



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;166:1370-6).

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

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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 T_1 ; 183 to 185 patients at T_2 ; 169 to 171 patients at T_3 ; and 149 to 150 patients at T_4 . 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

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