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Effectiveness of Structured Patient Education on the Knowledge Level of Adolescents and Adults with Congenital Heart Disease

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Abstract

Background: Patients with congenital heart disease (CHD) have poor understanding of their heart condition, treatment and prevention of complications. To improve their level of health-related knowledge, a structured education program was implemented at the adult congenital heart disease program. This study aimed (a) to evaluate the level of knowledge of patients who received structured CHD education as compared to patients who did not receive this education; (b) to explore if the provision of structured education is an independent determinant of knowledge; and (c) to evaluate if patients who received structured education reached the educational target (>80% correct answers).

Methods and results: A total of 317 patients were included: 226 in the education group, and 91 in the comparison group. Knowledge was assessed using the 'Leuven Knowledge Questionnaire for Congenital Heart Disease'. The mean total knowledge score in the education group (57%) was significantly higher as compared to the comparison group (43%) ($p<0.001$). However, only 24 patients (11%) in the education group reached the educational target of the program. After adjusting for patient's age, educational level and disease complexity, hierarchical multivariable linear regression analysis showed that the provision of structured CHD education was an independent determinant of higher levels of knowledge.

Conclusion: A structured education program was associated with a higher level of knowledge. However, the educational target for sufficient knowledge was reached in a very limited number of patients. Hence, continuous efforts in educating patients and developing alternative education methods are needed.

Keywords: Adolescent; Heart defects , Congenital; Knowledge; Transition; Patient education

Implications for Practice

- Structured patient education, provided by an advanced practice nursing team, was found to significantly improve the level of knowledge of adolescents and adults with congenital heart disease.
- Despite the promising results of this study, the educational target of this education program was only reached by a limited number of patients.
- Clinicians and researchers should explore and investigate alternative forms of patient education.

Introduction

A significant proportion of patients diagnosed with congenital heart disease (CHD) remain at risk for developing cardiac complications such as atrial arrhythmias, infective endocarditis and congestive heart failure (1,2). A good understanding of the heart condition, treatment and components of heart-healthy behavior is necessary to prevent these potential complications (3,4). Limited knowledge of patients might result in health-compromising behaviors or result in unseemly restrictions influencing the well-being of patients. A good understanding of the impact of the heart condition on daily living is fundamental especially for adolescents as they are prepared to become responsible for their healthcare and self-management in adult life (5).

Studies that comprehensively assessed the level of knowledge of adults (3,6) and adolescents with CHD (5) are scarce. Previous studies predominantly evaluated selected aspects of knowledge in these patients such as the name and location of the heart defect (7-13), prevention of endocarditis (8,10-12,14), inheritance (15), risk of pregnancy (11), restrictions to physical activity (16), use of contraceptives (17) and medication for anti-coagulation (18). These studies demonstrated that adolescents and adults with CHD have poor to moderate understanding of their heart condition (3,5-13), aspects of self-care activities preventing endocarditis (3,5,6,8-12,14,18), inheritance of CHD and reproductive issues(3,6,15,17), and safe levels of physical activity (3,5,9,16,18). The comparability of these cross-sectional studies is however limited since the level of knowledge was assessed using different methods: by interview (7,14); drawing techniques (13); or structured questionnaires (3,5,6,8-10,12,15,16,18-21). However, several studies that used questionnaires, these had limited or no data that supported their validity or reliability of the questionnaires (8-10,12,15,16,18).

To enhance the level of knowledge in patients, repetitive and structured educational interventions are recommended (11,12,19,22). Since provision of patient education is a time-consuming activity, requiring the investment of sufficient time, space and trained personnel, studies evaluating the effectiveness of patient education are highly needed (12,23). However, the evidence supporting the effectiveness of structured education programs is currently lacking. A preliminary pre-post study showed a promising 10% increase of knowledge levels in 31 adults with CHD after the implementation of a structured education program (19). Since no study comparatively investigated the effectiveness of educational efforts, this study aimed (a) to compare the level of knowledge between patients with CHD who received structured education and a comparison group of patients who did not receive prior structured education; (b) to explore if the provision of structured education was an independent determinant of higher levels of knowledge; and (c) to evaluate if patients who received education reached the educational target of the education program.

