ORIGINAL ARTICLE

Healthcare transition for youth with heart disease: a clinical trial

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ABSTRACT

Objectives Adolescents with heart disease have complex health needs and require lifelong cardiology follow-up. Interventions to facilitate paediatric to adult healthcare transition are recommended, although outcomes are unknown. We sought to determine the impact of a transition intervention on improving knowledge and self-management skills among this population.

Methods We conducted a clinical trial of 15–17 year olds with moderate or complex congenital heart disease (CHD) or cardiomyopathy. Participants were systematically allocated to either usual care (controls) or a 1 h nurse-led one-on-one teaching session about their heart. Allocation was determined by week of attendance in the cardiology clinic. The primary outcome was change in Transition Readiness Assessment Questionnaire (TRAQ) score at 6 months, possible scores ranging from 1 (low) to 5 (optimal). Cardiac knowledge (MyHeart score, range 0–100) was a secondary outcome. Analysis was intention to treat.

Results Of 58 participants (48% female), 52 had CHD and 6 had cardiomyopathy. 27 were allocated to the intervention group; 3 declined the intervention and received usual care. When comparing the intervention group with the usual care group at 6 months postintervention, the mean self-management TRAQ score was 3.59 (±0.83) vs 3.16 (±1.05), respectively (p=0.048, adjusted for baseline score); the mean self-advocacy TRAQ score was 4.38 (±0.56) vs 4.01 (±0.95) (p=0.18) and the mean MyHeart score was 75% (±15) vs 61% (±25) (p=0.019).

Conclusions A 1 h nurse-led transition intervention resulted in a significant improvement in self-management and cardiac knowledge scores. An educational intervention should be routine for youth with congenital or acquired heart disease.

Trial registration number NCT01286480

Major advances in the management of children with congenital heart disease (CHD) have resulted in exponential growth in the population of adolescents and young adults with CHD.[1] This emerging 'survivor' population has complex needs. These individuals are at risk of substantial morbidity[2,3] and mortality[4,5] in early-to-mid adult years, placing an important burden on healthcare resources.[5–8] Although some centres have reported good retention of patients,[9,10] national-level data from the USA[11] and the UK[12] demonstrate that many adolescents fail to successfully transfer to an adult CHD programme, the most common reason being a false sense that they have been 'cured'.[13] Indeed, most adolescents and young adults with CHD have limited knowledge about their heart.[14–16] Although there are recommendations for transition programmes[17,18] and a Scientific Statement from the American Heart Association,[19] at present there are no outcome data regarding the effectiveness of transition interventions and few paediatric cardiac programmes facilitate the transition of their patients.[20] This speaks to the urgency of developing evidence-based interventions that will optimise paediatric to adult healthcare transition using methods that can be readily adopted by clinical programmes.

The primary aim of this study was to determine the impact of a nurse-led *transition intervention* in combination with *usual care* compared with *usual care alone* on improving transition readiness (self-management and self-advocacy skills) among 15–17 year olds graduating from a tertiary care paediatric cardiology programme. A secondary aim was to assess change in adolescent knowledge of their heart disease.

METHODS

Study design and population

The Congenital Heart Adolescents Participating in Transition Evaluation Research (CHAPTER) study was a clinical trial conducted at the Stollery Children's Hospital, a tertiary care cardiology and cardiac surgical centre in Edmonton, Alberta, Canada. Participants were enrolled during attendance in the outpatient cardiology clinic. Inclusion criteria were (i) age 15–17 years and (ii) moderate or complex CHD as previously defined[21] or cardiomyopathy. We excluded those with a heart transplant or important developmental delay that in the opinion of a parent would preclude participation. Participants were enrolled between January 2011 and May 2012, with 6-month outcome follow-up to November 2012.

