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CLINICAL RESEARCH

Educational needs of adolescents with congenital heart disease: Impact of a transition intervention programme

Besoins éducatifs des adolescents atteints d'une cardiopathie congénitale : Impact d'un programme d'éducation à la transition

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KEYWORDS

Educational programme;
Adolescents;
Congenital heart disease;
Transition to adult care;
Health knowledge

Summary

Background. — Adolescents and young adults with congenital heart disease (CHD) have complex health needs and require lifelong follow-up. Interventions to facilitate the paediatric-to-adult healthcare transition are recommended, but outcomes remain largely under-investigated.
Aims. — To identify the educational needs and the impact of a transition intervention on knowledge and self-management skills in adolescents and young adults with CHD.
Methods. — From September 2014 to May 2015, 115 adolescents and young adults with CHD (mean age 17 ± 2 years; 47 girls) were consecutively enrolled. Among these, 22 had participated in a structured educational programme in the previous 11 ± 4 months (education group) and 93 had not (comparison group). Knowledge about their health status was assessed using a targeted CHD questionnaire.

Abbreviations: ACHD, adult congenital heart disease; CHD, congenital heart disease; CI, confidence interval; ICC, intra-class correlation coefficient; SD, standard deviation.

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Results. – The mean overall health knowledge score (maximum of 20) in the education group was significantly higher than in the comparison group (11.7 ± 3.5 vs. 8.6 ± 3.2 ; $P < 0.001$). We observed significant gaps in knowledge in the comparison group: e.g. 61.3% vs. 90.0% knew their condition name ($P = 0.01$), 21.5% vs. 63.6% were aware of recommended follow-up ($P = 0.004$), and 12.8% vs. 75.0% of girls knew to check their heart condition before pregnancy ($P < 0.01$). In multivariable analysis, after adjustment for age, structured CHD education and higher academic attainment were significant determinants of health-related knowledge ($P < 0.01$).

Conclusion. – Education during adolescent-to-adult transition has a significant impact on health knowledge. Structured CHD educational programmes could improve understanding and prevent potential future complications.

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MOTS CLÉS

Programme éducatif ;
Adolescents ;
Cardiopathie
congénitale ;
Transition vers les
soins pour adultes ;
Connaissances sur la
santé

Résumé

Contexte. – Les adolescents et jeunes adultes avec une cardiopathie congénitale (CC) ont des besoins médicaux spécifiques et nécessitent un suivi à vie. Des interventions visant à faciliter la transition entre les soins pédiatriques et les soins adultes sont recommandées, mais les résultats restent largement sous-étudiés.

Objectifs. – Identifier les besoins éducatifs et l'impact d'une intervention à la transition sur les connaissances et les compétences d'autogestion chez les adolescents et les jeunes adultes atteints d'une CC.

Méthodes. – De septembre 2014 à mai 2015, 115 adolescents et jeunes adultes avec une CC (âge moyen de 17 ± 2 ans ; 47 filles) ont été consécutivement inclus. Parmi eux, 22 avaient participé à un programme d'éducation thérapeutique au cours des 11 ± 4 mois précédents (groupe éduqué) et 93 n'avaient pas suivis ce programme (groupe témoin). Les connaissances sur leur état de santé ont été évaluées à l'aide d'un questionnaire spécifique ciblé sur les CC.

Résultats. – Le score global moyen de connaissances en santé (maximum 20) dans le groupe éduqué était significativement plus élevé que dans le groupe témoin ($11,7 \pm 3,5$ vs. $8,6 \pm 3,2$; $p < 0,001$). Nous avons observé des lacunes significatives dans les connaissances du groupe témoin : par exemple 61,3% vs. 90,0% connaissaient le nom de leur CC ($p = 0,01$), 21,5% vs. 63,6% savaient le suivi ($p = 0,004$) et 12,8% vs. 75,0% des filles savaient qu'elles devaient contrôler leur état cardiaque avant un projet de grossesse. En analyse multivariée, après ajustement pour l'âge, l'inclusion dans un programme éducatif à la transition et le niveau académique du patient étaient des déterminants significatifs sur le niveau de connaissances sur la santé ($p < 0,01$).

Conclusion. – L'éducation pendant la période de transition adolescent-adulte a un impact significatif sur les connaissances de santé des patients. Des programmes éducatifs structurés dédiés aux CC pourraient améliorer la compréhension et prévenir d'éventuelles complications futures.

