Adolescent health and well-being - Hope in a time of uncertainty” October 10th-11th, 2024, Copenhagen, Denmark. It was also published at Scandinavian Journal of Public Health as an abstract.

experience lapses in care—often around the age of 19-20 years, during the transition to adult services—largely due to a false sense of being "cured" or unawareness of the need for follow-up.[4-8] Many adolescents with CHD have a limited understanding of their condition, while greater knowledge is linked to better follow-up adherence and fewer risky health behaviors such as substance use, poor oral hygiene, and insufficient physical activity.[8-11] To address these gaps, transitional care programs have been developed to enhance disease knowledge, reinforce self-management skills, and emphasize the importance of lifelong care—ultimately improving adherence and reducing long-term health risks.[12-14]

Beginning in early adolescence, the programs gradually shift healthcare responsibilities from parents to adolescents, promoting a deeper understanding of their condition and encouraging greater self-management.[13,14] Current evidence indicates that participation in these programs not only enhances patient education and disease-related knowledge but also promotes autonomy, improves disease management, and fosters self-acceptance.[15-18] Research also demonstrates that greater disease knowledge is linked to engagement in positive health behaviors, and that integrated, clinic-based transition interventions can reduce loss to follow-up among adolescents and young adults with CHD.[19,20] However, the direct impact of disease knowledge on medication adherence remains unclear among adolescents with CHD. Existing data on disease knowledge among adolescents with CHD predominantly originates from studies conducted in high- and middle-income Western countries, whereas research from low-and middle-income countries remain limited in this area.

To the best of our knowledge, no Turkish studies have investigated disease knowledge or treatment adherence among adolescents with CHD, nor is there a validated tool available to assess CHD-related disease knowledge. With this study, we aimed to assess CHD-related knowledge and compliance among adolescents under our care.

Materials and Methods

Study population and design

This prospective, survey-based cohort study included adolescents and young adults with CHD and was conducted between April 2023 and May 2024 with the approval of local Ethics Committee. Youth with CHD (aged 14 to 24 years) who were followed up at our hospital and who attended at least one outpatient visit at our Pediatric Cardiology clinic or who were assessed by our Pediatric Cardiology team during inpatient admission were included in the study. Patients with known intellectual disability or with major congenital anomalies of other organ systems (apart from the existing congenital cardiac anomaly) were excluded from the study. For patient selection, the applications to the Pediatric Cardiology outpatient clinic were monitored daily, and patients with a diagnosis of CHD who met the inclusion criteria were identified and invited to participate in the study following their examinations at the pediatric cardiology outpatient clinic.

Informed consent was obtained from both adolescents and parents or guardians of the patients under 18 after introducing the study purpose and procedure. After obtaining the necessary consent, face-to-face interviews lasting around 12-15 minutes were conducted with the patients in the meeting room of the pediatric cardiology department. Patients were asked to fill out the Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD) along with the Medication Adherence Report Scale (MARS) if they were on any medication for their cardiac disease. All patients were also asked to fill out the "Demographic and Socioeconomic Assessment Form".

Information obtained from medical records

The cardiac diagnosis, the age at the time of diagnosis, history of any cardiac interventional procedures or surgeries, presence of bioprosthetic or mechanical valves, presence of an intracardiac defibrillator (ICD) or pacemaker, hospital admissions due to cardiac causes in the last 5 years, history of endocarditis, presence of accompanying pulmonary hypertension, and non-cardiac chronic diseases were queried through medical records obtained from the electronic records and patient files.

Participants were grouped based on the cardiac diagnoses, the anatomical complexity of their congenital cardiac defects using the Bethesda classification (simple, moderate and high complexity) and their functional limitations according to the New York Heart Association (NYHA) Functional Classification for Heart Failure. NYHA functional classification was determined based on the clinical complaints and physical limitation indicators assessed during the most recent Pediatric Cardiology outpatient visit. The scale responses, form answers, details of the individual's medical history, and NYHA classifications were processed into the study's database with a patient-specific assigned code.

Demographic and socioeconomic assessment form

This form was developed by the research team. The participant's age, the province they live in, their education level (the grade they are in if they are continuing their education, the last grade they attended if they took a break from their education, whether they took a break from their education due to heart disease, and the duration of the break), details about their parents (age, education, occupation, living status, and whether they live together), the number of people the participant shares their household with, and the presence of CHD or other chronic diseases among the household members were questioned.

