ORIGINAL ARTICLES

Effectiveness of Structured Education on Knowledge and Health Behaviors in Patients with Congenital Heart Disease

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Objective To investigate whether a single educational session increased the level of knowledge and changed the prevalence of health risk behaviors in young people with congenital heart disease (CHD).

Study design We conducted a longitudinal study of patients transferred to adult CHD care who received a single educational session (n = 201) at a tertiary care center. Their knowledge level and prevalence of health risk behaviors were assessed via the Leuven Knowledge Questionnaire CHD and the Health Behavior Scale CHD, respectively. A general linear model for longitudinal measurements was used to analyze the natural progression of patients' knowledge during a 27-month period and the effect of one educational session on outcomes.

Results Participating in an educational session resulted in a small-to-moderate, but significant, increase in total knowledge level and better understanding of deterioration symptoms, and rationale and frequency of follow-up; however, it did not improve patients' health behaviors.

Conclusions This type of education did improve knowledge but did not improve the patients' tendency to engage in better health behaviors. Future studies should assess the effect of repetitive exposure to educational sessions dealing with CHD. (J Pediatr 2015;■:■-■).

Adolescence is a critical and vulnerable period for young people with chronic conditions, such as congenital heart disease (CHD). During this developmental phase, young patients transition to adult life and are expected to develop an increased sense of responsibility by managing their lifestyle, health, and health care.[1,2] Like other teenagers, however, they are tempted to engage in high-risk health behaviors, such as experimentation with cigarettes, illicit drugs, and binge drinking.[3-5] Implementing transition programs is one suggested way to help young people with chronic conditions better navigate the transition into adulthood.

Structured patient education has been proposed as a standard element of a transition program.[2,6-10] Developmentally appropriate education about the patients' medical condition and other disease-related issues is hypothesized to be critical in fostering self-management in young people with CHD.[2] The objective of structured education is not merely to improve patients' understanding of their disease but also to encourage patients to adopt a healthy lifestyle, leading to a reduction in morbidity and increase in life expectancy.[11-13]

We sought to describe how disease-related knowledge and engagement of high-risk health behaviors develop in young people with CHD transitioning into adulthood. We also sought to determine whether a single structured educational session would increase the level of disease-related knowledge and decrease the prevalence of high-risk health behaviors among these young patients.

Methods

This longitudinal study was conducted at a large tertiary care center, housing both a pediatric and an adult CHD (ACHD) care program. In this center, patients are transferred from pediatric cardiology to ACHD care at the age of 16 years, provided they are medically stable. A multidisciplinary team specialized in adult care provides ACHD care. This team is distinct from the pediatric cardiology team. During a patient's last pediatric visit, the patient is given informa-

ACHD	Adult congenital heart disease
APN	Advanced practice nursing
CHD	Congenital heart disease
ES	Effect size
GLM	General linear model
HBS-CHD	Health Behavior Scale-Congenital Heart Disease
LKQ-CHD	Leuven Knowledge Questionnaire for Congenital Heart Disease
RR	Response rate

tion on the rationale and timing of transfer to ACHD care. With the consent of all parties, a designated adult provider generally is chosen. This recommendation is documented in the patient's file, and then a pediatric cardiologist writes a referral letter. Currently, a formal educational transition program does not precede this transfer of care within our hospital.

For adults, the frequency of outpatient visits is based primarily on the anatomical classification of the heart defect. The standard frequency of outpatient visits is every 6-12 months for those patients diagnosed with complex heart lesions, every 1-2 years for moderately complex defects, and every 3-5 years for simple lesions.[9,14,15] A routine ACHD outpatient visit comprises a consultation with a member of the ACHD advanced practice nursing (APN) team, followed by a medical check-up performed by an ACHD cardiologist. During the APN visit, patients have the opportunity to discuss their health status, symptoms experienced, and pending questions or concerns. Furthermore, every patient receives verbal structured education on disease-related and behavioral issues, including CHD diagnosis; current treatment; rationale for regular follow-up; infective endocarditis symptoms and strategies for preventing it; healthy lifestyle; vocational and educational choices; sexuality; inheritability of the defect; risks associated with the use of contraceptives; and pregnancy. Education and counseling sessions are approximately 15-30 minutes. To document which items were discussed, repeated, or already known by the patient, the APN team uses a computerized checklist. Detailed information on the comprehensive list of issues addressed during the education is provided in Table I (available at www.jpeds.com).