Methods

Study population

In this descriptive, cross-sectional study, patients with CHD were recruited at the outpatient clinic for adults with CHD. Patients were eligible if they had a structural heart defect, were literate, Dutch speaking, and gave verbal informed consent. Patients were excluded if they had learning disabilities, if they were not in regular follow-up at the pediatric cardiology or ACHD program of the hospital. Patients who were newly diagnosed as adults with an atrial septal defect or foramen ovale after a cryptogenic stroke were excluded since the congenital cardiac condition was diagnosed secondary to the stroke.

Participants were recruited on preselected dates during a 13-month period from January 2006 to February 2007. Overall, 493 patients were planned for an outpatient visit on these selected dates, 353 (72%) of which met the inclusion criteria and were therefore asked to partake in the study. Six patients refused to participate due to a lack of interest or time constraints. Thirty patients were excluded because of practical reasons, e.g. did not bring their glasses; physician was waiting; etc. Thus, 317 (90%) of the eligible patients participated. Participants were divided into two groups: (a) patients who previously had an outpatient visit at the ACHD clinic and therefore received at least once structured patient education, and (b) patients who transferred directly from pediatric cardiology or other adult services and had their very first ACHD visit. These latter patients comprised the comparison group since they did not receive structured education before. The education group consisted of 226 patients with a median age of 27.5 years; 54% were male. The comparison group consisted of 91 patients with a median age of 17 years; 53% were male. Demographic and clinical characteristics of both groups are detailed in **Table 1**.

Setting and Intervention

The division of Congenital Cardiology, established in 1960, is part of the University Hospitals of Leuven in Belgium and contains two programs: pediatric cardiology and the ACHD program. To date, more than 35,000 individuals have been examined and/or treated in this center. In 1995, a dedicated ACHD program with a different provider team was established. At this hospital, young people with CHD are transferred from pediatric cardiology to the ACHD program when they reach the age of 16, unless they are medically unstable. This transfer is not preceded by structured provision of information or instruction as part of a formal transition program.

According to the complexity of the heart defect, patients are planned to have an outpatient visit on a regular basis (24-26). For patients diagnosed with a simple heart lesion, outpatient visits to check the patient's cardiac condition, are planned every 3-5 years either in a non-specialized setting or at a shared care facility (24,25). In patients with a moderately severe condition, check-ups are recommended every 1-2 years preferably done at specialist centers (24). Patients who have a complex heart lesion are advised to have a follow-up visit at an ACHD program every 6-12 months (24).

A typical outpatient visit of an adult patient to the ACHD program starts with the registration of an electrocardiogram (ECG) by a nurse. Then patients will meet one of the nurses of the ACHD advanced practice nursing (APN) team to discuss their subjective condition, experienced symptoms, lifestyle issues and questions they have. Furthermore, structured patient education is provided verbally during this session. This education program was based on the framework of educational assessment in CHD (27) and provides information about the heart defect, the current treatment, the need for regular follow-up, characteristics and prevention of endocarditis, physical and vocational lifestyle issues, inheritability of the heart defect, potential risk of pregnancy, contraception, sexuality and traditional cardiovascular lifestyle issues. Education is provided to patients on an individual basis during an outpatient visit and takes 15-30 min. Topics are discussed repeatedly during subsequent outpatient visits to facilitate retention of the provided information. During the education session, a computerized intake form/checklist is used by the nursing team to guarantee that information is provided in a structured and systematic way. Finally, the last part of the outpatient visit entails a visit to the congenital cardiologist who performs the medical check-up using clinical examination, echocardiography, or other diagnostic tools.

To date, two advanced practice nurses and three specialized nurses are on the staff in the ACHD program, corresponding with 1.73 full-time equivalents. With the current staffing, education can systematically be provided during each outpatient visit, which resulted in 2528 patients who received education in the year 2012.