Medication Adherence Reporting Scale (MARS)

Participants taking at least one medication for their heart disease were asked to complete the Medication Adherence Report Scale (MARS), a five-item tool developed by Horne and Hawkins to assess adherence in individuals with chronic diseases, and adapted into Turkish by Temeloğlu Şen et al. in 2019.[21,22] Participants with a MARS score of 23 and above were considered to have high adherence to their medication therapy.[23,24]

The Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD)

The Leuven Knowledge Questionnaire for Congenital Heart Disease was developed by Dr. Philip Moons and colleagues to measure disease-related-knowledge in patients with CHD.[25] This tool involves 25 questions for males and 27 questions for females, evaluating knowledge on various areas including physical limitations, used medications and potential side effects, endocarditis, healthy behaviors to maintain general well-being, pregnancy risks related to heart disease and risk or recurrence in the offspring. Since CHDs are a heterogeneous group with variable anatomical and physiological complexity, causing different degrees of physical limitation, the accuracy of responses was evaluated based on the patient-specific congenital heart anomaly, in-line with the coding manual of the LKQCHD 2009 UK version, item related guidelines and literature.[26-30] Participants' responses to each LKQCHD item were evaluated as correct, incomplete, incorrect or unknown. Patients who answered 80% or more of the items of the LKQCHD correctly were considered to have sufficient knowledge, those with 50–80% considered to have moderate knowledge, and those with less than 50% considered to have insufficient knowledge.[8,9,25]

Translation, content and construct validity study of the Turkish version of LKQCHD

Following the approval of Dr. Moons, the developer of the LKQCHD, the Turkish translation and validation study of the scale was initiated. A three-step linguistic validation method: (i) forward translation, (ii) backward translation, and (iii) patient testing was used for adapting The Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD) into Turkish. During the forward translation phase, the questionnaire was translated into Turkish by a pediatrician who was a native Turkish speaker and demonstrated proficiency in English at a C1 level. Subsequently, the Turkish translation of the scale and the original version in English were presented to a panel of experts consisting of a pediatric cardiologist, two adolescent health specialists, and a pediatrician actively working in the field of pediatric cardiology. Each expert was asked to rate the relevance and the clarity of the items in the scale as "appropriate," "item should be slightly revised," "item should be seriously revised," and "item is not appropriate".[31]

Items with a I-CVI of 0.78 and above were considered to demonstrate good content validity.[32] Among the 27 items in the scale, only the 24th item (inquiry about physical limitations regarding sexuality in patients with CHD) was rated as "item should be seriously revised" by all four experts. I-CVI was calculated as 0 for the 24th item, the item was revised to make it more understandable and clearer. The CVI for the rest of the 26 items were calculated as 1, S-CVI of the questionnaire was calculated as 0.96. To assess interrater reliability, kappa analysis was used, which was calculated to be 1, indicating perfect agreement among raters.[33]

The Turkish questionnaire was translated into English by a professional translator with expertise in medical translation, then back-translated and reviewed alongside the original by researchers and experts to ensure consistency. A pilot test with five eligible patients confirmed its clarity, after which it was administered to a larger group. Construct validity was assessed using the known-groups method by testing three hypotheses based on prior studies involving adolescents with CHDs and other chronic conditions.

Hypothesis 1: Older patients will have higher LKQCHD scores.[34,35]

Hypothesis 2: There will be no significant relationship between the level of anatomical complexity of cardiac disease and LKQCHD scores.[35]

Hypothesis 3: Patients with high medication adherence will have higher disease knowledge levels compared to those with lower adherence.[23,24]

For the third hypothesis, participants using at least one medication for cardiac diseases were evaluated within themselves. The results demonstrated statistical significance, supporting the tool's validity.

The validity and reliability assessment of the Turkish version of the questionnaire included 96 participants, with an average age of 17.01±2.08 years. The group consisted predominantly of male participants (59.4%, n=57), and the majority (41.7%, n=40) had moderately complex cardiac defects. Patients aged 18 and above scored, on average, 8.33±2.74 points higher on the LKQCHD compared to those under 18 (58.30 vs. 49.97, p=0.002). Among the 61 participants using at least one medication for cardiac diseases, those with high medication adherence had an average LKQCHD score 5.88±3.15 points higher than participants with lower adherence (53.33 vs. 47.45, p=0.034). No significant association was observed between the level of anatomical complexity of the cardiac defect and knowledge scale scores. The confirmation of all three hypotheses validated the Turkish version of the scale.