Group allocation

Participants were systematically allocated to either a transition intervention or usual care (ie, no transition intervention) depending on their week of attendance in the cardiology clinic. Individual cardiologists have clinic on the same day each week; therefore, a given cardiologist's patients were

equally likely to be allocated to intervention or usual care. Participants allocated to the usual care group were unaware of the intervention being offered to the treatment group. This was intended to prevent contamination by self-education or other means.

Transition intervention

The intervention was conducted by one of three experienced cardiology nurses following intervention-facilitation training and fidelity assurance. The intervention involved a meeting with the nurse and the participant, with the exception of three interventions also attended by a father (n=1), an uncle (n=1) and a participant's friend (n=1). Interventions were held in a quiet room without other distractions, a short walk from the cardiology clinic. The elements of the intervention are described in box 1. The order of the intervention was consistently followed, and the study nurse completed a log and field notes to document any difficulties that were encountered during the intervention and the participant's reaction, level of engagement, questions and body language. Interventions were offered on the same day as a routine clinic visit, or at a later date, depending on the participant's preference.

Usual care

There was no standardisation of care in our centre with respect to (a) promotion of self-management or communication skills, or (b) education about the heart, either prior to or during the enrolment period. Participants were variably provided verbal and/or written information by their cardiologist or cardiology clinic nurse at the discretion of these providers. Care providers were not aware of group allocation of participants to avoid intervention contamination.

Primary outcome

All participants completed the Transition Readiness Assessment Questionnaire (TRAQ) at enrolment in the cardiology clinic and again at 1 and 6 months postenrolment in their home either online at a secure website or by paper with a stamped, self-addressed envelope provided by the study team. The TRAQ is the most rigorously evaluated transition readiness questionnaire available and was developed in the USA.[22] It has 29 items with two domains, self-management (16 items, including filling prescriptions and arranging medical follow-up appointments) and self-advocacy (13 items assessing communication skills and use of school and community resources). The TRAQ is at a grade 5.7 reading level and uses a Likert scale, with possible scores ranging from 1 (low) to 5 (optimal). Mean self-management TRAQ score among adolescents with chronic health conditions is 3.01 ($\pm$1.02) and mean self-advocacy score is 3.67 ($\pm$0.77).[22] The primary outcome was change in TRAQ self-management score from enrolment to 6 months.

Secondary outcome

Knowledge of the heart condition was assessed with the MyHeart scale (table 1) at enrolment, 1 month and 6 months. The MyHeart scale was developed for this study and has a grade 4.6 reading level. It consists of seven short answer or multiple-choice questions. This scale was piloted with 20 young adults to confirm face and content validity. Given the heterogeneity of prior medical and surgical interventions and need for medications in adolescents with heart disease, the denominator for some questions varied from one participant to the next (table 1). Accordingly, each participant was assigned a percentage correct score (numerator/denominator×100) at each time point. To determine interobserver variability in interpretation of responses, the MyHeart scale was scored independently for each participant by three reviewers; a paediatric cardiologist (ASM), a cardiology nurse (MS) and a research assistant (CR).

Sample size

Anticipating a mean TRAQ self-management baseline score of 3.01 (SD 1.02) (out of a possible 5.0) as reported for adolescents without a transition intervention[22] and an anticipated mean score of 4.0 postintervention resulting in a change score of 1 (ie, 1 SD), with α=0.05 and 90% power, we would require 23 patients in each intervention group (total of 46). Assuming that 30% of participants would either withdraw or not complete the 6-month TRAQ questionnaire, we enrolled 66 participants.

