

Illness understanding in adults with congenital heart disease

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Background. Adult patients with congenital heart disease need information regarding their clinical diagnosis, medications and side effects, endocarditis prophylaxis, reproductive issues, employment, future surveillance, treatments, and possible reoperations. Accurate understanding of chronic illness in these patients is associated with less distress, less confusion, improved satisfaction with medical care, better compliance with treatment, and a better emotional status, all key factors for good health-related quality of life. The aim of the present study was to assess the level of knowledge that adult patients with congenital heart disease followed in our Center have about their heart condition.

Methods. A questionnaire on knowledge about congenital heart disease was sent by mail to 200 adults affected by a cardiac congenital disease chosen randomly from all patients regularly followed in our department.

Results. Patients had good knowledge about the treatment received, the importance of follow-up, the prognosis of their condition, and the possibility of taking part in physical activities. The patients receiving drug treatment were moderately knowledgeable about their treatment. The anatomy of the heart defect, factors contributing to the onset of endocarditis, the impact of smoking and alcohol, and the possible inheritance of the heart condition were poorly understood by the patients. Most of female patients knew that the oral contraceptive pill was the most appropriate method of birth control; most of them were aware that pregnancy would cause additional risks to their health. Multiple logistic analysis showed that four correct answers were related to the age of the patient.

Conclusions. Overall the results indicated that the educational efforts of all the staff (physicians and nurses) have given encouraging results, but there are still significant gaps in knowledge that need more educational work.

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Accurate understanding of chronic illness in patients of any age is associated with less distress, less confusion, improved satisfaction with medical care, better compliance with treatment and a better emotional status, all keys to good health-related quality of life.

Adult patients with congenital heart defects, whether they have undergone surgery or interventional procedures, have a wide range of chronic conditions; for this reason specialized centers have been created to centralize clinical expertise, experience, research, and teaching facilities. Nevertheless, experts feel that transfer of care from a pediatric setting to an adult one is often less than ideal¹.

Several obstacles may impair the transition process, such as emotional bonds between pediatric cardiologists and families, and the poor knowledge that parents have about their child's condition².

Adult patients need information regarding clinical diagnosis, medications and side effects, endocarditis prophylaxis, reproductive issues, employment, future surveillance, treatments, and possible reoperations³.

To the best of our knowledge there are not structured transition programs in Italy to help adolescents and young adults with congenital heart disease go through this difficult period of life, which can be complicated by numerous factors such as the patient's comprehension of the diagnosis, anxiety and/or denial, parental support, distance from the medical center, insurance coverage, etc.

The aim of the present study was to assess the level of knowledge that adult patients with congenital heart disease followed in our center have about their heart condition.

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Methods

The “Leuven knowledge questionnaire for congenital heart disease”, modified with the consent of the authors⁴, was sent by mail to 200 adults affected by a cardiac congenital disease chosen randomly from all patients regularly followed in our department. We excluded adults who had attended our outpatient clinic only once. The demographic and clinical characteristics of the patients who filled in the questionnaire are summarized in table I. In order to evaluate the ability of patients to read and understand the questions, we conducted a pilot study involving 30 consecutive adult inpatients hospitalized in our department. The questionnaire was sent with a covering letter containing all the instructions needed to fill in the questionnaire; the patients were invited to answer every single question without the aid of their medical files.

The modified Leuven knowledge questionnaire measures knowledge in four domains: 1) the disease and its treatment; 2) the prevention of complications, including endocarditis; 3) physical activities; and 4) reproductive issues. Fifteen topics encompassing these four domains were identified (Table II).

The validity of the content of the questionnaire was examined by two physicians.

Information on the primary medical diagnosis, past and current treatment, drug regimen, and history of endocarditis was collected from the patients’ medical records. The researchers evaluated each patient’s answers as “correct”, “does not know”, or “incorrect”. Multiple answer questions and open questions could also be scored as “incomplete”. No specific scoring system was used.

Table I. Demographic and clinical characteristics of the 104 adults who returned the completed questionnaire.

Sex (M/F)	48/56
Age (years)	38.9 ± 15
Educational level	
Primary school	42 (41%)
High school	50 (48%)
University	12 (11%)
Employment status	
Blue collar worker	52 (50%)
White collar worker	36 (35%)
Other	16 (15%)
Primary medical diagnosis	
Aortic coarctation	4
TOF/pulmonary atresia + VSD	4
Valvular disease	16
Transposition of the great arteries	4
Atrial septal defect	34
VSD	6
Atrioventricular canal	4
Patent ductus arteriosus	6
Complex	26
Drug therapy	74

TOF = tetralogy of Fallot; VSD = ventricular septal defect.