Statistical analysis

An online kappa calculator (http://justusrandolph.net/kappa/) was used to calculate the free marginal multirater kappa coefficient. For descriptive and inferential statistics, IBM SPSS software version 29 was used. Quantitative data were presented as mean ± standard deviation or median (minimum–maximum), while categorical data were reported as frequency and percentage. For inferential statistics, the independent samples t-test and two-way analysis of variance (ANOVA) were applied. The Type II Sum of Squares method was used to obtain a balanced ANOVA model and to independently assess the main effects in the analysis. The effects of the variables on the dependent variables were interpreted using F-values and corresponding p-values. A significance level of $p < 0.05$ was considered statistically significant.

Results

This study included 120 patients with CHD. Two patients were excluded for incomplete responses, resulting in a final sample of 118 patients. Demographic and clinical characteristics of the patients are shown in Table I. The vast majority were using medication for cardiac diseases (63.6%, n=75), the group with the highest incidence of using two or more medications consisted of patients with severely complex cardiac anatomy.

The mean age of the mothers was 44.90 ± 6.02 years, whereas the mean age of the fathers was 47.58 ± 5.73 years. The majority of parents were primary school graduates (60.3% of mothers and 43.5% of fathers), while a smaller proportion were university graduates (13% of mothers and 15.6% of fathers).

Regarding employment status, 67.2% of mothers were unemployed, whereas the vast majority of fathers were employed (93.9%). Most participants lived in bi-parental households (89.8%). The presence of congenital heart disease (CHD) in other individuals sharing the same household was reported by 5.1%. Additionally, 43.2% of participants reported the presence of other chronic diseases among individuals sharing the same household.

Leuven Knowledge Questionnaire for Congenital Heart Disease scores

When evaluated on a scale of 100, the LKQCHD scores applied to assess the patients' disease knowledge indicated an average LKQCHD score of 51.09 ± 13.28 for all participants. Only two patients (1.7%) demonstrated sufficient knowledge (LKQCHD score ≥80), while 38.9% (n=46) answered fewer than half of the scale items correctly. Questionnaire items and distribution of correct responses among participants are given in Table II.

Disease knowledge and clinical symptom awareness

Only 37.3% (n=44) of patients correctly named their structural heart disorder, and 15.3% (n=18) could describe its location. 45.8% of patients identified all seven symptoms of heart failure progression, with palpitations most frequently recognized (71.2%, n=84) and swelling in the feet and legs was the least recognized (25.4%, n=30).

Knowledge about treatment and medications

While 85.6% of patients (n=101) understood the recommended follow-up frequency, only 57.6% (n=68) recognized its purpose in detecting unexpected deterioration. Additionally, 39.8% answered incorrectly when asked if CHD requires lifelong follow-up. Most participants (84.7%, n=100) knew their past treatments; however, among those on medication, only 8% (n=6) could accurately state key details about their therapy, including name, dosage, timing, function, side effects, and interactions.

Table I. Demographic and clinical characteristics of the patients

Characteristics	Value (N = 118)
Sex, n (%)	
Female	51 (43.2)
Male	67 (56.8)
Age (years), M ± SD	17.05 ± 2.09
Educational background, n (%)	
High school student	83 (70.3)
High school drop-out	3 (2.5)
High school graduate	20 (16.9)
University student	12 (10.2)
Complexity level of CHD according to the Bethesda classification, n (%)	
Simple	42 (35.6)
Moderately Complex	50 (42.4)
Severely Complex	26 (22)
Primary cardiac diagnosis, n (%)	
Tetralogy of Fallot (TOF)	26 (22)
Atrial septal defect (ASD)	17 (14.4)
Ventricular septal defect (VSD)	12 (10.2)
Single ventricle palliation	12 (10.2)
Coarctation of the aorta	11 (9.3)
Congenital aortic valve anomalies	9 (7.6)
Congenital mitral valve anomalies	5 (4.2)
Atrioventricular septal defect (AVSD)	5 (4.2)
Dextro-transposition of the great arteries (D-TGA)	5 (4.2)
Anomalous pulmonary venous return	5 (4.2)
Pulmonary atresia	4 (3.4)
Congenitally corrected transposition of the great arteries (L-TGA)	3 (2.5)
Pulmonary stenosis	2 (1.7)
Ebstein's anomaly	1 (0.8)
Cor triatriatum	1 (0.8)
Number of medications used for cardiac disease, n (%)	
None	43 (36.4)
≥1 medication	75 (63.6)
New York Heart Association (NYHA) Heart Failure Functional Class, n (%)	
Class 1	81 (68.6)
Class 2	28 (23.7)
Class 3	7 (5.9)
Class 4	2 (1.7)
Medical history, devices and complications, n (%)	
Prior transcatheter intervention	86 (72.9)
≥1 prior cardiac surgery	84 (71.2)