Variables and measurement

Demographic data were gathered during a patient interview. Clinical variables (primary diagnosis, disease complexity as defined by Task Force 1 of the 32nd Bethesda conference (28), history of endocarditis, history of pregnancy, prescribed contraception) were collected from patients' medical records. Assessment of the level of knowledge of all participants, irrespective of the group to which they were assigned, was performed using the Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD) (3,29). This instrument was developed and refined by Moons and coworkers as a comprehensive questionnaire assessing knowledge in patients with CHD. A revised version of the LKQCHD was developed in 2009 comprising 34 questions for female and 31 questions for male patients (29). The LKQCHD covers five domains: (a) knowledge of the heart defect and treatment, (b) knowledge of the prevention of complications, (c) knowledge of physical activities, (d) knowledge of sexuality and heredity, and (e) knowledge of contraception and pregnancy planning, and has been described in detail elsewhere (3). Expert review, pilot testing, and confirmation of theoretically derived hypotheses provided evidence for the content and construct validity of the LKQCHD (3,29).

Procedure

A nurse from the ACHD nursing team explained the purpose and procedure of the study to all patients prior to their scheduled outpatient visit at the ACHD clinic. After receiving verbal consent, the nurse gave the patients instructions on how to fill out the LKQCHD while they were sitting in the waiting room. To ensure that the patients filled out the questionnaire independently, the nurse asked relatives not to help. External sources (e.g. internet) could not be consulted. After completion of the LKQCHD, the nurse checked whether all items were filled out and asked for clarification if necessary. The researcher evaluated the patients' answers as 'correct,' 'does not know,' 'incorrect,' or 'incomplete.' The study was approved by the Institutional Review Board of the University Hospitals Leuven, Belgium.

Statistical analysis

Statistical analyses were performed using SPSS, version 17.0 (SPSS Inc., Chicago, Illinois, USA). Data derived from the LKQCHD were analyzed at two levels: item level and patient level. At the item level, knowledge variables were dichotomized as 'correct' or 'incorrect' (i.e. includes incomplete, does not know, and incorrect responses), and the proportion of patients that gave a correct answer was calculated. At the patient level, a total knowledge score was calculated by computing the percentage of correct answers per patient. The educational target for individual patients in this education program was set at an overall knowledge score of $\geq 80\%$ based on a cut-off used in previous studies (3,5). Descriptive statistics for nominal variables were expressed in absolute numbers and percentages. Continuous data were presented as means and standard deviations if data were normally distributed. To test differences in overall knowledge score between the education and comparison group, an unpaired *t*-test was used. The effect size was

determined by calculating the Cohen's *d*. Effect sizes were categorized as a small (0.2–0.5); moderate (0.5–0.8); or large difference (>0.8) (30).

To explore if the level of knowledge was independently determined by the structured education provided, a hierarchical multivariable linear regression analysis (enter method) was performed, adjusting for confounding factors, potential differences between the groups, and interaction effects. Based on empirical evidence, three potential confounders were included in this analysis: age (3,7,9,10,12), level of education (3,9,12,15), and complexity of disease (3). The assumptions of normality and linearity of residuals, and absence of multicollinearity were met. Furthermore, to test the robustness of this model a matched (1:1) control analysis was performed, in which the difference in knowledge levels was directly tested between pairs of patients, matched on the confounders emerging from the multivariable model. All tests were two-sided, and the level of significance was set at $p < 0.05$.

Results

Comparison of the level of knowledge

Patients who previously received education displayed adequate knowledge in 8 of 34 (24%) questions (>80% respondents answered correctly); moderate knowledge in 11 of 34 (32%) questions (50-80% respondents answered correctly); and poor knowledge in 15 of 34 (44%) questions (<50% respondents answered correctly).

Patients who did not receive prior education (comparison group) displayed adequate knowledge in 5 of 34 (15%) questions; moderate knowledge in 7 of 34 (20%) questions; and poor knowledge in 22 of 34 (65%) questions. The proportion of patients providing a correct answers for

all items of the LKQCHD was consistently higher in the education group, with the exception of items 5 and 17 (**Table 2**).

Patients in the education group had a significantly higher mean total knowledge score (57%), as compared to the comparison group (43%)($t=8.737$; $p<0.001$). The difference between the scores of the two groups was not only statistically different, but also clinically meaningful as shown by the calculation of the Cohen's d ($d = 1.24$).