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Background

Transition from paediatric to adult care constitutes a critically vulnerable period for adolescents with congenital heart disease (CHD). During this time, patients are expected to acquire significant responsibilities in managing their lifestyles and health care [1,2]. As stated by the American Heart Association [3], age-appropriate education about medical conditions, decision-making, self-care and self-advocacy are among the major goals of formal transition programmes in CHD. The development of structured patient education programmes has been proposed as a key element in the transition of adolescents with CHD into the adult care

settings [4–7]. However, the implementation of systematic and structured intervention programmes before transition is still relatively uncommon in many paediatric cardiology centres. To date, few studies have investigated the direct impact of structured interventions targeting not only disease-specific knowledge but also general health lifestyle behaviours and medical care in patients with CHD [6–8].

Our primary aim was to determine the educational needs of adolescents and young adults with CHD and the impact of a structured education programme at transition on improving health knowledge (CHD and general lifestyle and medical care knowledge) as well as self-management skills in this population. Our secondary aim was to identify

patient-specific factors associated with general health knowledge in adolescents and young adults with CHD.

Methods

Study setting and participants

This descriptive, cross-sectional study was conducted in the paediatric department of Necker Hospital (Paris, France) between September 2014 and May 2015. Patients were consecutively included according to the following criteria: (1) patients with CHD, mainly repaired tetralogy of Fallot, transposition of the great arteries, congenital aortic valve dysfunction, aortic coarctation, atrioventricular septal defect and CHD with univentricular physiology; (2) follow-up at the outpatient clinic by a paediatric cardiologist during the study period; (3) candidate patients for a transition programme according to US guidelines [3,9], concerning CHD patients aged 14–19 years' old. We excluded (1) patients with important developmental delays; (2) those with a cardiac disease other than CHD (such as arrhythmia, dilated or hypertrophic cardiomyopathy); (3) patients who had already initiated the transfer to adult cardiac care; and (4) non-French speakers. Participants were divided into two groups: those who had previously been included in a structured educational programme for patients with CHD during the transition from adolescence to adulthood (the education group) and those who had not been included in this programme (comparison group).

Transitional educational programme and standard of care

A structured education programme for patients with CHD during the transition from adolescence to adulthood was developed at our centre. The education programme was conducted by two experienced cardiology nurses (CP and MT). It consisted of individual consultations with the specialized nurses before the standard cardiology check-up examination. Each appointment sought to evaluate patients' level of knowledge on diverse health questions, such as knowledge of their CHD and their treatments using a structured questionnaire covering curriculum objectives of the transition programme (see [Supplementary material](#)). Nurses recorded possible general cognitive difficulties (i.e. reading or calculation difficulties), family situation (i.e. presence of siblings) and patients' academic level. They also recorded risky behaviours (e.g. drugs, alcohol, smoking), noted potential adolescent emotional difficulties about cardiac disease, and level of engagement. At each session of the education programme, patients were educated on several health issues, such as (1) potential cardiac symptoms that require medical assistance (e.g. arrhythmias, shortness of breath); (2) the importance of long-term, frequent medical follow-up by a cardiologist; (3) risky behaviours to avoid (e.g. drugs, tattoos, piercings); and (4) a discussion on healthy habits and the prevention of sexually transmitted diseases and Osler endocarditis. These individual meetings were associated with group sessions addressing a common topic (e.g. gynaecology, sport). If patients were identified as at risk, they were referred to a specialist for further clinical

evaluation. The transition education programme used several educational tools including flyers, a detailed brochure called "Health Passport" with information on adult transition process and recommendations as well as a video game that trained patients on knowledge about their own CHD.

A total of 183 patients had been already included in the structured education programme at the start of this study. Patient participation depended on their cardiologist recommendation and on patients' and their parents' motivation. The education programme has been approved by Ile-de-France Regional Health Service since July 2011 (ARS authorization number: ETP 12/20).

Standard care was provided to all participants. There was no standardization of care in our centre with respect to promotion of self-management or communication skills, or education about the heart. Some participants were provided verbal and/or written information by their cardiologist at their discretion.