%: patients as a percentage, CHD: congenital heart disease, M:mean, n: number of patients, SD: standart deviation.

Table I. Continued

Characteristics	Value (N = 118)
Prior admission to the hospital within last 5 years due to cardiac causes	28 (23.7)
Prosthetic valve (prosthetic or mechanical)	23 (19.5)
Pacemaker or implantable cardioverter defibrillator	7 (5.9)
Pulmonary hypertension or Eisenmenger syndrome	5 (4.2)
History of endocarditis	3 (2.5)
Additional chronic disease	23 (19.5)

%: patients as a percentage, CHD: congenital heart disease, M:mean, n: number of patients, SD: standart deviation.

Patients were most familiar with antiplatelets and anticoagulants, often described as "blood thinners," while other drugs like diuretics, antiarrhythmics, beta-blockers, angiotensin-converting enzyme inhibitors, and angiotensin II receptor blockers were partially recognized by their general effects. Only those taking acetylsalicylic acid identified bleeding as a side effect, and all patients aware of food and drug interactions (n=3) were on warfarin.

Knowledge about endocarditis

Items 11-14, which assessed patients' knowledge about endocarditis (definition, clinical findings, recurrence risk, and risk factors), had the lowest percentage of correct responses on the scale. In item 14, the percentage of patients who correctly identified all the risk factors for endocarditis presented in the options (sharing dirty or contaminated needles, bacteria causing skin infections, dental abscesses, poor skin and nail care or hygiene, and piercing or tattoo procedures) was 1.7% (n=2). The least recognized risk factors were piercing and tattoo procedures (4.2%; n=5) and poor skin and nail hygiene (5.9%; n=7), while the most recognized risk factor was sharing dirty or contaminated needles (13.6%; n=16). The percentage of patients who were aware that dental abscesses or infections could cause endocarditis was 8.5% (n=10). When questioned about the healthy lifestyle habits they should adopt to protect their overall health, it was found that 44.9% of patients (n=53) believed they should use antibiotics before every visit to the dentist.

Knowledge about sports participation and physical limitations

Most participants (65.3%; n=77) correctly understood that licensed sports participation is deemed appropriate by cardiologists. However, it was found that even patients who are permitted to engage in licensed sports (a total of 16 patients, constituting 13.5% of the entire sample) believed that they could not participate in sports that require regular training.

Knowledge about sexual and reproductive health

The percentage of patients who answered incorrectly or indicated that they did not know the answer to item 24, which assessed their knowledge about physical limitations in sexuality, was 62.7% (n=74); the average age of these patients was 16.82 years. Only 36.4% (n=43) of patients accurately understood the risk of CHD recurrence in the next generation. Among those who answered incorrectly or chose "I don't know," the average age was 16.86 years, with 40% female and 60% male. Additionally, just 5.9% (n=3) of female patients had sufficient knowledge of contraceptive methods, while 37.3% (n=19) were aware of pregnancy-related risks associated with their heart condition.

