

Transition Intervention for Adolescents With Congenital Heart Disease



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ABSTRACT

BACKGROUND There is little evidence regarding the efficacy of interventions to prepare adolescents with congenital heart disease (CHD) to enter adult care.

OBJECTIVES The goal of this study was to evaluate the impact of a nurse-led transition intervention on lapses between pediatric and adult care.

METHODS A cluster randomized clinical trial was conducted of a nurse-led transition intervention for 16- to 17-year-olds with moderate or complex CHD versus usual care. The intervention group received two 1-h individualized sessions targeting CHD education and self-management skills. The primary outcome was excess time to adult CHD care, defined as the interval between the final pediatric and first adult cardiology appointments, minus the recommended time interval, analyzed by using Cox proportional hazards regression accounting for clustering. Secondary outcomes included scores on the MyHeart CHD knowledge survey and the Transition Readiness Assessment Questionnaire.

RESULTS A total of 121 participants were randomized to receive the intervention (n = 58) or usual care (n = 63). At the recommended time of first adult appointment (excess time = 0), intervention participants were 1.8 times more likely to have their appointment within 1 month (95% confidence interval: 1.1 to 2.9; Cox regression, p = 0.018). This hazard increased with time; at an excess time of 6 months, intervention participants were 3.0 times more likely to have an appointment within 1 month (95% confidence interval: 1.1 to 8.3). The intervention group had higher scores at 1, 6, 12, and 18 months on the MyHeart knowledge survey (mixed models, p < 0.001) and the Transition Readiness Assessment Questionnaire self-management index (mixed models, p = 0.032).

CONCLUSIONS A nurse-led intervention reduced the likelihood of a delay in adult CHD care and improved CHD knowledge and self-management skills. (Congenital Heart Adolescents Participating in Transition Evaluation Research [CHAPTER 2]; NCT01723332) (J Am Coll Cardiol 2018;71:1768-77) © 2018 by the American College of Cardiology Foundation.

More than 90% of children with congenital heart disease (CHD) in the current era reach adulthood (1), and the population of adolescents and young adults with CHD is growing exponentially (2). However, this emerging “survivor” population has complex needs. Unfortunately, between 21% and 76% of adolescents and young adults have a lapse in cardiology care (3-9). Loss to follow-up is an important challenge, as lapses in adult CHD care may predispose patients to delayed recognition



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of new cardiac problems (4,7,10). Yeung et al. (4) reported that a lapse in care of ≥ 2 years since leaving a pediatric cardiac program was associated with a 3-fold need for catheter or surgical intervention within 6 months of obtaining adult CHD care. However, the clinically meaningful threshold duration of a gap in care is unknown and may vary among subtypes of CHD.

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Transition from pediatric to adult health care is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (11). Few data are available on how to facilitate transition; only a single study of patients with CHD met criteria for entry in a recent Cochrane systematic review of transition interventions for adolescents, and this study did not assess timeliness of the first adult cardiology appointment (12). We therefore sought to evaluate the impact of a nurse-led transition intervention on lapses in care. We hypothesized that a transition intervention in combination with usual care would result in more timely first adult CHD clinic attendance compared with usual care alone. Secondary aims of the study were to describe the following: 1) change in participants’ knowledge of their CHD; 2) change in self-management and self-advocacy skills using validated instruments (13,14); and 3) incidence of cardiac procedures post-enrollment.

METHODS

The CHAPTER 2 (Congenital Heart Adolescents Participating in Transition Evaluation Research) study was a cluster randomized clinical trial using 2 parallel groups of adolescents attending outpatient clinics in 1 of 2 tertiary care pediatric cardiology programs in Canada. Institutional review board approval was obtained at each site. Written informed consent was obtained from participants and, if required, from their parent or guardian. The details of the methods and study design have been described previously (15). Eligible patients were 16 to 17 years old with moderate or complex CHD (16) who had not yet been transferred to adult care. We excluded patients with less than a grade 6 level of reading or comprehension, based on parent report, and those with a heart transplant.

Patients were assigned to clusters based on week of attendance in the cardiology clinic. Weeks were randomly assigned to “intervention” or “usual care” by a biostatistician. A 1:1 ratio of intervention:usual

care was used until midway through enrollment, after which the enrollment ratio was changed to a ratio of 1.5 intervention weeks:1 usual care week due to lower enrollment during intervention weeks. Randomization was stratified according to site. Permuted blocks of 2, 4, and 6 were used for 1:1 randomization; this method was changed to blocks of 5 and 10 when randomization was changed to 1.5:1 midway through enrollment.

The transition intervention consisted of 2 nurse-led 1-on-1 sessions. Parents were purposefully not present to promote the independent self-management of the transitioning youth. The first session was held in person on the day of a cardiology clinic appointment. The second session was held 2 months later, either in person or by teleconference or Skype for participants living far from the hospital. Details of the intervention have been published (15) and included 2 sessions; a brief description is given here.

Session 1 involved the creation of a MyHealth passport (17). This passport included review of the participant’s CHD anatomy, previous cardiac interventions, and name, dose, and rationale of cardiac medications; discussion of potential future cardiac complications; review of the names and location of local adult CHD cardiologists; introduction to relevant youth-friendly health care websites; discussion of 3 third-person scenarios (alcohol, smoking/street drugs, and sexuality/contraception); an introductory visit to the adult CHD clinic; and the setting of 1 education-related goal.