Statistical analysis

The intervention and control participants were described using proportions for binary characteristics and means and SDs for continuous characteristics. Linear mixed models with random effects were used to evaluate the intervention effect at 1 and 6 months. To account for the cluster allocation and longitudinal nature of the trial, both effects of weeks (clusters) and those of individual participants were considered random. Each participant had three measurements: at baseline (enrolment), 1 month and 6 months. We adjusted for the baseline score and modelled 1- and 6-month scores longitudinally. With two indicator variables, intervention (0=control and 1=intervention), time t

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Box 1 Transition intervention protocol

A. Introduction to transition and its importance
B. Discussion of confidentiality and what that means to promote trust with study nurse
C. Creation of a MyHealth passport*,[25] including
   - name of cardiac condition
   - previous cardiac interventions
   - name and purpose of medications
   - need for endocarditis prophylaxis (yes/no)†
D. Review diagram of cardiac anatomy (participant-specific)
E. Discussion of three potential future cardiac complications (participant-specific)
F. Review contact names and location of local adult congenital heart disease cardiologists
G. Introduction to websites of ACHA, CCHA, The Hospital for Sick Children Good2Go program and YoungAndHealthy.ca
H. Discussion of three brief third-person scenarios addressing alcohol, smoking/street drugs and sexuality/contraception
I. Introduce youth-oriented take-home written materials (sexually transmitted infections, substance abuse)
J. Provide study email address and study cell number and encourage follow-up emails or text messages with study nurse

*Wallet-sized paper copy provided to participant in a plastic protective sheath and an electronic copy emailed to participant.
†Based on chart-documented recommendation by participant's cardiologist.
ACHA, Adult Congenital Heart Association; CCHA, Canadian Congenital Heart Alliance.

Table 1 MyHeart scale

Question #	Question	Question format	Maximum score
1	What is the name of your heart defect/condition? Be as specific as possible.	Short answer	6
2a	Have you had any heart surgeries? ☐ (a) Yes ☐ (b) No ☐ (c) Not sure (score 0) If yes, how many have you had? If yes, what was the name of the operation(s), or what did the surgeon do?	Multiple choice and short answer	5 (1 if no prior heart surgery)
2b	Have you had any heart catheterisations? ☐ (a) Yes ☐ (b) No ☐ (c) Not sure (score 0) If yes, how many have you had? _____ If yes, what were they for?	Multiple choice and short answer	5 (1 if no prior heart catheterisation)
3	Could you explain your heart defect to someone else? ☐ (a) Not at all (0) ☐ (b) A little (1) ☐ (c) Yes (2)	Multiple choice	2
4	What are the medications you take for your heart, and what dose do you take?	Short answer	3 (1 if on no heart medication)
5	What are the purposes/ reasons for your heart medications?	Short answer	2 (0 if on no heart medication)
6	How long do you think you should be followed by a cardiologist who specialises in congenital heart disease? ☐ (a) When new problems arise (0) ☐ (b) For a few more years (0) ☐ (c) For the rest of my life (2) ☐ (d) I don't know (0)	Multiple choice	2
7	Do you need to take an antibiotic before you see a dentist? ☐ (a) Yes ☐ (b) No ☐ (c) Don't know (0) If 'Yes', why is this antibiotic recommended?	Multiple choice and short answer	2 (1 if correct answer is 'no')

8	Did you get help with answering these questions?
	 Yes, from (indicate all that apply)
	   The internet
	   A MyHealth passport
	   Pamphlets/brochures previously given to me about my heart
	   Other (please specify): _____
	 No, I answered these questions from memory alone
		Multiple choice	Not scored

(0=1 month and 1=6 months) and baseline scores as covariates, we fitted the following linear mixed model:

$$y_{it} = (\beta_0 + b_{0i} + b_{0j}) + \beta_1\ \text{intervention} + (\beta_2 + b_{2i} + b_{2j})t$$
$$+ \beta_3\ \text{baselinescore} + \varepsilon_{it}$$

where y_{it} is the score of ith participant at time t, (b_{0i}, b_{2i}) is a bivariate Gaussian random effects for ith participant, (b_{0j}, b_{2j}) is a bivariate Gaussian random effects for jth week and ε_{it} is a Gaussian error term (all random effects/terms are independent). The main parameter of interest is β_1, representing the baseline-adjusted mean score differences between the intervention and control groups. Standard large-sample inference for linear mixed models was used for assessing the statistical significance of the β_1 estimate and obtaining its 95% CI. We also assessed effect modification by time on intervention, introducing an (intervention×time) interaction term in the model.