Exploration of independent determinants of knowledge

In order to correct for confounding factors and for differences between the groups, a hierarchical multivariable linear regression analysis was conducted. This analysis revealed that, after adjusting for age, educational level, and disease complexity (block 1), structured patient education (block 2) was significantly associated with the total knowledge score (**Table 3**). This model demonstrated that a higher educational background and a higher disease complexity were significant correlates of a higher level of knowledge. This means that structured patient education was a significant factor in explaining improved levels of patient knowledge, over and above the impact of educational background and disease complexity. The knowledge score was not related to patients' age, suggesting that knowledge in this population is not time-dependent. Moreover, no interaction effect between age and structured education was observed. The final regression model explained 28% of the variance for the level of knowledge (**Table 3**).

The matched control analysis, comparing the level of knowledge of 85 pairs of patients matched on educational background and disease complexity showed that the knowledge score of the education group was significantly higher as compared to the matched controls ($t=-4.474$;

$p<0.001$). This displays the robustness of the model and provides additional support for the effectiveness of structured patient education.

Proportion of patients reaching the educational target

Although the level of knowledge was significantly higher in the education group, the educational target of the program, defined as a total knowledge score of ≥ 80 , was only achieved in 24 (11%) patients of the education group.

Discussion

This study showed that patients who partook in a structured education program were significantly more knowledgeable about their heart defect, its treatment, and various preventive measures than patients who did not receive structured education. Furthermore, this difference in knowledge levels of both groups was found to be large and clinically relevant.

Hierarchical multivariable regression analysis showed that the provision of structured patient education was a significant and independent predictor of higher levels of knowledge in patients. Additionally, higher levels of educational background and a more complex heart defect were identified as significant predictors of increased levels of knowledge in this study. Higher levels of knowledge might be expected in patients with more complex CHD, since these patients are recommended to have an outpatient visit at least once a year. Therefore, these patients will receive structured education more frequently and as a result information might be better retained. Furthermore, this study confirmed previous study results that indicated a positive correlation between knowledge of CHD and higher educational levels(3,9,12,15,29). This finding stresses the importance of providing more attention to patients with lower educational levels because they might need more time or repetition in order to understand the information and lifestyle

instructions. As in line with previous studies in adolescents (3,10,12) and adults (7) with CHD, the level of knowledge was found to be independent of age. Since there were significant differences in the size of the two groups and in the characteristics of patients belonging to either the education or comparison group, a matched case control analysis was performed. This analysis created 85 pairs of patients matched on their educational background and CHD complexity. Since age was not identified as a significant determinant of knowledge, patients were not matched with a control on their respective age. In sum, this study was the first to show that structured patient education by an advanced practice ACHD nursing team is effective in improving patient's knowledge about their heart condition, treatment, lifestyle issues and health-promoting behaviors.

Nonetheless, this study revealed that patients with CHD who received structured patient education still have a relatively low level of knowledge on multiple aspects of their condition since only 1 in 10 patients achieved the predefined educational target. Analysis of the responses of patients in the education group showed that most patients still had a poor understanding of the definition, symptoms, and risk factors of endocarditis; the signs of deterioration of the heart condition; inheritance of the defect; the risk of pregnancy; the anatomy of the lesion; and the suitability of intrauterine devices as contraceptives. Hence, the educational efforts currently implemented in the ACHD program of the hospital were not capable of achieving the anticipated educational target. This result might be disappointing, given the investment of supplementary resources which are needed to systematically and repetitively provide education to these patients. However, previous studies showed that retention of health-related information is generally low in patients (31-33). Therefore, complementary or alternative forms of patient education should be explored. To date, education was provided verbally in this ACHD program. Alternative forms of education could be provided by means of written information (booklets), video education, or

interactive computer programs such as digital game-based learning (34-36). This latter type of education seems to be a promising method to educate young people with a chronic condition. Rönning and colleagues performed an initial evaluation of the implementation of an Education and Psychosocial Support (EPS) model (21). This model comprised three components: medical consultation by an ACHD cardiologist, computer-based education, and psychosocial support provided by a multidisciplinary team. A 3-month follow-up of 55 adults who received this type of education showed an increase in self-perceived levels of knowledge. Unfortunately, this pre-post study did not objectively assess the impact of this model on the level of knowledge through the use of a questionnaire (21).