Medication Adherence Report Scale scores

The average MARS score for patients using medication (n=75) was calculated to be 22.08 (min-max10-25). Sixty percent of the patients using medication (n=45) showed high adherence

Table II. Leuven Knowledge Questionnaire for Congenital Heart Disease questions and correct answer rates among participants

Questions	Correct Answer n (%)
Disorder and treatment	
What is the correct name of your heart defect?	44 (37.3)
Describe below or indicate on the diagram where your heart defect is located.	18 (15.3)
How often do you have to come to the clinic for follow-up of your heart disease?	101 (85.6)
What is the main purpose of this follow-up?	68 (57.6)
How has your heart condition been treated to date?	100 (84.7)
If you are on medication, give the name, dose, schedule, reason or function, most important side effects, and interactions with other medication or foods.	6 (8.0)
If you experience side effects of your medication, does this mean you should stop taking them?	28 (23.7)
Do you have to follow a diet? If you answer yes, please indicate the type of diet.	100 (84.7)
Mark all symptoms which may occur if your heart condition deteriorates and for which you have to contact your cardiologist.	54 (45.8)
If the cardiologist informs you that everything is alright, does that mean that you do not need further follow-up?	71 (60.2)
Prevention of complications	
What is endocarditis?	21 (17.8)
Indicate the most characteristic or typical sign of endocarditis.	11 (9.3)
Can you only get endocarditis once in your lifetime?	5 (4.2)
A number of risk factors for endocarditis are listed below. Do you think these factors contribute to the onset of endocarditis?	2 (1.7)
As you have a congenital heart disease, you should take antibiotics immediately if you have a temperature (without consulting a doctor).	86 (72.9)
You should have a dental check-up at least once a year.	84 (71.2)
You should take antibiotics before every visit to the dentist.	65 (55.1)
Bleeding gums need extra attention.	95 (80.5)
You should clean your teeth at least once a day.	105 (89.0)
Smoking is more harmful for someone with a congenital heart disease than for someone without such a disorder.	7 (5.9)
Consuming three or more alcoholic drinks per day is more harmful for someone with a congenital heart disease than for someone without such a disorder.	91 (77.1)
Physical activity	
You may take part in competitive sports (regional or national) requiring daily training?	77 (65.3)
You should choose an occupation that is not too physically demanding, as you should be careful not to over-exert yourself.	82 (69.5)
May you engage in all physical sexual activity of which you feel you are capable?	44 (37.3)
Sexuality and heredity	
What is the chance that your children will have a congenital heart disease?	43 (36.4)
Which contraceptives are the most advisable for you to use in the light of your congenital heart disease?	3 (5.9)
Do you run a risk for complications during pregnancy?	19 (37.3)

%: patients as a percentage, n: number of patients.

to their medication (MARS score ≥23). Neither the anatomical complexity level of the CHD nor the number of medications used had a significant impact on medication adherence ($p > 0.05$).

Factors associated with disease knowledge

When the patients were classified according to their anatomical complexity and the average LKQCHD scores for the three groups were analyzed using the Kruskal-Wallis test, no statistically significant difference was found ($p=0.701$).

In order to assess the overall impact of age and clinical characteristics on disease knowledge, a two-way analysis of variance (ANOVA) was conducted, using the LKQCHD score as the dependent variable and the following as independent variables: age, complexity level of CHD, NYHA functional class, number of medications used, history of hospitalization due to cardiac reasons in the past 5 years, history of cardiac catheterization, history of cardiac surgery, and the presence of additional chronic diseases (Table III). The age and history of cardiac catheterization were shown to have a significant impact on disease knowledge scores. Participants aged

Table III. Factors influencing leuven knowledge questionnaire for congenital heart disease scores

Variable	Category	n	LKQCHD score (M ± SD)	F	p
Age (years)	<18	83	49.03±13.13	9.367	0.004*
	≥ 18	35	55.97±12.49		
Complexity level of CHD	Simple	42	52.32±12.22	0.318	0.728
	Moderately complex	50	50.56±13.38		
	Severely complex	26	50.14±15.02		
New York Heart Association (NYHA) Functional Class	Class 1	81	50.72±13.55	0.497	0.610
	Class 2	28	51.99±12.32		
	Class 3 and 4	9	51.70±15.07		
Number of medications used for cardiac disease	0	43	53.39±13.46	1.313	0.274
	1	34	49.42±11.91		
	2	23	48.93±16.15		
	3 and more	18	51.52±11.29		
Prior admission to the hospital within last 5 years due to cardiac causes	No	90	50.32±12.00	3.647	0.059
	Yes	28	53.58±16.76		
Prior transcatheter intervention	No	32	55.33±10.13	5.528	0.021*
	Yes	86	49.52±14.00		
≥1 prior cardiac surgery	No	34	53.01±11.88	0.090	0.764
	Yes	84	50.32±13.80		
≥2 prior cardiac surgery	No	88	50.46±13.48	2.284	0.134
	Yes	30	52.97±12.71		
Presence of pacemaker or implantable cardioverter defibrillator	No	95	51.28±12.47	0.731	0.395
	Yes	23	50.33±16.52		
Additional chronic disease	No	95	50.93±13.26	0.025	0.875
	Yes	23	51.79±13.64		

CHD: congenital heart disease, LKQCHD: Leuven Knowledge Questionnaire for Congenital Heart Disease, M: mean, n: number of patients, SD: standart deviation.

