

Adolescents' Understanding of Their Congenital Heart Disease on Transfer to Adult-Focused Care

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Adolescents with congenital heart disease (CHD) must take responsibility for their life and care. This requires that they have sufficient knowledge about their heart disease, treatment, and preventive measures. Thus, CHD-related education should be directed to adolescents. Research on adolescents' understanding and knowledge of CHD is limited. It is unknown what adolescents with CHD know about their heart defect, treatment, and preventive measures necessary to avoid complications. We addressed these questions in a descriptive cross-sectional study of 91 adolescents with CHD (53% males; median age 17 years). In the present study, we assessed the subjects' knowledge of CHD using the Leuven Knowledge Questionnaire for Congenital Heart Disease. The results showed that the patients had adequate knowledge (>80% correct answers) about the need for regular follow-up, their required diet, past treatment, and dental practices. They had moderate knowledge (50% to 80% correct answers) about the frequency of follow-up, occupational choices, medication regimen, and sexual activities. However, the patients had poor knowledge (<50% correct answers) of the name of their heart defect; the reasons for follow-up; the effects of competitive sports; the symptoms that reflect deterioration of their heart disease; the definition, characteristics, and risk factors of endocarditis; the possibility of recurrent episodes of endocarditis during their lifetime; the effect of smoking and alcohol on their heart disease; the hereditary nature of their condition; the suitability of intrauterine devices as contraceptives; the appropriateness of oral contraceptives; and the risks of pregnancy. In conclusion, the results of the present study have showed that the level of knowledge of adolescents with CHD has significant gaps. © 2010 Elsevier Inc. All rights reserved. (*Am J Cardiol* 2010;106:1803–1807)

To date, several studies investigating the level of knowledge of patients with congenital heart disease (CHD) have been undertaken. Five studies have been conducted in children,^{1–5} and 9 studies have been performed in adults.^{6–14} To our knowledge, only 4 studies have included adolescents among their subjects.^{3,4,5,15} One study specifically targeted adolescent patients, focusing on their knowledge of bacterial endocarditis.¹⁵ Other aspects of CHD, however, were not addressed. Thus, information on the level of knowledge of adolescents with CHD is scant. Therefore, we designed a study to investigate what adolescents with CHD know about their heart defect, its treatment, and the preventive measures necessary to avoid complications.

Methods

We recruited literate, Dutch-speaking adolescents with CHD to participate in our descriptive cross-sectional study. Adolescents were eligible for the study at their initial visit to the Adult Congenital Heart Disease (ACHD) program's

clinic after their transfer from pediatric cardiology. At the University Hospitals of Leuven, Belgium, it is standard practice for pediatric patients with CHD to be transferred to adult-focused care when they reach 16 years of age, unless the patient is medically unstable.¹⁶ Patients were excluded from our study if they had learning disabilities. In a 13-month period, 100 adolescents who met the inclusion criteria were asked to participate. Of these 100 patients, 1 refused to participate because of a lack of interest, and 8 were excluded because of practical reasons. Hence, we recruited 91 adolescents with CHD. Of these, 53% were males and 47% were females. The patients had a median age of 17 years. The demographic and clinical characteristics of the study sample are summarized in Table 1.

The demographic and clinical variables were gathered during patient interviews and from the patient medical records. The patients' CHD knowledge was assessed using the Leuven Knowledge Questionnaire for Congenital Heart Disease, developed by Moons et al¹⁰ in 2001. We adapted the questionnaire using our experiences in the first study. The most current version of the questionnaire consists of 27 items and covers 5 domains, which were identified as relevant aspects of patients' knowledge about CHD: (1) knowledge of the heart defect and treatment, (2) knowledge of the prevention of complications, (3) knowledge of physical activities, (4) knowledge of sexuality and heredity, and (5) knowledge of contraception and pregnancy planning. The researchers evaluated

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Table 1
Demographic and clinical characteristics of 91 adolescents with congenital heart disease (CHD)