This longitudinal study was conducted as part of the i-DETACH project (ie, Information Technology Devices and Education Program for Transitioning of Adolescents with Congenital Heart Disease). Patients were selected from the database of pediatric and congenital cardiology of the hospital. They were eligible for inclusion if they had a confirmed diagnosis of CHD, were 14-18 years of age at the start of the study, had their last outpatient visit at our hospital ≤5 years ago, were able to read and write Dutch, and if their valid contact details were available in the hospital administration. CHD was defined as "structural abnormalities of the heart and/or great intrathoracic vessels that are actually or potentially of functional significance."[15] Patients were excluded if they had cognitive and/or physical limitations, preventing them from filling out questionnaires; had undergone heart transplantation; or if they and/or their parents did not consent to participate in the study. Overall, 498 patients met the inclusion criteria.

During a period spanning 3 years, 4 measurements (T_1-T_4) were taken once every 9 months. A set of questionnaires was sent by mail to the patients' home address. Patients were asked to fill-out the questionnaires and to return them in a prestamped envelope. They received a movie ticket upon completion of the questionnaires. The study was approved by the Institutional Review Board of the University Hospitals

Leuven and was performed in line with the principles outlined in the Declaration of Helsinki.[16] A total of 429 (response rate [RR] = 86%), 398 (RR = 86%), 366 (RR = 82%), and 337 (RR = 77%) adolescents participated at T_1, T_2, T_3, and T_4, respectively.

For the present study, data on a selected group of patients were analyzed. Because our aim was to evaluate the impact of a single structured educational session on the knowledge and health risk behaviors of young patients with CHD, we analyzed only data from patients who were in current follow-up within our center. Patients who had already transferred to the ACHD program before the start of the study were excluded from data analysis. Our final sample comprised 210 patients. RRs varied between measurement points because a limited number of patients decided to cease participation during the longitudinal data collection (Figure 1; available at www.jpeds.com). Self-reported questionnaires were completed by patients at home and some patients had missing values for particular items. Complete data for the respective items were available for 193 to 196 patients at T1; 183 to 185 patients at T2; 169 to 171 patients at T3; and 149 to 150 patients at T4. These respective ranges varied between measurement points.

Apart from a few exceptions, patients who transferred to ACHD care during the study period had one outpatient visit and thus were exposed to one educational session. A total of 37, 36, and 33 patients received the educational session after T_1, T_2, and T_3, respectively. One hundred four patients (49.5%) did not transfer during the study period and therefore were not exposed to patient education (noneducation group). Figure 1 presents a detailed flowchart diagram of the sample selection.

Demographic data were collected using a self-report survey. Clinical characteristics were collected by means of chart review and included primary CHD diagnosis, anatomical complexity of the heart defect based on guidance from Task Force 1 of the 32nd Bethesda Conference,[9] and history of surgery or catheter-based interventions. The precise date when patients were transferred to ACHD care was determined on the basis of chart reviews. The patient's first ACHD outpatient visit coincides with the first time the patient received structured patient education. The patients were not exposed to this type of education in the pediatric cardiology clinic.