We calculated intraclass correlation coefficient (ICC) to assess interobserver variability of the MyHeart score using two-sided p values and setting p<0.05 as statistically significant. All statistical analyses were conducted using Stata V.12.1 (StataCorp LP, College Station, Texas, USA). The ICC was measured in R software (V.3.0.1) using package irr (V.0.84).

Ethical considerations

The study was approved by the Health Research Ethics Board at the University of Alberta. Written informed consent was obtained from the participant and a parent or guardian in all cases. The study was registered at http://www.clinicaltrials.gov (registration # NCT01286480).

RESULTS

We approached 105 potential participants, of whom 21 were excluded for developmental delay and 18 declined (figure 1). Three participants in the intervention arm declined an intervention but agreed to complete questionnaires and were analysed in the intervention group (intention to treat). Baseline characteristics are summarised in table 2. Mean intervention duration was 68 ± 18 min. The intervention protocol (box 1) was successfully completed for all intervention participants. The proportion of participants responding to questionnaires was 45/58 (78%) and 47/58 (81%) at 1 and 6 months, respectively. TRAQ self-management and self-advocacy scores and MyHeart scores are summarised in table 3 and figures 2–4.

Linear mixed models

Time significantly modified the effect of intervention on self-management TRAQ score (p=0.040). At 1 month after the intervention, the mean self-management score, adjusted for the baseline score, was 0.07 higher in the intervention group compared with the usual care group (95% CI −0.27 to 0.41 p=0.690). At 6 months, the mean self-management TRAQ score, adjusted for baseline score, was 0.47 higher in the intervention compared with the usual care group (95% CI 0.00 to 0.93, p=0.048). The mean self-advocacy TRAQ score postintervention, adjusted for baseline score, was 0.21 higher in the intervention compared with the usual care group (95% CI −0.09 to 0.51, p=0.18). The mean MyHeart score postintervention, adjusted for baseline score, was 10% higher in the intervention than in the usual care group (95% CI 1.6 to 18.0, p=0.019).
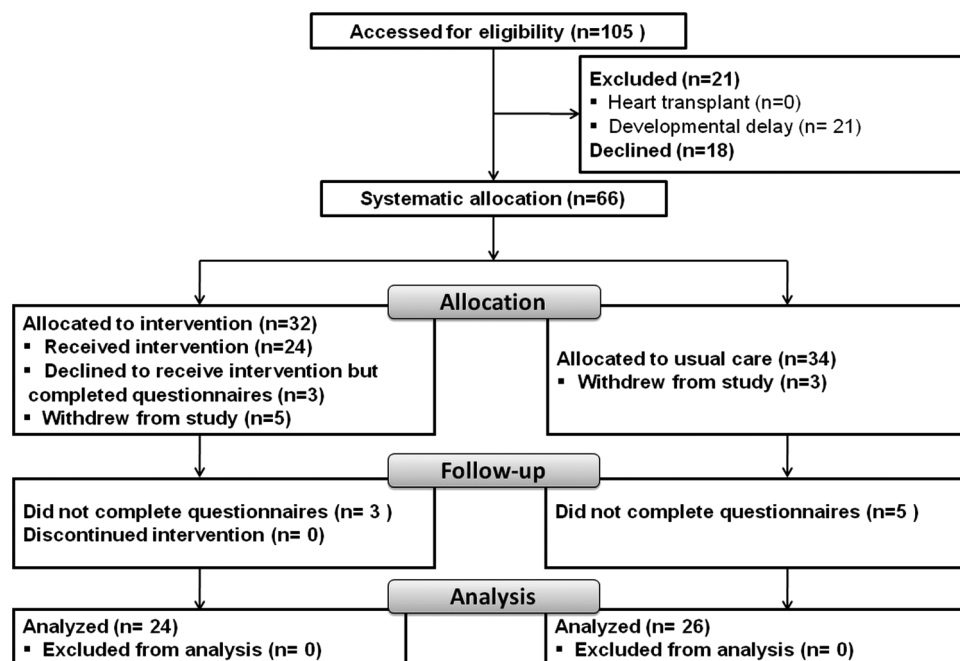
Congenital heart disease

Figure 1 CONSORT diagram.