Methodological issues

One must consider some methodological limitations inherent to this study when interpreting these findings. First, since this cross-sectional study was conducted in a single outpatient clinic of a university hospital in Belgium, study results have limited generalizability. However, this single-center approach was critical to yield a relatively large sample size, low attrition rate, and no missing data. An RCT-design is generally used to test the effectiveness of an intervention in patients. Since structured education is a standard element of the current care provision, it would be unethical to withhold part of the patients of this intervention. Therefore, this study used a non-randomized comparison design using a convenience comparison group reflecting the day-to-day practice. Furthermore, knowledge about CHD was measured using the LKQCHD, an instrument for which previous studies provided evidence to support the content validity and validity based on relations with other variables (3,29). However, additional aspects of reliability and validity of this instrument remain subject to scrutiny (29). Third, the LKQCHD questionnaire gives the same weighting to all items although it might be argued that some items, e.g. prevention

of endocarditis, would be of more importance to a subset of patients than to others. For the purpose of this study, a total knowledge score was calculated by simply computing the percentage of correct answers. Future studies should evaluate whether calculation of a summary score based on weighing factors assigned to items with a higher relevance would be meaningful and relevant. Fourth, although all nurses of the APN team were trained to provide structured education in a standardized way, variation in the education provided by these nurses could not be excluded. This variation might result in bias, but is a reflection of the real-life clinical practice.

Conclusion

This study was the first to support the effectiveness of structured patient education provided by an advanced practice nursing team in improving the level of knowledge of adolescents and adults with CHD using a comparative study design. Unfortunately, the educational target of this program was only reached by a limited number of educated patients. Therefore, clinicians and researchers should continue their efforts in teaching patients and in developing alternative education methods.

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Disclosures

None

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Table 1: Demographic and clinical characteristics of 317 patients with congenital heart disease

Variable	Education group (n=226)	Comparison group (n=91)
Sex		
Male	123 (54%)	48 (53%)
Female	103 (46%)	43 (47%)
Median age (years)	27.5 (Q ₁ = 23; Q ₃ =34) (Range: 16-60)	17 (Q ₁ = 16; Q ₃ =18) (Range: 15-32)
Complexity of disease		
Simple	40 (18%)	32 (35%)
Moderate	152 (67%)	48 (53%)
Complex	34 (15%)	11 (12%)
Marital status		
Unmarried (living with parents)	98 (43%)	87 (96%)
Married or living together	18 (8.0%)	3 (3%)
Living alone	110 (49%)	1 (1%)
Highest educational level		
Vocational high school	60 (28%)	29 (31%)
Technical high school	35 (16%)	32 (34%)
High school/College/University	123 (56%)	30 (32%)
Primary medical diagnosis		
Tetralogy of Fallot	47 (21%)	4 (4%)

Aortic valve disease	44 (19%)	11 (12%)
Coarctation of the aorta	29 (13%)	12 (13%)
Ventricular septal defect	24 (11%)	26 (29%)
Transposition of the great arteries	14 (6%)	5 (5%)
Pulmonary valve disease	11 (5%)	11 (12%)
Other	57 (25%)	22 (24%)

Responsible for the daily management of care

Parents		1 (1%)
Patient	210 (93%)	23 (25%)
Patient and parents	16 (7%)	67 (74%)

History of endocarditis

9 (4%)	0 (0%)
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History of pregnancies (for women only)

36 (35%)	0 (0%)
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Contraception (for women only)

Pill	66 (66%)	19 (43%)
Other methods	10 (10%)	1 (2%)
No contraception	24 (24%)	24 (55%)

Table 2: Proportion of correct answers in patients who previously received education (education group) and those without prior education (comparison group)