Variable	n
Gender	
Male	48 (53%)
Female	43 (47%)
Age (years)	
Median	17
Quartile 1	16
Quartile 3	18
Range	15–32
Marital status	
Unmarried (living with parents)	87 (96%)
Living together	2 (2%)
Living alone	1 (1%)
Married	1 (1%)
Highest educational level	
Vocational high school	29 (31%)
Technical high school	32 (34%)
High school/college/university	30 (32%)
Responsible for daily management of care	
Parents	1 (1%)
Patient	23 (25%)
Patient and parents	67 (74%)
Treatment	
Surgery	31 (34%)
Medication	4 (4%)
No treatment	30 (33%)
Surgery and catheter intervention	7 (8%)
Surgery, catheter intervention, and medication	2 (2%)
Surgery and medication	6 (7%)
Catheter intervention	8 (9%)
Medication and catheter intervention	3 (3%)
History of endocarditis	0 (0%)
Number of pregnancies	0 (0%)
Contraception (for women only)	
Pill	19 (43%)
Other methods	1 (2%)
No contraception	23 (55%)
Primary medical diagnosis	
Ventricular septal defect	26 (29%)
Coarctation of the aorta	14 (16%)
Pulmonary valve stenosis	11 (12%)
Transposition of great arteries	5 (6%)
Aortic valve stenosis	5 (6%)
Tetralogy of Fallot	4 (5%)
Atrial septal defect type secundum	3 (3%)
Congenitally corrected transposition of great arteries	3 (3%)
Mitral valve regurgitation	3 (3%)
Aortic valve regurgitation	3 (3%)
Univentricular heart	2 (2%)
Atrioventricular septal defect	2 (2%)
Patent ductus arteriosus	2 (2%)
Mixed aortic valve disease	1 (1%)
Truncus arteriosus	1 (1%)
Pulmonary atresia	1 (1%)
Double aortic arch	1 (1%)
Total anomalous pulmonary venous return	1 (1%)
Marfan syndrome	1 (1%)
Atrial septal defect type primum	1 (1%)
Atrial septal defect type sinus venosus	1 (1%)

each patient's answers as "correct," "does not know," or "incorrect" or "incomplete."¹⁰

When the patients arrived for their scheduled outpatient visit at the ACHD program's clinic, a nurse from the advanced practice nursing team approached the patients and explained the aims and protocol of the present study. After oral informed consent was obtained, the nurse asked the patient to complete the knowledge questionnaire while in the waiting room. The nurse explicitly asked family members not to help the patient complete the questionnaire. Moreover, the patient was forbidden from consulting external sources. The advanced practice nurse checked the questionnaire for completeness and asked for additional information, if necessary. On completion, each patient and their parents entered the consultation room, where the advanced practice nurse used the completed questionnaire as a guide to provide appropriate patient education.¹⁷ The institutional review board of the University Hospitals Leuven approved the study protocol.

The data were analyzed using the Statistical Package for Social Sciences, version 16.00 (SPSS, Chicago, Illinois). The descriptive statistics of demographic and clinical variables are expressed in percentages, medians, and quartiles. The knowledge variables were dichotomized as correct or incorrect answers (the latter included the incomplete, does not know, and incorrect responses).

Results

Fewer than 1/2 of the patients knew the name of their heart defect, and only 28% could describe their heart defect or locate the lesion on a diagram (Table 2). Most of the patients knew the frequency of follow-up required and the need for regular follow-up; however, only 46% indicated that the main purpose of follow-up was to detect clinical deterioration. Most of the patients had adequate knowledge about their past treatment. Of the 15 patients who took medications on a regular basis, 53% knew the name of the medication. Almost all the patients knew which diet they should follow. A small number of the patients could identify the symptoms that reflect deterioration of the heart disease, including dizziness, shortness of breath, palpitations, chest pain, fainting, increasing fatigue, and swollen feet and legs (Table 2).

Only 21% of the adolescents could correctly define endocarditis, and only 1 adolescent recognized unexplained fever for >5 days as the most characteristic sign of endocarditis (Table 3). Few knew that endocarditis could recur, and 78% knew that they should not take antibiotics without consulting a doctor. Only a small number of patients knew the risk factors for endocarditis, including contaminated needles, bacteria from skin infections, dental abscesses, poor nail and skin care, and body piercing and tattooing. The patients, however, had good knowledge of dental practices. Most patients incorrectly believed that smoking and alcohol consumption, respectively, were more harmful to them than to their healthy counterparts (Table 3).

In the present study, 39% of the adolescents knew that engaging in high-level competitive sports, requiring daily training, was not allowed (Table 4). A large proportion of

Table 2
Frequency of patients' knowledge about their disease and its treatment (n = 91)