Interobserver variability

Independently scored MyHeart questionnaires yielded similar scores among the three observers; the ICC for enrolment questionnaires was 0.95 (95% CI 0.91 to 0.97, p<0.0001), for 1-month questionnaires was 0.96 (95% CI 0.93 to 0.97, p<0.0001) and for 6-month questionnaires was 0.91 (95% CI 0.85 to 0.95, p<0.0001).

DISCUSSION

This nurse-led 1 h transition intervention, in combination with usual care, resulted in improved self-management skills and cardiac knowledge among adolescents with congenital or acquired heart disease in comparison to a control group receiving usual care alone. The intervention was delivered in conjunction with a cardiology appointment and placed little time burden on adolescents, increasing its feasibility for implementation.

The TRAQ, our primary outcome measure, was first described in a large sample of adolescents and young adults living with chronic health conditions, including cardiac disease.[22] The self-management and self-advocacy scores at baseline in our intervention and control groups were similar to each other and to scores previously described in adolescents.[22] There was a significant increase in the self-management score at 6 months, but not at 1-month postintervention. This delayed effect was expected given that behaviours such as filling one's own prescriptions might not be implemented in the short term (eg, if no prescription renewal is needed). The TRAQ has a relatively low reading level (grade 5.7) and is therefore readily understood by most adolescents. TRAQ scores increase with increasing age, underscoring the importance of having a control group in studies that evaluate transition interventions with longitudinal follow-up.

Table 2 Baseline characteristics of participants

Variables	Intervention (n=27)	Usual (n=31)
Sex: female	11 (41)	17 (55)
Mean age (±SD)	16.6±1.0	16.4±1.0
Primary cardiac diagnosis		
Coarctation of the aorta	6 (22)	5 (16)
d-Transposition of the great arteries	5 (19)	4 (13)
Tetralogy of Fallot	4 (15)	4 (13)
Double outlet RV	0	3 (10)
Moderate or severe aortic valve stenosis	3 (11)	4 (13)
Other congenital heart disease	6 (22)	8 (26)
Dilated cardiomyopathy	2 (7)	1 (3)
Hypertrophic cardiomyopathy	1 (4)	2 (6)
Previous cardiac surgery	19 (70)	21 (68)
Pacemaker or defibrillator	2 (7)	1 (3)
Previous cardiac catheterisation	19 (70)	24 (77)
On medication at enrolment	10 (37)	15 (48)

Results are presented as N (%) unless otherwise indicated.