Study procedures

The following data were collected from medical records and self-reported questionnaires: age, CHD diagnosis, paternal and maternal socio-economic status according to the Institut National de la Statistique et des Etudes Economiques (INSEE) national classification (www.insee.fr), history of hospitalizations for cardiac reasons during the 5 years preceding inclusion, and family structure (whether the patient had any siblings and parental status [single-parent family, married or re-married]). The complexity of CHD was classified as simple, moderate or severe according to the Bethesda classification [4]. Written informed consent was obtained from participants and their parent or legal guardian.

All participants in both groups (education and comparison) completed a specific knowledge questionnaire in the paediatric cardiology clinic at study enrolment. Before the present study, four experts (i.e. one adult CHD cardiologist, one paediatric cardiologist, and two paediatric cardiology nurses) were invited to rate the relevance and the clarity of each item of the specific knowledge questionnaire. Patients completed the questionnaire onsite and were not provided with alternative ways to complete it (e.g. web access). This questionnaire also underwent pilot testing by 12 adolescents with CHD before the beginning of the study to confirm content validity. Patients who participated in the pilot study were not enrolled in the present study. The questionnaire included 29 items for boys and 34 for girls, targeting six domains: knowledge on CHD and cardiac surgery, cardiac follow-up and treatment, cardiac symptoms and self-management, risky behaviours and healthy lifestyle, insurance and professional orientation, recurrence and gynaecological issues. Accordingly, each participant was assigned a score (numerator/denominator \times 20). Given the heterogeneity of previous medical and surgical interventions and the need for medications in adolescents with heart disease, not all questions were applicable to all patients so the denominator varied between questions. Patients could freely write answers to the question. If necessary, they received feedback by a cardiologist specialized in CHD (ML). Scores ranged from 0 (incorrect answer) to 1 (correct answer). The reproducibility of the questionnaire was studied by a test–retest procedure (comparison of scores and

Table 1 Baseline characteristics of the education and comparison groups.

| | Education group (<i>n</i> = 22) | Comparison group (<i>n</i> = 93) |
|---|-------------------------------------|--------------------------------------|
| Men | 14 (63.6) | 54 (58.1) |
| Age (years) | 17 ± 2 | 17 ± 1 |
| Complexity of CHD | | |
| Simple | 3 (13.6) | 24 (25.8) |
| Moderate | 10 (45.5) | 35 (37.6) |
| Complex | 9 (40.9) | 34 (36.6) |
| Parental status | | |
| Married | 16 (72.7) | 55 (59.1) |
| Divorced | 4 (18.2) | 27 (29.0) |
| Reconstituted family | 2 (9.1) | 11 (11.8) |
| Highest academic attainment | | |
| Middle school | 3 (13.6) | 20 (21.5) |
| High school | 14 (63.6) | 60 (64.5) |
| College/university | 5 (22.7) | 13 (14.0) |
| Hospitalization during the last 5 years | 5 (22.7) | 19 (20.4) |
| History of endocarditis | 0 | 0 |

Data are expressed as number (%) or mean ± standard deviation.

item by item). For this, the questionnaire was mailed to 12 subjects who had already filled in the questionnaire.

To determine inter-observer variability in interpretation of responses, the scale was scored independently for 20 participants by two reviewers: a cardiologist (ML) and a nurse (MT) specialized in CHD. The study was performed in accordance with the principles set out in the declaration of Helsinki and was approved by the Ethics Review Board of our institution (Comité de Protection de la Personne Ile de France 3, Ref. DS/LG/2013-301).

Statistical analysis

Participants' characteristics in the education and comparison groups are described using proportions for qualitative characteristics and means ± standard deviations (SDs) for continuous variables. A non-parametric Mann–Whitney test or a two-sample *t* test, when appropriate, was used to evaluate the differences between the groups. Qualitative values were compared using a chi-square or Fisher test. Association between variables related to patient characteristics and questionnaire scores was tested by simple and multiple regression models. Only variables with a normal distribution and meeting the statistical *P* value threshold of <0.1 in univariate analysis were included in the multivariable model adjusted for age. The questions were categorized into six areas of knowledge according to recommendations [3]. The internal consistency of these six areas was tested by the Cronbach alpha coefficient. To measure the level of concordance of all questions between test and retest, concordance rates and Kappa coefficients were calculated. We also calculated intra-class correlation coefficients (ICCs) to assess intra- and inter-observer variability of the questionnaire score. *P* values <0.05 were considered significant. All data were analyzed using MedCalc Statistical Software

version 12.7.7 (MedCalc Software bvba, Ostend, Belgium; <http://www.medcalc.org>; 2013).