Table II. Topics attributed to the four knowledge domains in congenital heart disease.

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1. Disease and treatment
 - a. name of the heart defect
 - b. anatomy of the heart defect (patients were asked to indicate the major defect on a diagram)
 - c. reason for and intervals of follow-up
 - d. treatment of the heart defect
 - e. symptoms of deterioration
 - f. prognosis
 2. Measures to prevent complications
 - a. definition of endocarditis
 - b. characteristics of endocarditis
 - c. risk factors for endocarditis
 - d. behavior to prevent complications
 3. Physical activities
 - a. physical capacities
 - b. physical restrictions
 4. Reproductive issues
 - a. inheritance
 - b. contraception
 - c. pregnancy
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Statistical analysis. Continuous variables are presented as mean ± SD. Two-way ANOVA was used to compare answers according to age. *Post-hoc* comparisons were made with the Bonferroni test. The Kruskal-Wallis test was used to compare answers according to educational level. All tests were two-sided. A p value of < 5% was considered as statistically significant.

Results

Of the 200 questionnaires we mailed, 104 (52%) were returned completely filled in; about 3% of the questionnaires sent were returned by the National Mail Service because of changes of the patients’ address.

Despite a good knowledge of the name of their cardiac disease, a significant number of patients (41%) were unable to indicate where the defect is located on a diagram (Table III).

The frequency of outpatient appointments, and the purpose of the follow-up were well understood. The majority of the patients showed a good understanding of the kind of treatment of the disease given by the medical and surgical staff. A large part of the subjects showed a quite good understanding of the prognosis of their condition (Table III).

Patients taking drugs were knowledgeable about the name, regimen, function and side effects of their treatment; they appeared less informed about possible interactions with other drugs or food (Table III).

To assess knowledge about symptom management, the Leuven questionnaire lists 11 symptoms, of which 7 reflect deterioration of the heart disease requiring appropriate medical care (dizziness, shortness of breath, palpitations, chest pain, fainting, increasing fatigue, and swollen feet and legs); 44% of the patients identi-

Table III. Frequency distribution of patients' knowledge about the disease and its treatment.

Question	Correct	Incorrect	Does not know	Incomplete
What is the name of the heart defect?	80 (76%)	16 (15%)	8 (9%)	
Indicate on the diagram where the heart defect is located	46 (44%)	42 (41%)	16 (15%)	
How often do you have to go to the clinic for a follow-up?	100 (96.1%)	4 (3.9%)		
What is the main purpose of the follow-up?	84 (80.8%)	20 (19.2%)		
How has the heart condition been treated to date?	100 (96.1%)	4 (3.9%)		
What is the prognosis of the disease?	68 (65%)		36 (35%)	
If you are on drug treatment, give the name of the drug(s), dose, schedule, reason or function, most important side effects, and interactions with other drugs or foods	Name 74/74 (100%) Dose 74/74 (100%) Schedule 74/74 (100%) Function 54/74 (72.3%) Side effects 40/74 (54.1%) Interactions 18/74 (24.3%)	10/74 (13.5%) 24/74 (32.4%) 48/74 (75.7%)	10/74 (13.5%) 10/74 (13.5%)	
If you experience side effects of drugs, does this mean you should stop giving them?	26/74 (35.1%)	22/74 (29.8%)	26/74 (35.1%)	
Mark the symptoms which may occur if your heart condition deteriorates and which should make you contact your cardiologist	46/104 (44%)		18/104 (17%)	40/104 (39%)

fied these items correctly and a large percentage (39%) tried to do so but gave an incomplete answer. We considered an answer correct if the patient had recognized ≥ 5 of the 7 relevant symptoms.

A large number of subjects (71%) knew the definition of endocarditis, and 38.4% were aware that unexplained fever for > 5 days was the most typical symptom, but < 30% of them knew that endocarditis could recur. Patients showed poor knowledge about the most

significant factors contributing to the onset of endocarditis except for dental abscess. Others results about this topic are summarized in table IV.

Most of the patients thought that smoking and alcohol consumption were more harmful for subjects with congenital heart disease than for their healthy counterparts.