Question	Correct	Incorrect	Does Not Know	Incomplete
1. What is the name of your heart defect?	41 (45%)	9 (10%)	33 (36%)	8 (9%)
2. Describe or indicate on the diagram where your heart is located.	25 (27%)	12 (13%)	46 (51%)	8 (9%)
3. How often do you have to come to the clinic for follow-up for your congenital heart disease?	71 (78%)	14 (15%)	6 (7%)	—
4. What is the main purpose of the follow-up?	42 (46%)	0 (0%)	0 (0%)	49 (54%)
5. How has your heart condition been treated to date?	77 (85%)	2 (2%)	4 (4%)	8 (9%)
6. If you are receiving drug treatment, give the name, dose, schedule, reason or function, most important side effects, and interactions with other drugs or foods.*	8 (53%)	2 (13%)	1 (7%)	4 (27%)
7. If you experience side effects from your drugs, does this mean you should stop taking them?	37 (41%)	3 (3%)	50 (56%)	—
8. Do you have to follow a diet? If you answer yes, please indicate the type of diet.	86 (94%)	0 (0%)	5 (6%)	—
9. Mark all symptoms that may occur if your heart condition deteriorates and for which you have to contact your cardiologist.	8 (9%)	0 (0%)	39 (43%)	44 (48%)
10. If the congenital cardiologist informs you that everything is all right, does that mean that you do not need further follow-up?	79 (87%)	8 (9%)	4 (4%)	—

* Only 15 of the 91 patients received drug treatments for their CHD at the survey.

Table 3
Frequency of patients' knowledge about preventive measures (n = 91)

Question	Correct	Incorrect	Does Not Know
11. What is endocarditis?	19 (21%)	11 (12%)	61 (67%)
12. What is the most typical sign or symptom of endocarditis?	1 (1%)	19 (21%)	71 (78%)
13. Can you only get endocarditis once in your lifetime?	13 (14%)	3 (3%)	75 (83%)
14. Do the following factors contribute to the onset of endocarditis?			
Needle contamination (drug addicts)	18 (20%)	7 (8%)	66 (72%)
Smoking	7 (8%)	25 (28%)	59 (64%)
Bacteria from skin infections	10 (11%)	8 (9%)	73 (80%)
Dental abscesses	20 (22%)	8 (9%)	63 (69%)
Sexual activity	22 (24%)	1 (1%)	68 (75%)
Poor nail and skin care	7 (8%)	17 (19%)	67 (73%)
Body piercing and tattooing	14 (15%)	17 (19%)	60 (66%)
15. Because you have a congenital heart disease, should you take antibiotics immediately (without consulting a physician) if you have a temperature?	71 (78%)	7 (8%)	13 (14%)
16. Should you have a dental checkup at least once a year?	76 (84%)	8 (9%)	7 (7%)
17. Should you take antibiotics before every visit to the dentist?	71 (78%)	18 (20%)	2 (2%)
18. Do bleeding gums need extra attention?	68 (75%)	10 (11%)	13 (14%)
19. Should you clean your teeth at least once a day?	87 (96%)	3 (3%)	1 (1%)
20. Is smoking more harmful for patients with congenital heart disease than for other people?	7 (8%)	64 (70%)	20 (22%)
21. Is consuming alcohol 3 times a day more harmful for patients with congenital heart disease than for other people?	22 (24%)	31 (34%)	38 (42%)

Table 4
Frequency of patient's knowledge about physical activity (n = 91)

Question	Correct	Incorrect	Does Not Know
22. Can you take part in competitive sports requiring daily training?	35 (39%)	42 (46%)	14 (15%)
23. Should you choose an occupation that is not too physically demanding, as you should be careful not to overexert yourself?	68 (75%)	11 (12%)	12 (13%)

Table 5
Frequency of patient's knowledge about reproductive issues (n = 91)

Question	Correct	Incorrect	Does Not Know
24. In terms of sexual physical effort, can you do all that you feel you are able to do?	71 (78%)	1 (1%)	19 (21%)
25. What is the chance that your children will have congenital heart disease?	18 (20%)	24 (26%)	49 (54%)
26. Which contraceptives are the most advisable for you to use in light of your congenital heart disease? (only for women)			
Contraceptive pill	15 (35%)	—	28 (65%)
Intrauterine device	6 (14%)	3 (7%)	34 (79%)
27. Are you at risk of deterioration during pregnancy? (only for women)	5 (12%)	11 (25%)	27 (63%)

the patients were aware that they had to choose an occupation that would not be too physically demanding.

About 78% of the patients knew they were allowed to engage in sexual intercourse if they felt capable of doing so (Table 5). Only 20% of the adolescents knew about the hereditary nature of their condition.

With regard to contraceptives, 14% and 35% of the female patients did not know whether intrauterine devices and oral contraceptives, respectively, were suitable or appropriate choices (Table 5). Most of the female patients had insufficient knowledge of the risks of pregnancy.