Question	Education group (n=226)	Comparison group (n=91)
1. What is the name of your heart defect?	150/226 (66%)	41/91 (45%)
2. Describe or indicate on the diagram where your heart defect is located.	109/226 (48%)	25/91 (27%)
3. How often do you have to come to the clinic for follow-up for your congenital heart disease?	206/226 (93%)	71/91 (78%)
4. What is the main purpose of the follow-up?	128/226 (57%)	42/91 (46%)
5. How has your heart condition been treated to date?	177/226 (78%)	77/91 (85%)
6. If you are on drug treatment, give the name, dose, schedule, reason or function, most important side effects, and interactions with other drugs or foods.	59/89 (66%)	8/15 (53%)
7. If you experience side effects from your drugs, does this mean you should stop taking them?	137/226 (61%)	37/91 (41%)
8. Do you have to follow a diet? If you answer yes, please indicate the type of diet.	218/226 (97%)	86/91 (94%)
9. Mark all symptoms that may occur if your heart condition deteriorates and for which you have to contact your cardiologist.	71/226 (31%)	8/91 (9%)
10. If the (congenital) cardiologist informs you that everything is alright, does that mean that you do not need further follow-up?	209/226 (93%)	79/91 (87%)
11. What is endocarditis?	96/226 (43%)	19/91 (21%)
12. What is the most typical sign or symptom of endocarditis?	44/226 (20%)	1/91 (1%)
13. Can you only get endocarditis once in your lifetime?	88/226 (39%)	13/91 (14%)

14. Do the following risk factors contribute to the onset of endocarditis?

Needle contamination (drug users)	95/226 (42%)	18/91 (20%)
Smoking	48/226 (21%)	7/91 (8%)
Bacteria from skin infections	90/226 (40%)	10/91 (11%)
Dental abscesses	133/226 (59%)	20/91 (22%)
Sexual activity	91/226 (41%)	22/91 (24%)
Poor nail and skin care	72/226 (32%)	7/91 (8%)
Body piercing and tattooing	85/226 (38%)	14/91 (15%)

15. As you have a congenital heart disease, should you take antibiotics immediately (without consulting a physician) if you have a temperature? 191/226 (85%) 71/91 (78%)

16. Should you have a dental check-up at least once a year? 209/226 (93%) 76/91 (84%)

17. Should you take antibiotics before every visit to the dentist? 152/226 (67%) 71/91 (78%)

18. Do bleeding gums need extra attention? 200/226 (89%) 68/91 (75%)

19. Should you clean your teeth at least once a day? 220/226 (97%) 87/91 (96%)

20. Is smoking more harmful for patients with congenital heart disease than for other people? 32/226 (14%) 7/91 (8%)

21. Is consuming alcohol 3 times a day more harmful for patients with congenital heart disease than for other people? 60/226 (27%) 22/91 (24%)

22. Can you take part in competitive sports (regional or national) requiring daily training? 125/226 (55%) 35/91 (39%)

23. Should you choose an occupation that is not too physically demanding, as you should be careful not to overexert yourself? 173/226 (77%) 68/91 (75%)

24. In terms of sexual physical effort, can you do all what you feel you are capable of doing? 205/226 (91%) 71/91 (78%)

25. What is the chance that your children will have congenital heart disease? 66/226 (29%) 18/91 (20%)

26. Which contraceptives are the most advisable for you to use in light of your congenital heart disease? (only for women)

Contraceptive pill	65/103 (63%)	15/43 (35%)
Intrauterine device	29/103 (28%)	6/43 (14%)

27. Are you at risk for deterioration or complications during pregnancy? (only for women) 51/103 (50%) 5/43 (12%)

Questions in this table replicate the Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD) questionnaire

Table 3: Hierarchical multivariable linear regression analysis on the effect of education on total knowledge score in 317 patients with congenital heart disease, adjusted for age, education background, and disease complexity.

Variable	Estimate	Standard error	Standardized estimate	p-value
Intercept	9.28	4.27	-	0.031
Education (vs. no prior education)	11.45	2.20	0.31	<0.001
Age	0.03	0.11	0.02	0.790
Educational level	6.64	0.94	0.35	<0.001
Disease complexity	4.65	1.36	0.17	0.001
Adjusted $R^2=0.277$				