The level of disease-related knowledge was measured longitudinally using the Leuven Knowledge Questionnaire for CHD (LKQ-CHD), which comprises 34 items relevant for female patients and 31 items relevant for male patients.[17,18] For each patient, a total knowledge score was calculated by computing the number of correct answers divided by the number of eligible answers, multiplied by 100. The total knowledge score ranged from 0 to 100. In addition, 8 thematic subscale scores were calculated, representing the level of patient knowledge regarding: (1) CHD diagnosis; (2) treatment; (3) follow-up; (4) cardiovascular risk; (5) symptoms; (6) endocarditis; (7) physical activity; and (8) reproduction. These subscale scores also ranged from 0 to

100 and were calculated as the percentage of correct answers on the respective items comprising these 8 subscales. The total knowledge score and the 8 thematic scores were calculated for a patient only if at least two-thirds of the survey items were filled out. A patient was said to have adequate understanding if he/she had >80% correct answers, moderate understanding with 50%-80% correct answers, and poor understanding with <50% correct answers.[18] The LKQ-CHD is a valid instrument for assessing the level of knowledge in patients with CHD based on content validity and relationships with other variables.[17]

Health risk behaviors were assessed longitudinally using the 22-item Health Behavior Scale-CHD (HBS-CHD).[19] This is a self-report instrument that addresses 4 important components of health behaviors in patients with CHD: (1) the use of alcohol; (2) the use of tobacco and illicit drugs; (3) oral hygiene; and (4) engagement in physical activities. Three health behavior risk scores can be calculated. A substance use risk score (range 0-3) is based on whether: (1) binge drinking occurred at least once a month; (2) ≥1 of 7 predefined drugs were used once a month or less; and (3) cigarettes were smoked. A dental hygiene risk score (range 0-3) is based on whether: (1) the patient failed to visit a dentist annually; (2) did not brush his/her teeth daily; and (3) did not floss his/her teeth. Finally, an overall health risk score (range 0-7) is based on the individual's substance use risk score, dental hygiene risk score, and the absence of sports participation. These 3 risk scores are transformed into a scale ranging from 0 (no risk) to 100 (maximum risk) to facilitate interpretation and to allow for comparisons. The HBS-CHD was found to be a valid and responsive tool for assessing various components of health risk behavior of young people with CHD.[19]

Statistical Analyses

Differences in demographic and clinical characteristics of patients included in the education group or noneducation group were tested using a χ^2 test for nominal-level data, a Mann-Whitney U test for ordinal-level data, and an unpaired t test for continuous-level data.

A general linear model (GLM) for longitudinal measurements was used to analyze both the natural progression of patients' knowledge during a 27-month period and the effect of education on LKQ-CHD and HBS-CHD scores. More specifically, a direct likelihood approach was adopted using an unstructured 4×4 covariance matrix for the 4 longitudinal measurements,[20] while considering the measurement point as a categorical predictor.[21] The exposure to the educational session was considered to be a binary, nonreversible, time-dependent predictor. That is, the variable is "0" before transfer and "1" after transfer to ACHD care with exposure to structured education. The exact timing of the educational session was determined based on the date at which patients had their first ACHD outpatient visit. For statistical purposes, it was determined whether the educational session was provided to patients after T1, T2, or T3, respectively. At T_1, the baseline levels of knowledge and prevalence of health risk behaviors were determined in 196 patients.

Some basic characteristics of the patients in the present analyses have been previously reported.[17,22,23] Because significant differences in levels of knowledge according to patients' age; sex; educational level (ie, high school/college/university, technical high school, vocational high school); and anatomic classification of the heart defect (ie, mild, moderate, complex) were found,[17,22,23] these characteristics were added to the model as potential confounding variables. By including an interaction term between education and when education was provided, the effect of structured education was allowed to differ between T_2, T_3, and T_4. Patients of the same age, sex, education level, and level of CHD anatomical classification were assumed to follow the same knowledge progression as long as they were not exposed to the educational session. This latter assumption allowed for a direct estimation of the effect of the single educational session at the various measurement times and was justified, based on clinical and statistical considerations. P values <.05 were considered to be significant. No corrections for multiple testing were considered.