More than 70% of the patients knew that they can take part in any activity that they feel capable of doing,

Table IV. Knowledge about preventive measures, physical activities, and recurrence risk.

Question	Correct	Incorrect	Does not know	Incomplete
What is endocarditis?	74 (71.1%)	2 (1.9%)	13 (12.5%)	15 (14.5%)
Indicate the most typical sign or symptom of endocarditis	40 (38.5%)	12 (11.5%)	28 (27%)	24 (23%)
Can you get endocarditis more than once in your lifetime?	30 (28.9%)	35 (33.6%)	2 (1.9%)	37 (35.6%)
Factors contributing to the onset of endocarditis:				
- needle contamination	24 (23%)	42 (40.4%)	38 (36.5%)	
- smoking	42 (40.4%)	24 (23%)	20 (19.2%)	18 (17.4%)
- bacteria from skin infection	28 (26.9%)	16 (15.4%)	60 (57.7%)	
- dental abscesses	94 (90.3%)	4 (3.9%)	6 (5.8%)	
- poor nail and skin care	28 (26.9%)	16 (15.4%)	11 (10.6%)	49 (47.1%)
- body piercing and tattooing	16 (15.4%)	76 (73%)	12 (11.6%)	
Should you have a dental check up at least once a year?	74 (71.2%)	8 (7.7%)	22 (21.1%)	
Should you take antibiotics before every visit to the dentist?	24 (23.1%)	20 (19.2%)	60 (57.7%)	
Do bleeding gums need extra attention?	20 (19.2%)	56 (53.8%)	28 (26.9%)	
Should you clean your teeth at least once a day?	100 (96.1%)	2 (1.95%)	2 (1.95%)	
Is smoking more harmful for patients with congenital heart disease than for other people?	94 (90.3%)	8 (7.8%)	2 (1.95%)	
Is alcohol consumption more harmful for patients with congenital heart disease than for other people?	86 (82.7%)	8 (7.8%)	10 (9.5%)	
Do you take part in competitive sports?	74 (71.2%)	10 (9.5%)	20 (19.3%)	
Do you think that it is necessary to choose an occupation That is not too physically demanding?	82 (78.8%)	18 (17.4%)	4 (3.8%)	
What is the risk of having a child with a congenital heart disease? (high, low, no risk, do not know)	6 (5.8%)	32 (30.7%)	66 (63.5%)	
Which contraceptives are the most advisable for you to use in the light of your congenital heart disease? (for women only)	40/56 (71.4%)	16/56 (28.6%)		
Are you at risk of deterioration during pregnancy? (for women only)	34/56 (60.7%)	6/56 (10.7%)	16/56 (28.6%)	

but that competitive sports with frequent training may be not indicated. About 80% of patients thought that they may need an occupation that is not too physically demanding owing to the restrictions imposed by their heart condition. The majority of patients did not know whether their heart disease could be inherited by their children.

Most of the female patients knew that the oral contraceptive pill was the most appropriate method of birth control; most of them were aware that pregnancy would cause additional risks to their health.

The two-way ANOVA showed that correct answers to four questions were related to the patient's age. These questions were on: physical restrictions, the possibility of taking part in competitive sports, risk associated with pregnancy, and the need for follow-up controls. Patients who answered these questions correctly were around 35 years old ($p = 0.005$).

Discussion

Adults with chronic disease may feel more difficulties making decisions for themselves and being responsible for their actions. They have to make choices about family planning, career goals, contraception and pregnancy, knowing the limits imposed by their heart disease.

Previous studies have concentrated on psychological and social questions^{5,6}.

It is usual practice in our Center to explain to all patients in lay terms their heart defect (often with the use of simple diagrams), its short- and long-term implications, problems related to physical activities, and prophylaxis of endocarditis at the time of the initial diagnosis and on subsequent consultations or during any periods of inpatient care. We do not, however, routinely assess whether the information given has been understood.

Our questionnaire was a formal but open forum for patients to express their beliefs regarding their health and allowed the researcher some quantitative assessment of individual understanding.

Patients were very knowledgeable about the name of their lesion but less able to indicate its anatomical position on a diagram. We do not understand this discrepancy. Every patient is shown a diagram with a simple explanation of the heart defect at least once, but we have never assessed whether this has been understood. Our findings indicate that it may be useful to discuss the anatomic items several times in order to improve patients' knowledge.