Results

Study population

We approached 117 potential participants, of whom two refused to participate (neither were included in the education programme). Our sample therefore consisted of 115 patients with CHD enrolled at our cardiology clinic, of whom 22 (19.1%) were in the education group. Educated patients were enrolled a mean of 11 ± 4 months after the last educational session. The mean age of the cohort was 17 ± 2 years. Baseline characteristics of the education and comparison groups are summarized in Table 1. No significant differences in sex, age, CHD complexity, family status or medical history of hospitalization for cardiac complications were observed. There was no significant difference in academic attainment level between the two groups: most were in high school (64.3%), 20.0% were in middle school (including vocational training) and 15.75% were at college/university.

In the education group, the nurse evaluation reported that 10 (45.5%) had occasionally consumed alcohol, six (27.3%) smoked tobacco, two (9.0%) smoked cannabis, one (4.5%) was tattooed and five (22.7%) had ear piercings. Among the women, only 3/8 patients (37.5%) had discussed contraception and pregnancy risk with their cardiologist before the educational intervention, and two were sexually active, but none had experienced abortion.

Level of knowledge

Questionnaire results are detailed in Table 2. Patients in the education group obtained a higher global score compared to the comparison group (11.7 ± 3.5 vs. 8.6 ± 3.2 [out

Table 2 Comparison of questionnaire scores in the educated versus comparison groups (patients who did not receive any transition educational programme).

| Questions | Education group (n = 22) | Comparison group (n = 93) | P |
|---|-----------------------------|------------------------------|-------|
| 1. What is the name of your cardiac defect? | 20/22 (90.9) | 57/93 (61.3) | 0.01 |
| 2. Can you explain what is abnormal in your heart? | 11/22 (50.0) | 29/93 (31.2) | 0.09 |
| 3. If you were operated upon, what procedure would the surgeon do? | 13/21 (61.9) | 24/80 (30.0) | 0.01 |
| 4. Do you think you will need another cardiac intervention? | 3/10 (30.0) | 26/93 (28.0) | 1.00 |
| 5. Do you think you are completely cured, and you have no residual cardiac lesions? | 2/13 (15.4) | 12/72 (16.7) | 0.09 |
| 6. How do you think you will be followed up in the next 30 years (who, where, at what frequency)? | 14/22 (63.6) | 20/93 (21.5) | 0.004 |
| 7. How does your doctor check your heart rhythm? | 8/22 (36.4) | 34/93 (36.6) | 0.91 |
| 8. How does your doctor check your heart function? | 11/22 (50.0) | 42/93 (45.2) | 0.68 |
| 9. If you experience palpitations, what could it mean? | 22/22 (100) | 68/93 (73.1) | 0.02 |
| 10. If you experience palpitations, what should you do? | 13/22 (59.1) | 33/93 (35.5) | 0.04 |
| 11. If you are breathless, what should you do? | 11/22 (50.0) | 33/93 (35.5) | 0.21 |
| 12. If you feel dizzy, what should you do? | 15/22 (68.2) | 41/93 (44.1) | 0.02 |
| 13. Can you participate in sport? | 22/22 (100) | 83/93 (89.2) | 0.20 |
| 14. What are the effects of sport on your health? | 7/22 (31.8) | 20/93 (21.5) | 0.31 |
| 15. Can you perform any sports without asking your cardiologist for advice beforehand? | 17/22 (77.3) | 39/93 (41.9) | <0.01 |
| 16. What sport do you participate in? ^a | 15/22 (68.2) | 45/93 (48.4) | 0.10 |
| 17. Is having piercings risky for your health? | 8/10 (80.0) | 21/62 (33.9) | 0.04 |
| 18. Are tattoos risky for your health? | 8/10 (80.0) | 17/62 (27.4) | <0.01 |
| 19. How can you prevent cardiac infection? | 6/10 (60.0) | 27/62 (43.5) | 0.50 |
| 20. What are the risks of alcohol consumption? | 4/22 (18.2) | 13/93 (14.0) | 0.74 |
| 21. Can you give examples of fatty, sugary and salty foods? | 4/22 (18.2) | 11/93 (11.8) | 0.48 |
| 22. What are the health risks related to tobacco consumption? | 4/22 (18.2) | 23/93 (24.7) | 0.59 |
| 23. What are the health risks related to cannabis consumption? | 4/22 (18.2) | 11/93 (11.8) | 0.48 |
| 24. What does it mean to have hypertension, and what are its health consequences? | 4/22 (18.2) | 19/93 (20.4) | 1.00 |
| 25. Could your offspring be born with congenital heart disease? | 11/22 (50.0) | 28/93 (30.1) | 0.07 |
| 26. If you are treated, what is the action of your treatments? | 4/8 (50.0) | 17/30 (56.7) | 1.00 |
| 27. What job you would like to do later? ^b | 14/17 (82.4) | 52/75 (69.3) | 0.06 |