Sensitivity analysis was also performed using Friedman repeated measures ANOVA test to assess the robustness of the results obtained through the GLM analysis for the natural progression of knowledge level and risk behaviors over 27 months. This supplementary sensitivity analysis was performed on the complete data of patients in the non-education group who participated in the four subsequent measurements (n = 65). SPSS version 20.0 (SPSS Inc, Chicago, Illinois) and SAS software, version 9.2 of the SAS System for Windows (SAS Institute Inc, Cary, North Carolina) were used.

Results

Patients had a mean ± SD age of 16 ± 1.1 years (range, 14.1-18.2 years). The most commonly diagnosed heart defect was ventricular septal defect (25.7%), followed by aortic valve abnormality (19.5%) and pulmonary valve abnormality (15.7%). Almost one-half of the sample was diagnosed with a mild defect (49.1%). Moderately and highly complex heart defects were diagnosed in 41.4% and 9.5% of the sample, respectively. More details about demographic and clinical characteristics at baseline (T_1) are presented in Table II.

Patients in the education group (n = 106) did not differ from patients in the noneducation group (n = 104) in terms of sex (χ^2 = 0.017; P = .897); level of CHD anatomical classification (U = 5.708; P = .621); prevalence of cardiac surgery (χ^2 = 0.001; P = .970); or educational level (U = 4.884; P = .437). Patients of the education group were significantly older than those in the noneducation group (16.2 ± 1 years vs 15.7 ± 1 years; t = −3.47; P = .001). However, a difference in mean age of 7 months would likely not be clinically relevant (Table II).

Before transferring from pediatric to ACHD care (ie, at T_1) the prevalence of health risk behaviors and the level of knowledge were measured in the overall sample (T_1, n = 196). From this baseline assessment, we were able to calculate the health

Table II. Demographic and clinical sample characteristics at baseline of sample (n = 210)

Variables	Total sample, n = 210	Education group, n = 106	Noneducation group, n = 104	Test statistics
Sex, n (%)				
Male	112 (53.3)	57 (53.8)	55 (52.9)	$\chi^2 = 0.017$
Female	98 (46.7)	49 (46.2)	49 (47.1)	NS
Age, y, mean ± SD	16 ± 1.1	16.2 ± 1	15.7 ± 1.1	t = −3.47 NS
Anatomical classification of primary CHD diagnosis, n (%)[9]				
Complex	20 (9.5)	12 (11.3)	8 (7.7)	U = 5.708
Moderate	87 (41.4)	43 (40.6)	44 (42.3)	NS
Simple	103 (49.1)	51 (48.1)	52 (50)	
Cardiac surgery for CHD, n (%)				
Yes, ≥1 cardiac surgical intervention	77 (36.7)	39 (36.8)	38 (36.5)	$\chi^2 = 0.001$
No	133 (63.3)	67 (63.2)	66 (63.5)	NS
Current level of education, n (%)				
High school/college/university	90 (46.9)	40 (42.1)	50 (51.5)	U = 4.884
Technical high school	61 (31.3)	36 (37.9)	25 (25.8)	NS
Vocational high school	41 (21.4)	19 (20.0)	22 (22.7)	

NS, not statistically significant.

behavior risk scores and the overall and thematic knowledge scores of all participants, both the education group and noneducation (control) group.

The prevalence of health-compromising behaviors in the overall sample of patients with CHD (n = 196) was low, because the mean ± SD overall health risk score was 17.5 ± 14.5 (m_e = 14; IQR = 15), on a scale from 0 to 100. The mean ± SD substance use risk score was even lower (5.4 ± 16.7; m_e = 0; IQR = 0). The greatest risk score was related to dental hygiene, with a mean ± SD risk score of 29.1 ± 24.4 (m_e = 33; IQR = 33).

The overall level of knowledge at baseline was poor, with a total knowledge score of 43 ± 14 for the overall group of patients with CHD (n = 210). None of the patients achieved an adequate understanding (>80% correct) on the 8 thematic subscales. At baseline, we observed moderate levels of knowledge (50%-80% correct) for the subscales CHD treatment (56.2 ± 29.2), rationale and frequency of follow-up (55.6 ± 29.4), and physical activity (67.9 ± 26.2). Poor understanding (<50% correct) was found for CHD diagnosis (37.2 ± 39.8), endocarditis prevention (40.2 ± 22.7), issues related to sexual reproduction (15.7 ± 29.4), cardiovascular risk factors (47.8 ± 20.3), and symptoms of illness deterioration (11.7 ± 32.3).