Table 3 Summary of scores for intervention and usual care group

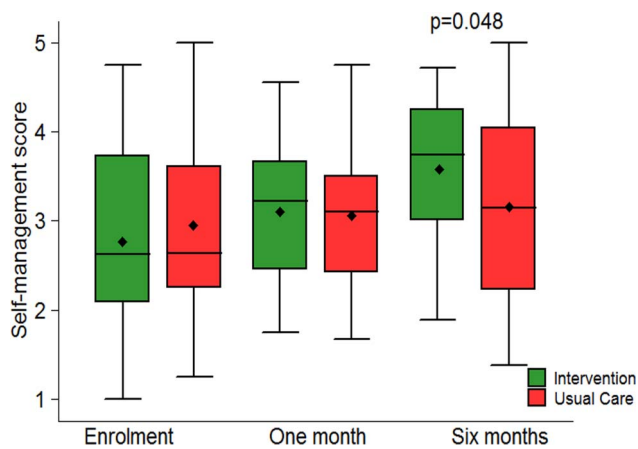| Outcome variables	Intervention Mean (±SD)	Usual care Mean (±SD)
Baseline		
Self-management	2.77 (±1.07)	2.95 (±0.98)
Self-advocacy	3.80 (±0.79)	3.92 (±0.67)
MyHeart score (%)	57 (±20)	58 (±25)
One month		
Self-management	3.12 (±0.75)	3.08 (±0.93)
Self-advocacy	4.03 (±0.52)	3.88 (±0.75)
MyHeart score (%)	74 (±15)	61 (±25)
Six months		
Self-management	3.59 (±0.83)	3.16 (±1.05)
Self-advocacy	4.38 (±0.56)	4.01 (±0.95)
MyHeart score (%)	75 (±15)	61 (±25)

Figure 2 Self-management Transition Readiness Assessment Questionnaire (TRAQ) scores. The bottom and upper borders of boxes represent the 25th and 75th centiles, respectively. The horizontal line within each box represents the median (50th centile). Diamonds (♦) represent the mean. Lower and upper whiskers are defined as the lowest datum still within (1.5×IQR) of the lower quartile, and the highest datum still within (1.5×IQR) of the upper quartile, respectively.

Figure 4 MyHeart scores. The bottom and upper borders of boxes represent the 25th and 75th centiles, respectively. The horizontal line within each box represents the median (50th centile). Diamonds (♦) represent the mean. Lower and upper whiskers are defined as the lowest datum still within (1.5×IQR) of the lower quartile, and the highest datum still within (1.5×IQR) of the upper quartile, respectively.

The MyHeart score was responsive to intervention, was readily understood by participants and had high interobserver consistency between a cardiologist, a cardiology nurse and a research assistant having no cardiology training. Knowledge of their heart condition has been consistently poor among adolescents and young adults with cardiac disease.[14–16] Valente et al[23] demonstrated that adults with CHD were slightly more able to name their heart condition 3 months following an educational intervention (78% preintervention, 83% postintervention). However, their study lacked a control group and was potentially limited by response bias; only 57% of participants completed the follow-up survey, and those who did respond had more education than those who did not. In contrast, our study had a control group and a response rate of 78% and 81% at 1 and 6 months, respectively. The increased MyHeart scores of the intervention group at short-term follow-up
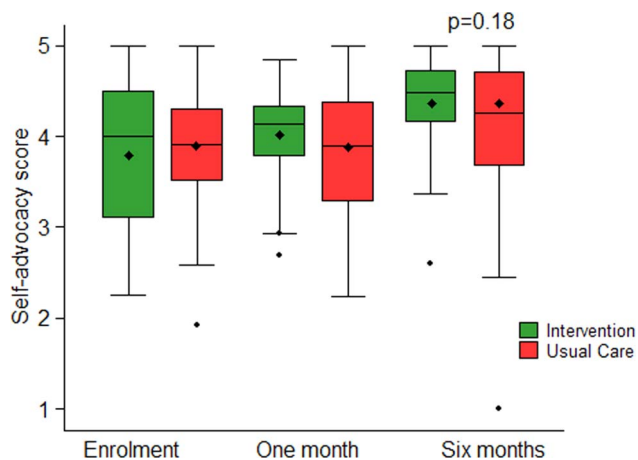
(1 month) were sustained at medium term follow-up (6 months), with all intervention respondents indicating that they completed the 6-month MyHeart questionnaire 'from memory alone' (table 1, question 8). The opportunity to refer to their MyHealth passport may have contributed to the retained cardiac knowledge of the intervention group participants. This wallet-sized summary of their cardiac history allows participants easy access to their health information.