18 and older exhibited a statistically significant higher average LKQCHD score compared to their younger counterparts (55.97 ± 12.49 vs. 49.04 ± 13.13, F = 9.367, p=0.004). Participants who had undergone cardiac catheterization previously demonstrated significantly lower knowledge scores compared to those who never had such procedures (49.52 ± 14.00 vs 55.33 ± 10.13, F = 5.528, p = 0.021). No statistically significant associations were identified between demographic or socioeconomic variables obtained from the Demographic and Socioeconomic Assessment Form, including parental education level, parental employment status, household income, and living conditions, and disease knowledge scores (all p > 0.05).

The average LKQCHD score of patients considered to have high medication adherence was significantly higher compared to those with lower medication adherence (One-way t-test; difference of 5.96 points, 52.16 vs. 46.20; p=0.026).

Discussion

Although CHDs require lifelong follow-up, patients often neglect appointments or drop out of care after transitioning from pediatric to adult services.[5,6,36,37] These lapses in care have been shown to result in increase in morbidity and mortality.[4,36,38] While educational transitional care programs exist globally to educate youth with CHD and prevent related morbidity and mortality due to lapses in care, no such program currently exists in Türkiye.[14,17] Our study highlights the need for a structured transitional care program. Despite most patients being at or beyond the usual age for transitioning from pediatric to adult care, they were only able to answer, on average, just over half of the questions correctly. Only 1.7% of participants had sufficient disease knowledge; many couldn’t define their condition or recognize the warning signs of deterioration.

Among patients on medication, most knew the name, dosage, and frequency, but lacked awareness of side effects and interactions. As in prior studies, those with higher adherence showed better disease knowledge.[23,24] Despite many participants’ limited understanding of their cardiac condition, overall medication adherence in our cohort was acceptable. Medication adherence is known to be influenced by a variety of factors, including patient-related elements such as perceptions and beliefs about illness, health system factors like the availability and accessibility of medications, and broader socioeconomic and cultural influences.[39] The relatively high adherence rates observed in our cohort may be partly explained by the prevailing collectivist cultural background in Türkiye and the involvement of family members in patients’ care.[40]

Factors such as functional impairment, invasive procedures, presence of prosthetic devices, recent hospitalizations, and a history of endocarditis were evaluated to assess disease severity. While some studies link severe cardiac disease to better adherence, only a history of cardiac catheterization showed a significant association in our cohort—and unexpectedly, those patients had lower disease knowledge scores.[41] This may be due to unequal group sizes or the heterogeneous nature of catheterization, which is often performed for both diagnostic and interventional purposes in CHD. These limitations highlight the need for further research with larger, more balanced samples.

Our patients particularly lacked knowledge in two areas; endocarditis and reproductive health. Incidence of infective endocarditis in individuals with CHD is twice as high as in the general population but most of our patients had a very little understanding of the disease.[42] In our study, 17.8% of patients were able to define endocarditis, while studies conducted with individuals aged 12 to 32 with CHD reported a varying percentage between 4% and 50%.[8,34,43]