Exactly when patients were exposed to the structured educational session varied. Therefore, we evaluated the effect of education as a function of when it was provided (ie, after T_1, T_2, or T_3). Because the effect of the educational session might depend on when it was provided during the study, an interaction effect between the timing of education and the actual exposure was tested. This interaction effect, however, was not significant. Hence, the effect of education could be averaged over the respective times of exposure. **Figure 2** summarizes the longitudinal evolution of knowledge scores during a period of almost 3 years. Furthermore, **Figure 2** illustrates the significant effects of education in 4 different groups of patients according to the timing at which education was provided. Total knowledge scores increased after exposure to education, regardless of

when the session took place (ie, after T_1, T_2, or T_3 vs noneducation group). Providing education produced an average increase in knowledge level of 3.48 (95% CI 0.63-6.32), and was statistically significant (P = .017), adjusted for potential confounding factors. The effect size (ES), however, was small (ES = 0.23; 95% CI 0.04-0.42). The effect of education did not depend on when it was provided. That is, the interaction between the timing of the educational session and the actual exposure to the education session was not significant (P = .726).

Analysis of the 8 thematic subscale scores revealed a significant but small effect of education on the subscale that assessed patients' understanding of "symptoms of deterioration" (0.14, 95% CI 0.05-0.24, P = .0006; ES = 0.39, 95% CI 0.17-0.60) (**Figure 2**). Furthermore, a moderate but significant effect of education was found for the subscale "rationale and frequency of follow-up" (0.11, 95% CI 0.05-0.17, P = .0026; ES = 0.43, 95% CI 0.15-0.70) (**Figure 2**). Education did not affect the scores of the remaining thematic subscales.

Regarding health risk behaviors, the educational session did not have a significant effect on overall health risk behavior, substance use, and dental hygiene risk scores.

The GLM analysis revealed that over time the mean overall knowledge score (P < .0001), overall health risk score (P < .0001), and substance use risk score (P < .0001) increased significantly in patients who did not receive an educational session. The dental hygiene risk score, however, decreased significantly over time (P < .0001) in the noneducation group.