Table 2 (Continued)

| Questions | Education group (n = 22) | Comparison group (n = 93) | P |
|--|--------------------------|---------------------------|-------|
| 28. How is your care covered? | 6/22 (27.3) | 15/93 (16.1) | 0.22 |
| 29. If you need extra-cardiac interventions (e.g. orthopaedic surgery), do you need to check your heart condition before? How? | 4/22 (18.2) | 5/93 (5.4) | 0.06 |
| 30. Which contraception is allowed for you? ^c | 4/8 (50.0) | 16/39 (41.0) | 0.71 |
| 31. Should you discuss contraception with your cardiologist before consulting the gynaecology clinic? ^c | 4/8 (50.0) | 21/39 (53.8) | 1.00 |
| 32. What complications can occur during pregnancy? ^c | 3/8 (37.5) | 3/39 (7.7) | 0.05 |
| 33. If you desire to become pregnant, do you need to check your heart condition beforehand? ^c | 6/8 (75.0) | 5/39 (12.8) | <0.01 |
| 34. What kind of follow-up do you require during pregnancy? ^c | 5/8 (62.5) | 8/39 (20.5) | 0.02 |

Data are expressed as number with correct answer/number for whom the question was applicable (%).

^a The answer was counted right (=1) if the sport was appropriate for the patient's cardiac condition.

^b The answer was counted right (=1) if the job was compatible with the patient's cardiac condition.

^c Girls only.

of 20]; $P < 0.001$). This improvement concerned knowledge of their cardiac disease, appropriate follow-up, ability to cope with new symptoms and prevention of risky behaviours. Knowledge about the impact of their cardiac condition on pregnancy was also better in the education group.

Factors influencing the questionnaire's total score

In univariate analyses, only inclusion in the education programme at transition and higher academic attainment were significantly related to a better global score on the health questionnaire (Table 3). In multivariable analysis, the educational programme and academic level remained significantly associated with better results, even after adjustment for age, (adjusted $R^2 = 0.20$, $P < 0.05$). These two variables explained 20% of the questionnaire results.

Reliability and reproducibility of the questionnaire

The responses of the 115 subjects were analyzed by grouping the items according to the six areas of knowledge. Internal consistency of the questionnaire was acceptable, with a Cronbach alpha coefficient of 0.72. We observed a low average proportion of missing values (0.87%). In the 12 patients who participated to the test–retest, the concordance rate was satisfactory for most items (average 77.9%; range 50–100%). Kappa was statistically significant for 15 items. The ICC between the test and the retest scores was 0.70 (95% confidence interval [CI] 0.11–0.90).

Inter-observer variability

Independently scored questionnaires yielded similar scores from the two observers; the ICC for questionnaires was 0.95 (95% CI 0.91–0.97; $P < 0.0001$).

Discussion

We found that adolescents and young adults with CHD who had never participated in an educational programme at transition have concerning gaps on cardiac health knowledge, particularly on the rationale and frequency of follow-up, potential cardiac symptoms and adequate skills to cope with them, and critical prevention of risky behaviours. The results showed that our structured educational programme for transition significantly improved health knowledge as well as self-management skills in this population. However, low educational attainment could influence this outcome, highlighting the requirement of personalized intervention in such patients.

Gaps in knowledge about their cardiac conditions are still observed in adults with CHD (ACHD) [5]. Conversely, in our adolescent population, the results of implementing a well-structured educational programme translated into a significant increase in health knowledge level, as has been shown by others [6,7,10], even if there is still little evidence that it may improve ACHD patients' health behaviours. Knowledge on the rationale and frequency of specialized follow-up is essential for patients with CHD. Indeed, lapses in care and inappropriate follow-up (i.e. in a centre not specialized in CHD care) are associated with a decrease in patient survival [11] and an increase in morbidity [12], especially in those with complex CHD. Therefore, patients with complex CHD specifically require active educational intervention well before their transfer to the adult care system. CHD nurse coordinators of paediatric and adult care are key elements in the success of patient transfer and regular follow-up. Improving knowledge on cardiac health and self-management may also impact long-term outcomes of ACHD health.