The European Society of Cardiology recommends that all female patients diagnosed with CHD receive counseling on reproductive health starting from menarche.[27] While studies in the literature indicates that psychosocial maturation in young people with chronic illnesses may be somewhat delayed compared to healthy peers, other studies involving adolescents with CHD have shown that a portion of those aged 16 to 18—between 14% and 26%—are sexually active, and among those who are sexually active, 72% engage in risky sexual behaviors (such as having two or more sexual partners and not using protective methods to prevent unwanted pregnancies).[44-46] It is believed that providing comprehensive sexual health education to adolescent girls with CHDs, would be effective in preventing unwanted pregnancies that could pose medical risks for the patient, as well as adverse events arising from incorrect contraceptive use.[27,47] However, studies show that physicians often avoid these discussions related to sexuality and reproductive health, leaving many female CHD patients with inadequate knowledge.[48,49] Similarly, our study found that adolescent and young adult female patients have insufficient information about pregnancy risks and contraceptive methods. Patients' lack of knowledge on this topic may stem from physicians' assumptions about their sexual activity or readiness for parenthood. This issue is not unique to adolescents with CHD though; the 2023 Türkiye Youth Research report highlights major gaps in sexual and reproductive health knowledge among all youth aged 15–24, including poor understanding of anatomy, sexually transmitted infections, declining HIV/AIDS awareness, and persistent misconceptions about pregnancy and contraception.[50] A lack of training in reproductive counseling during cardiology subspecialty education and physicians' discomfort with the topic may further limit access to accurate information.[49] Collaborating with adolescent health specialists experienced in contraception counseling could enhance the quality of comprehensive sexuality education which lacks in this group.

A notable finding was participants' views on licensed sports participation. While 65.3% correctly understood it is generally permitted, 13.5% of patients unnecessarily restricted themselves despite having no medical limitations. Misconceptions, especially among those with simple defects such as isolated ASD or VSD, may lead to sedentary lifestyle, negatively impacting physical and mental health.[26,51,52] Families' overly protective approach, which does not even allow patients to participate in sports or games that do not physically strain them, may have led to this perception.[14,53]

Previous studies indicate that family structure and parental education significantly influence children's health literacy.[54] Higher parental education is also associated with a better understanding of a child's diagnosis and management.[55] Although we found no statistically significant association between parental or household characteristics—such as educational background, cohabitation status, or the presence of congenital heart disease (CHD) in another household member—and disease knowledge, this may be due to limited statistical power.

Our study findings point to our failure to inform our patients age appropriately. The high number of daily visits to our hospital's pediatric cardiology clinic, absence of specialist nurses and such supporting health professionals in our department restrict the time that can be dedicated to patient education. It can be suggested that physicians' failure to provide age-appropriate information without considering the patients' cognitive and psychosocial development may also have had an impact.[14] During adolescence, patients should gradually be encouraged to attend clinic appointments independently and assume greater responsibility for their health and treatment, such as taking their medications at the correct times and dosages without needing parental reminders.[14] While pediatric providers often focus on family involvement, adolescents should directly receive age-appropriate information from early adolescence on heart-healthy habits, substance risks, contraception, pregnancy, recurrence risks, and long-term prognosis.[14,47,48] Vocational and employment guidance should extend into early adulthood.[14]

This study has several limitations. As a single center study, it relied on self-reported measures (LKQCHD and MARS), which may be affected by response bias. Objective adherence measures, such as parental reports or serum drug levels, were not included. The sample size may have been too small to detect significant effects of adolescent, family, and household factors, limiting generalizability. Additionally, the knowledge scale lacked questions specific to patients with pacemakers or ICDs, potentially missing important knowledge gaps. Future research should use larger samples and include device-specific questions for a more comprehensive assessment. In conclusion, our study shows the lack of adequate knowledge our patients have concerning their cardiac condition. A structured transition program involving collaboration between Pediatric Cardiology, Adolescent Medicine, Adult Cardiology, and Nursing Faculty has the potential to significantly improve outcomes for adolescents with CHD as they move from pediatric to adult care. By enhancing health literacy, promoting self-management skills, and supporting adherence to treatment, such a program could serve as a crucial intervention to ensure long-term health and well-being. Establishing a comprehensive educational transition framework would not only empower patients but also help prevent avoidable health complications and reduce mortality associated with a lack of knowledge. A multidisciplinary approach is essential to bridging this critical gap in care and securing a healthier future for adolescents with CHD.

Ethical approval

The study was approved by Hacettepe University Health Sciences Research Ethics Committee (date: 04.04.2023, number: GO 22/1324).

Author contribution

The authors confirm contribution to the paper as follows: Study conception and design: EYK, SA, MPK, İE; data collection: EYK; analysis and interpretation of results: EYK, EK, SA, MPK, İE, OD; draft manuscript preparation: EYK, SA, MPK, İE, OD, TK, HHA. All authors reviewed the results and approved the final version of the manuscript.

Source of funding

The authors declare the study received no funding.

Conflict of interest

The authors declare that there is no conflict of interest.

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