These findings were consistent with those from the sensitivity analyses performed on data from a subgroup of 65 patients with CHD who participated in each of the 4 subsequent measurements and who were not exposed to education during the study. This confirmed that, over time, the prevalence of health risk behaviors in the non-education group increased significantly. Indeed, the mean ± SD overall health risk scores (T_1 15.4 ± 13.9 to T_4 30.8 ± 12.7; χ^2 = 60.51; P < .001) and the mean ± SD substance use risk scores (T_1
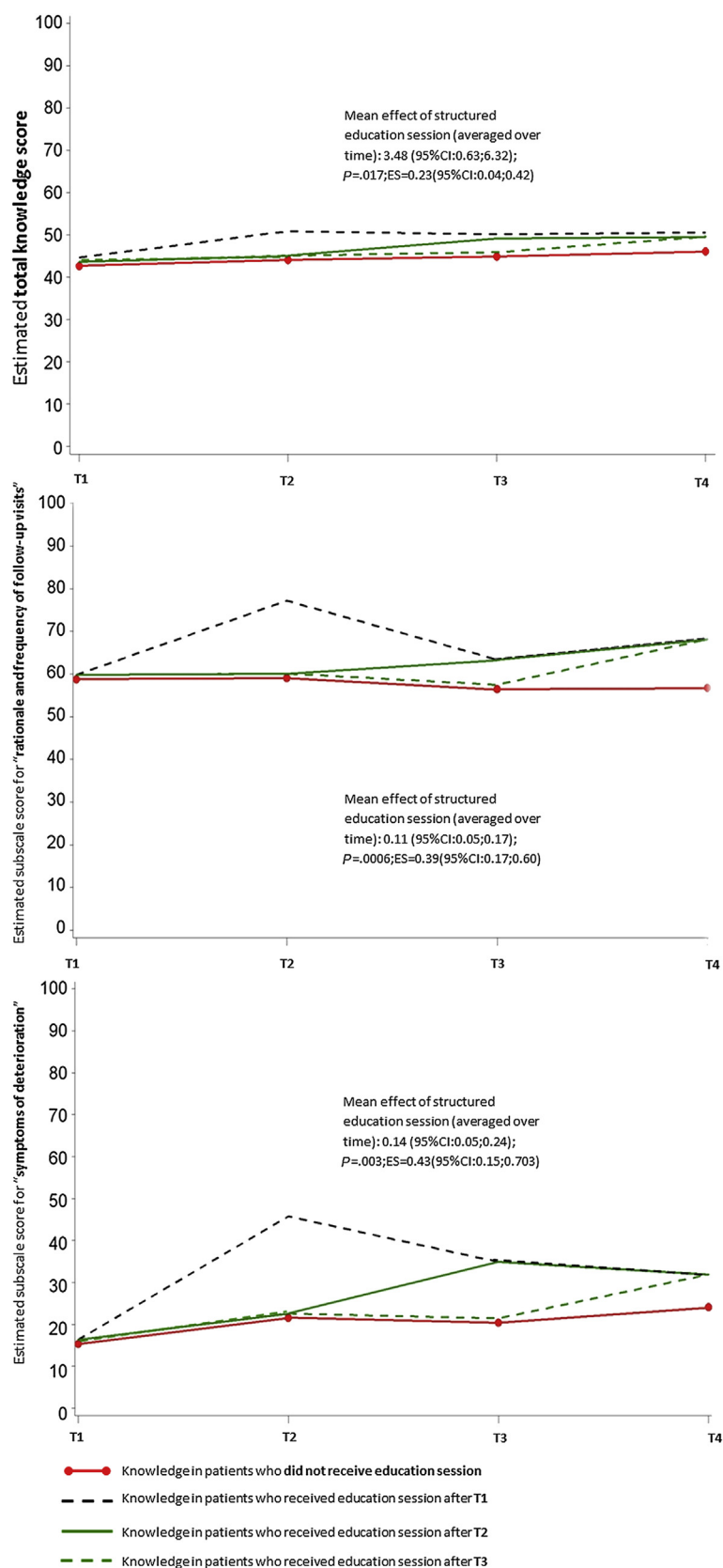
Figure 2. Effect of a single education session on knowledge scores (LKQ-CHD) plotted as a function of when a session was given.

Table III. Results of sensitivity analysis: disease-related knowledge and health risk behaviors in patients who did not participate in education session (n = 65)

	T_1	T_2	T_3	T_4	Test statistics
Total Knowledge Score	45.6 ± 13.7	46.3 ± 14.0	47.1 ± 13.6	47.9 ± 17.1	F = .71; P = .55
Overall Health Risk Score	15.4 ± 13.9	16.1 ± 14.6	18.1 ± 16.9	30.8 ± 12.7	χ^2 = 60.51; P < .001
Substance Use Risk Score	4.6 ± 15.5	5.1 ± 17.9	10.2 ± 22	15.7 ± 17.7	χ^2 = 35.51; P < .001
Dental Hygiene Risk Score	25.4 ± 25.7	23.8 ± 21	23.3 ± 25	26.5 ± 25.4	χ^2 = 1.99; P = .575

Values are mean ± SD.
P values reported in italics indicate statistical significance.

4.6 ± 15.5 to T_4 15.8 ± 17.7; χ^2 = 35.51; P < .001) increased from T_1 to T_4 in the noneducation group of patients. The dental hygiene risk score, however, did not differ significantly over the study (T_1 25.4 ± 25.7 vs T_4 26.5 ± 25.4; χ^2 = 1.987; P = .575). The mean total knowledge score increased from 45.6 ± 13.7 at T_1 to 47.9 ± 17.1 at T_4, but this difference was not significant (F = .709; P = .548) (Table III).