Transition interventions that are effective for young adults having other chronic health conditions may not be generalisable to those with cardiac disease. For example, availability of a healthcare system 'navigator' has been well received by adolescents and young adults with type 1 diabetes, resulting in a higher proportion attending adult specialty diabetes care.[24] However, unlike persons with diabetes, who have a daily reminder of their health condition (ie, need for insulin), many patients with congenital or acquired heart disease are asymptomatic and on no medications and therefore do not have a daily reminder of their cardiac condition. This may contribute to the sense of 'being cured'.[13] For this reason, efforts to adopt transition interventions for the cardiac population that have been used in other chronic paediatric health conditions may fail. Rather, transition interventions need to be rigorously evaluated in cardiac patients before being widely adopted.

This study has several limitations, including being a single-centre trial. Most, though not all, interventions were conducted by a single nurse. However, the intervention protocol was strictly adhered to for all interventions based on a review of a detailed checklist and nursing logs. We assessed self-management behaviours based on self-report, though to our knowledge no superior method exists. Long-term follow-up and attendance in an adult cardiac clinic were not assessed. Developing the skills of participants to interact with healthcare providers (self-advocacy domain) was not part of the intervention. A larger two-centre study addressing both education and communication skills is currently underway by our team and will evaluate subsequent attendance in a specialised adult cardiology clinic.

In summary, this clinical trial demonstrated that a nurse-led 1 h transition intervention resulted in greater self-management

Figure 3 Self-advocacy Transition Readiness Assessment Questionnaire (TRAQ) scores. The bottom and upper borders of boxes represent the 25th and 75th centiles, respectively. The horizontal line within each box represents the median (50th centile). Diamonds (♦) represent the mean. Lower and upper whiskers are defined as the lowest datum still within (1.5×IQR) of the lower quartile, and the highest datum still within (1.5×IQR) of the upper quartile, respectively. Circles (•) represent outliers.
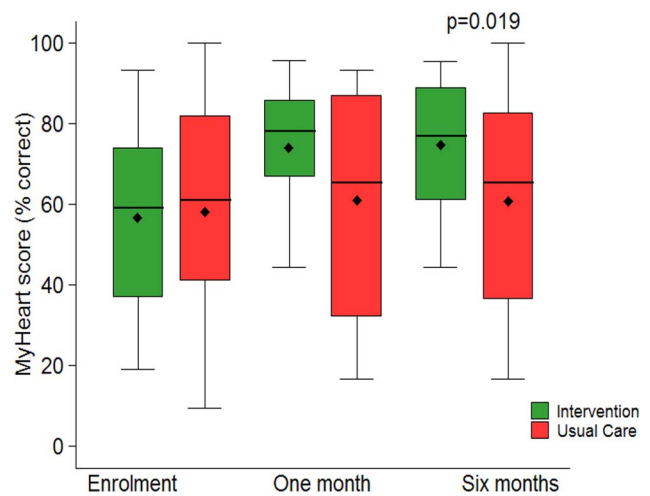
skills and knowledge of their heart among older adolescents with congenital or acquired heart disease. The intervention protocol requires relatively few resources other than nursing time and expertise, and space near the outpatient clinic area. Accordingly, this protocol could be readily adopted by many clinical programmes. Based on these findings, transition interventions should be routinely provided by paediatric cardiac centres.

Key messages

What is known on this subject?
▸ Adolescents and young adults with congenital and acquired heart disease have little knowledge about their heart condition. Many are not aware of potential late complications or the need for lifelong cardiology follow-up. Consequently, loss to follow-up is common in this population.

What might this study add?
▸ This study demonstrates that an individualised nurse-led teaching session for older adolescents with heart disease results in improved knowledge of their heart and greater self-management skills relative to controls. Clinical programmes should adopt an educational intervention for adolescents undergoing transition to adult care.

How might this impact on clinical practice?
▸ There is a paucity of data as to how to prepare adolescents with heart disease to assume responsibility for their health management.

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Heart

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http://heart.bmj.com/content/100/14/1113

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References

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Notes