Discussion

As they grow older, adolescents with CHD presumably take responsibility for their own health and care. Transition programs should be implemented to prepare adolescents for this task.^{18–21} A critical element of these transition programs is developmentally appropriate education for patients^{18,22} with the aim of improving the patients' level of knowledge and increasing their awareness of adopting adequate health behaviors, while taking the transition through puberty into account. With the exception of one study that assessed bacterial endocarditis knowledge,¹⁵ studies that have specifically investigated the level of knowledge of adolescents with CHD, to the best of our knowledge, do not exist. Hence, we studied the level of knowledge in a sample of adolescents on their transfer from pediatric cardiology to adult-focused care.

In general, our findings have indicated that the level of knowledge of adolescents who recently transferred to adult care is poor. The findings of our study are to a certain extent comparable to those of previous investigations. In the studies by Veldtman et al³ and Cetta et al,¹⁵ 30% to 69% of the patients were able to describe or provide the name of their heart defect. In the present study, 45% of the patients were within this range. In contrast, substantial differences also exist between our study and previous studies. For instance, the level of knowledge about medication was considerably lower in our study (53%) than in the study by Cetta et al,¹⁵ and the knowledge of risk factors for endocarditis (8% to 24%) was lower than in the study by Knirsch et al.⁵ In contrast, our patients were more knowledgeable about other areas than patients of previous studies, including the definition of endocarditis (21% vs 4%),¹⁵ preventive measures (75% to 96% vs 0%),¹⁵ and antibiotic prophylaxis (78% vs 40%).^{5,15} However, the findings of the different studies are not comparable, because the age ranges, focus of the research, and measurements differed across the studies.

Currently, it is the policy of our institution to transfer adolescents from pediatric cardiology to the ACHD program when they reach 16 years of age.¹⁶ This policy has been successful, with, to date, 84% of the patients having received specialist care after they have left pediatric cardiology.²³ A formal transition program, however, does not precede this transfer. The findings of the present study would advocate for such a transition program. Patient education is a critical element of transition programs,^{18,22} particularly because the responsibility of healthcare management shifts from the family to the patient.¹⁸ To support adolescent patients to take responsibility for their health-

care, healthcare professionals should inform and instruct them before they transfer to adult-focused care. Although pediatric cardiologists and the patients' families have already discussed several topics covered in the education program, this strategy apparently does not ensure that patients retain the information. A huge disparity was found between the information provided, the information understood, and the information retained. In addition, the growth rate of each adolescent varies; thus, their mental maturity, sense of responsibility, and self-care can differ widely. It is therefore of paramount importance to realize that the onset of puberty can hinder patients from being open to information and instruction by healthcare professionals. Therefore, ACHD programs should also continuously invest in patient education to ensure that information is retained. Therefore, the integration of nurse specialists in ACHD teams is advocated.^{24–26}

Structured patient education has proved to be effective in increasing the level of knowledge in patients with CHD. At our ACHD program, the effects of a structured education program were evaluated using a prepost design, with an interval of 5 years.²⁷ An improvement of >10% was observed for knowledge about the name of the heart defect, side effects of medication, symptoms of deterioration, risk factors for endocarditis, appropriate use of antibiotics, appropriateness of contraceptive pills and intrauterine devices, definition of endocarditis, and characteristics of endocarditis.²⁷ In another study, we demonstrated that advanced practice nursing teams can have an effect on the pregestational counseling of patients with CHD.²⁸ Before the implementation of advanced practice nursing, 44% of female patients received cardiac follow-up during pregnancy. This proportion increased to 71% after the advanced practice nursing team implemented systematic educational interventions that contributed to a better understanding of the rationale for cardiac appointments during pregnancy and a better adherence to follow-up recommendations.²⁸ Admittedly, we do not have empiric evidence supporting the effectiveness of such an education program in adolescents. Additional research in this respect is imperative. Furthermore, it is important to determine which aspects of knowledge are indispensable. This would help ACHD professionals to set priorities in the content of patient education programs, because too much information will overload the patients and hinder information retention.

Some methodologic limitations require that the results of the present study be interpreted with caution. First, the present study was a single-center study conducted at an outpatient clinic. Therefore, we must be careful in generalizing the study results. Second, the Leuven Knowledge Questionnaire for Congenital Heart Disease was developed in 2001.¹⁰ The scale was initially tested using 62 adults with CHD.¹⁰ The content validity of the questionnaire was not examined in adolescents with CHD, nor was the ability of these adolescents to read and understand the questions in this instrument examined. Although we did not experience problems in this respect in the present study, additional testing of the validity and reliability of the questionnaire in this specific population is needed. Third, the instrument is multidimensional; thus, the calculation of an overall knowledge score has little meaning. The absence of a total score

might in some situations be an obstacle. It might be useful to find a method by which the level of knowledge of a patient could be aggregated into a single index value.

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