Discussion

Within the field of CHD care, there is limited evidence on the benefit of educational interventions designed to improve patients' understanding and knowledge of their condition. Previous studies assessed the effect of education using a matched case-control,[22] a pre-post design in a relatively small sample of adults with CHD,[24] or a small interventional study without randomization.[25] Studies assessing the effect of education on the health risk behaviors of patients with CHD are clearly lacking.

In line with previous reports, our study showed that young people with CHD generally possess poor knowledge of their condition prior to education.[11,25-29] Our results also confirm poor-to-moderate levels of understanding of the diagnosis, alarming symptoms, cardiovascular risk factors, reproductive issues, and possible preventive measures against infective endocarditis, as previously reported in a comparable but smaller sample of young people who were not exposed to an educational program.[22] Before exposure to the educational session, the prevalence of health-compromising behaviors in our sample was low. This relatively infrequent occurrence of risky behaviors was expected, because published data show low rates of risky health behaviors in comparable samples of young people with CHD[30,31] and because our respondents were fairly young.

Although the primary aim of this educational session is to improve patients' understanding of their disease and treatment, the ultimate goal is to optimize their self-management and behaviors, thereby improving outcomes in the long run. Unfortunately in the present study, a single educational session failed to significantly affect the prevalence of health-compromising behaviors. However, this finding should be evaluated in the context of the pattern of risk behaviors in young patients with CHD generally. Longitudinal analysis of the noneducation group revealed a significant increase in the overall health risk and substance use scores as they grew older. Hence, young patients with CHD tend to acquire more risk behaviors regardless of the type of education, coaching, or guidance they might be exposed to while transitioning to adulthood. One should also bear in mind that the baseline prevalence of risk behaviors in this sample was fairly low, leaving limited room for any possible improvement related to the education. Another possibility is that data were collected for only 3 years, and this might be too brief of a period to detect significant behavioral changes.

Although a longitudinal observational study design was used, data were collected in a sample of young people receiving care and education within a single tertiary care center, limiting generalizability of our study results; however, this sample could be considered highly representative of the population of young adults with CHD, because the distribution of CHD anatomical classification levels was in line with those reported in epidemiologic studies.[32,33] Because our ACHD clinic is located in a tertiary care center, which is easily accessible in Belgium, the entire spectrum of CHD is represented at our clinic, including a fairly high proportion of mild CHD. Patients who underwent heart transplantation or patients who had cognitive limitations, however, were excluded from our study. We sent a set of questionnaires to patients four times during a period of 3 years, and a good high RR (range: 77%-86%) was achieved, arguing against selection affecting our results. Although data were analyzed for a subset of 210 patients derived from the overall i-DETACH sample (n = 429),[19] comparative analyses of the characteristics of these 2 samples demonstrated a high level of comparability. Another possible limitation of the study was that the 9-month intervals between measurement points might have been too brief to detect significant improvements in the respective outcomes, especially in terms of altering health risk behaviors. Furthermore, we can state that during their first outpatient visit at the ACHD clinic, patients were exposed to structured and comprehensive education for the first time. Although we cannot claim that no disease-related information is provided at pediatric cardiology, information is given rather ad hoc than in a systematic and structured way.