Discussion of contraceptives and pregnancy with ACHD patients are suggested as Class I recommendations in the current ACHD management guidelines [13]. Cardiac diseases

Table 3 Univariate analysis of factors influencing the global score.

| Independent variables | Proportion of variation in the global score explained by the variable (%) | P |
|------------------------------------|---|--------|
| Education programme | 12.5 | 0.0004 |
| Academic attainment | 7.7 | 0.0063 |
| Parental situation ^a | 3.7 | 0.07 |
| Age | 2.1 | 0.14 |
| Sex | 1.7 | 0.13 |
| Socio-professional mother category | 0.5 | 0.57 |
| Socio-professional father category | 0.5 | 0.75 |
| CHD complexity | 0.04 | 0.83 |
| Sibling(s) | 0.01 | 0.79 |

CHD: congenital heart disease; SP: socio-professional.
^a Married, single-parent family or re-married.

are the primary cause of maternal death [14,15], while 34–38% of pregnancies in women with CHD and World Health Organization pregnancy risk classification III or IV are still unintended [16,17]. In the overall cohort, only half of the girls (25/47) had discussed this issue with their cardiologist. Similar results have also been observed in women with ACHD [13,14]. Indeed, it has been reported that one in four women with CHD does not use contraception or uses unsafe contraceptives [18,19]. Key educational interventions during adolescence, particularly education about sexual health, are essential and should improve long-term outcomes.

Even though our education group obtained higher scores than the comparison group, total scores were only increased by 36%. We can hypothesize that younger patients might not feel as concerned or invested by some topics, and others could need educational strengthening with repeated interventions. Indeed, there is important variation in cognitive and emotional maturity in adolescents with CHD. Some patients with CHD may experience cognitive and behavioural challenges [20] that may interfere with their ability to process educational information about health-related risks [21]. Even though we excluded patients with evidence of intellectual dysfunction, it cannot be excluded that some patients may still have had residual neuropsychological difficulties.

Our study should be interpreted in light of some limitations. Eligible patients were consecutively enrolled during the study. However, the fact that only 19% of them were involved in the educational transition programme underlines barriers to include patients in the educational programme which may, in turn, reflect those related to the transfer to adult care. The most frequent barrier to the transition to ACHD care is emotional attachment of parents and patients to the paediatric cardiologists, with more than 85% being reluctant to transition [22]. In parallel, clinician attachment to the patient/family has also been indicated as barrier [22]. The consequence is that both patients and parents of adolescents with CHD appear to lack important medical knowledge crucial to the principles of life-long care and optimal health maintenance. Separate interventions to patients and parents, and meeting with the ACHD doctor before the transfer are probably viable options to reduce these barriers. Moreover, our study showed that lower academic attainment influenced patients' results, regardless of their age. Patients

with academic or cognitive difficulties may need specific attention and/or programme adaptations. Individualized evaluation and educational interventions should be essential in this group of patients. Finally, as a single-centre study, this study had a relatively small number of patients in the education group. We evaluated only health knowledge and not behaviours, thus, we do not have data on patients' willingness to engage in healthy habits. As opposed to randomized controlled trials, our study had a descriptive, cross-sectional design and thus may be subject to certain limitations, including selection bias. Finally, it is unclear whether the efficacy of such a programme impacts the transfer options, the morbidity and mortality of patients with CHD and their quality of life [23]. Larger studies evaluating the broader impact of structured educational interventions on ACHD follow-up are needed.

Conclusions

Structured educational programmes during the transition from paediatric to adult care may significantly improve health knowledge, particularly regarding their recommended follow-up and cardiovascular risk. Based on the findings from the present study, transition interventions should be routinely provided by paediatric cardiac centres. Personalized intervention in adolescents with cognitive difficulties may be necessary to improve their cardiac health knowledge and behaviours, and to prevent breaks in follow-up. Larger studies evaluating the impact of educational intervention during adolescence on the quality of life, morbidity rate and mortality in patients with ACHD are required.

Sources of funding

None.

Disclosure of interest

The authors declare that they have no competing interest.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.acvd.2017.02.001>.

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