We were positively impressed by the good understanding of the purpose of follow-ups, and the specific treatment received. Patients also showed a good understanding of drug treatment, doses, schedule, its function and side effects; the possibility of interactions with other drugs or foods was not well understood. This is

probably related to the fact that the physician usually spends a large amount of time stressing the importance of drug treatment; the interactions are not well explained routinely because this is a difficult and specialist topic. The same results are described by Moons et al.⁴; they reported a patient's very good knowledge about past treatment (95%). Patients taking drugs ($n = 9$, 15%) were apparently well informed about their drug regimen (78%) and what to do in case of side effects (89%).

Patients showed moderate knowledge about the symptoms of deterioration. This is an important point because access to outpatient or inpatient care can be rapid if a patient is aware that a specific symptom may be the first sign of a deteriorating health status.

Except for the definition, all the other items about the prophylaxis of endocarditis (recurrence, symptoms, risk factors) were not well known by the patients. These data are comparable to those of other previous reports^{7,8}. Moons et al.⁴ showed that only 16% of the patients in their study knew the definition of endocarditis, and only 8% were aware that unexplained fever for > 5 days was the most typical symptom. It is clear that this is a difficult topic for all patients and more should be done in order to improve their knowledge. All our patients routinely receive a leaflet at home about endocarditis. We have not regularly checked the understanding of what is reported in this leaflet. We should probably go through it and explain it in detail.

Most of the patients had a correct understanding of the limitations related to their condition. This is probably the result of a good transmission of this information by their parents and/or by the medical staff.

Inheritance of the malformation was not well understood by the majority of patients. We believe that we have a large responsibility for this lack of knowledge. Dore et al.² in a study about transition of care to adults showed that questions about the potential risks of pregnancy were pertinent in 56 women. Of these 37 (67%) had never discussed the potential risks of pregnancy with their previous physician. There were 37 women referred by pediatric cardiologists and 19 referred by other physicians. Patients referred by pediatric cardiologists were less likely to have discussed pregnancy issues before transfer than the patients referred by other physician (28/37 [76%] vs 9/19 [47%]). This topic is difficult and is not usually mentioned during admissions or evaluations in the outpatient clinic. This major topic should be better explained using a specific and dedicated leaflet and also including genetic counseling at some point during the follow-up.

Women showed good knowledge about problems related to their sexuality. This is probably the result of good cooperation with gynecologists.

Unlike a previous study⁴, we did not find any correlation between some correct answers and the sex of the patient at multivariate analysis. It was an interesting, but unexpected, finding in our patients that questions

about physical activities, sports and pregnancy were correctly answered by subjects < 35 years. This finding is probably related to the fact that younger patients are more interested in and sensitive to these problems than older patients.

Clinical implications. Our patients' poor knowledge about some particular aspects of their disease, its treatment and preventive measures may be a problem with major consequences. For instance, patients need a clearer understanding about the risk factors for endocarditis, how they can avoid potential exposure and symptoms of a deteriorating heart condition.

The good understanding of the purpose of follow-ups is important in order to motivate patients to comply with the scheduled outpatient appointments. This emphasizes the importance of good patients' education. Even in benign heart defects, health care professionals need to explain the nature and progression of the disease in detail^{9,10}.

Before this study we felt that our policy for providing information to patients was adequate, but the study shows that our patients' understanding is lacking in some specific areas.

Educational efforts should be an integral part of follow-up, in order to enhance patients' understanding of the different aspects of their heart condition.

There is good evidence to suggest that quality of life in terms of anxiety, "coping" with disease and satisfaction with treatment are enhanced by a good understanding of the condition⁸. There can be no doubts that these aspects of quality of life of patients with a heart disease can be improved by intensified audit efforts to ensure better understanding. Such a process is likely to have important implications for centers caring for adults with congenital heart diseases.

Study limitations. Only 52% of the patients surveyed actually filled in and sent back the questionnaire. We can suppose that we received answers from the most motivated and satisfied patients and this is a source of bias.

Patients filled in the questionnaire at home and it is possible that there was a "refreshment effect" as they could have read their clinical files before answering a question.

In conclusion, in this study we assessed how knowledgeable adult patients with congenital heart defects were about their disease, its treatment and measures to prevent complications. The results indicate that the educational efforts of all the staff (physicians and nurses) have given encouraging results, but there are still significant gaps in knowledge that need more educational work.

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