The limited education provided improved understanding of CHD but did not significantly improve patients' health risk behaviors. Additional longer-term studies are needed to assess the effect of repetitive exposure to education on improving knowledge and risk behaviors in young adults with CHD. ■

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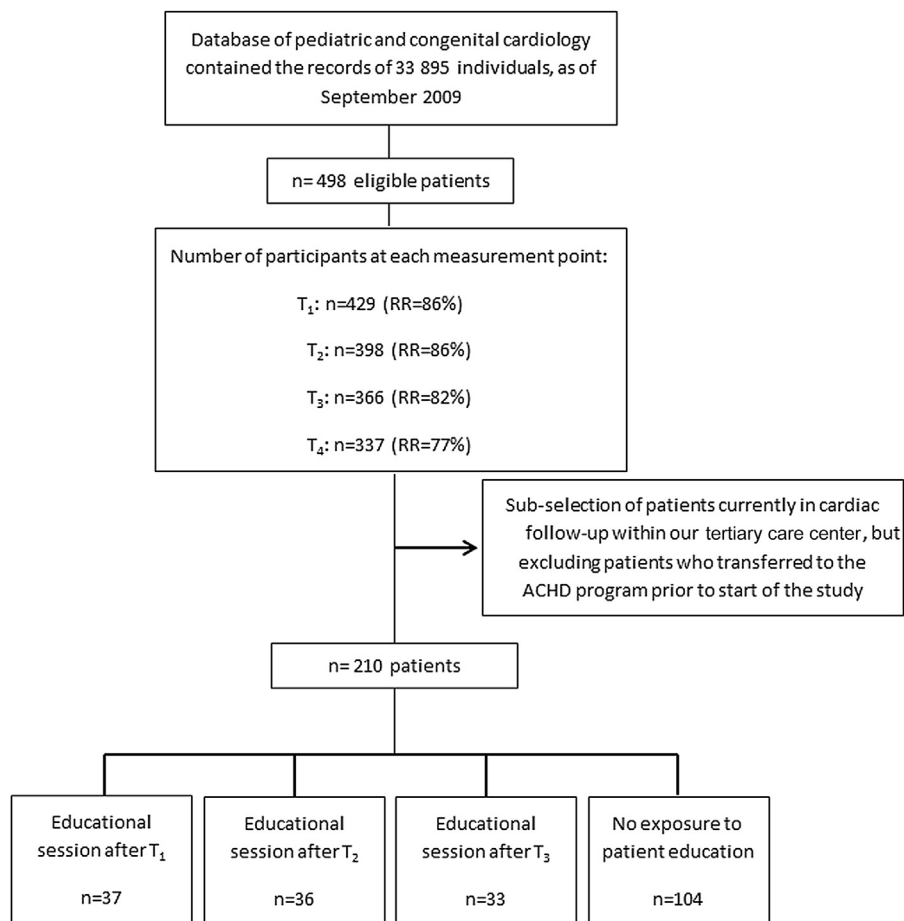33. Hoffman L, Kaplan S, Libertson RR. Prevalence of congenital heart disease. Am Heart J 2004;147:425-39.

Figure 1. Flow diagram of subject selection, group composition, and RRs.

Table I. Overview of content and working sequence of structured education session

Congenital heart defect
- Description of congenital heart defect
- Anatomical drawing of heart defect on diagram

Treatment regimen
- Medical treatment performed in the past (ie, surgery, interventional procedures, medication)
- Current medication plan (ie, name of drugs, dose, indications, special points of attention)
- Future medical treatment (if applicable)

Rationale for regular follow-up
- Rationale for regular continuous cardiac follow-up and requirements (ie, setting, type of provider, frequency)

Infective endocarditis
- Definition, characteristics, and symptoms of infective endocarditis
- Preventive measures
- Antibiotic prophylaxis (if applicable)
- Importance of dental hygiene

Healthy lifestyle
- Importance of and requirements of a heart-healthy lifestyle:
  - Cardiovascular risks associated with unhealthy lifestyle
  - Preventive behaviors in terms of substance use, dental hygiene, engagement in physical activity, diet

Vocational and educational choices
- Discussion of choice of education and vocation in adulthood

Sexuality and inheritability
- Sexual concerns relevant for patients with cardiac disease
- Hereditary nature of congenital heart defect
- Information on cardiogenetic services

Pregnancy and contraceptives
- Issues regarding family planning
- Cardiovascular risks associated with pregnancy and delivery
- Choice of contraceptives