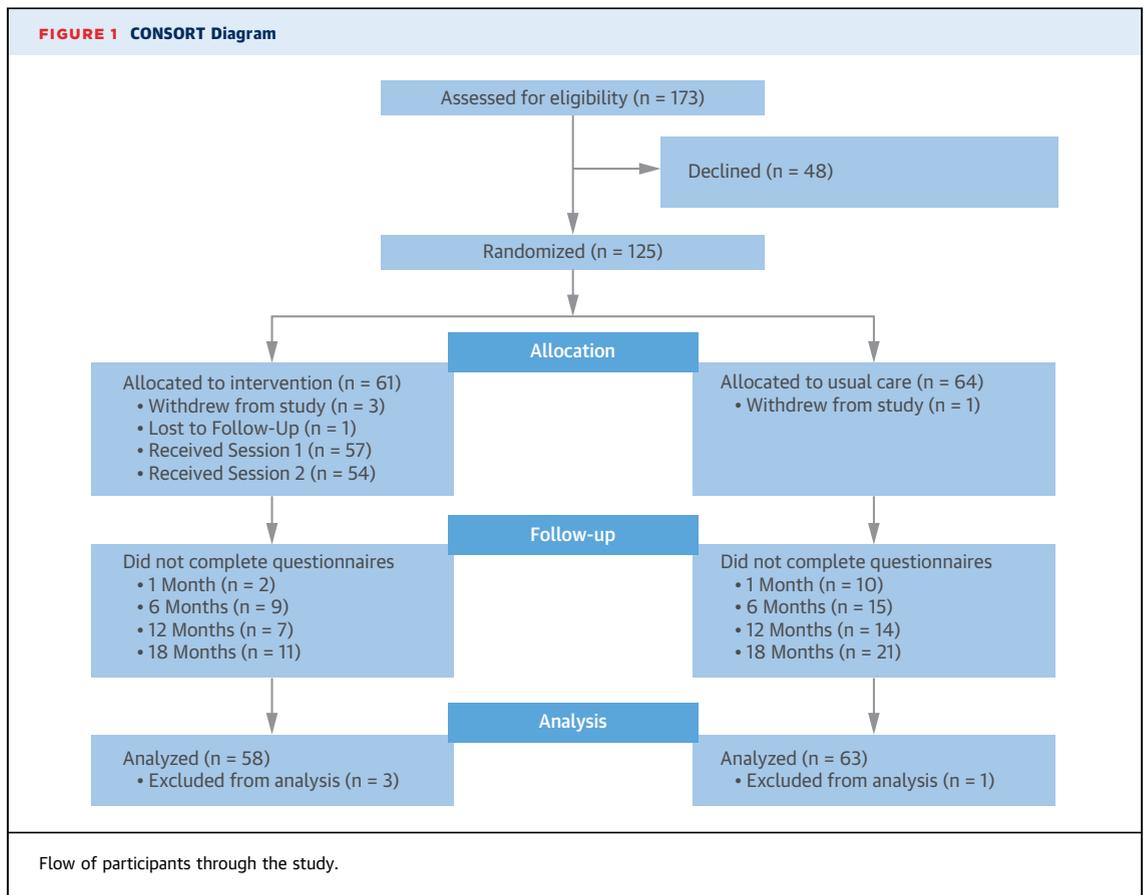
Session 2 included review of the education-related goal; discussion of 6 short videos illustrating young adults with poor versus strong communication skills with health care providers; viewing and discussion of a video titled “Talking With Your Doctor” (18); role-play of 2 standardized health care scenarios; discussion of effective goal-setting; review (and take home) of the booklet “When You’re 18” (19); and review of the “Health Care Transitions” website (20). Both sessions were followed by text message or e-mail interaction between the study nurse and participant within 7 days. Nurses documented the completion of each element of the intervention after each session. Intervention fidelity and quality assurance are described in the published protocol (15).

The usual care group did not receive the same educational materials as the intervention group. No transition program was formally in place at either site during the study period. At both sites, pertinent medical records were sent to adult CHD providers at the time of transfer. Both adult CHD clinics sent a

ABBREVIATIONS AND ACRONYMS

CHD = congenital heart disease

TRAQ = Transition Readiness
Assessment Questionnaire



welcome letter to patients indicating approximately when their first adult CHD appointment would be. A second letter was sent 1 month before the first adult CHD appointment. Patients who did not attend were contacted by telephone to reschedule.

The primary outcome was excess time between pediatric and adult CHD care, defined as the time interval (in months) between the final pediatric visit and the first adult visit, minus the recommended time interval between these visits. The “recommended time” interval was the interval suggested by the cardiologist at the final pediatric visit. For example, if the time between the final pediatric visit and the first adult visit was 20 months but the pediatric cardiologist recommended this duration be 12 months, the excess time would be 8 months. If the first adult visit took place before the recommended time, the excess time was zero. Participants who did not have an adult appointment were censored at the end of the study. For the rare study participant not having a documented “recommended time,” the recommended time was set at 12 months for participants with complex CHD and 24 months for participants with moderate CHD (21,22).

Secondary outcome 1 was change in the CHD knowledge (MyHeart) score (23) between baseline, 1, 6, 12, and 18 months. Secondary outcome 2 was measured by the following: 1) change in Transition Readiness Assessment Questionnaire (TRAQ) score (14) between baseline, 1, 6, 12, and 18 months; 2) change in the Williams’ self-management scale (13) between baseline, 1, 6, 12, and 18 months; and 3) assessment of self-management via a cardiologist questionnaire. Secondary outcome 3 was incidence of cardiac re-intervention (surgery or interventional catheterization) at 12 and 24 months’ post-enrollment. Participants received \$50 Canadian each time questionnaires were completed. There was no payment for participating in intervention sessions.

Any information that the pediatric cardiologist provided the adolescents about their CHD and/or transition (either group) was at the clinical discretion of the cardiologist. Cardiologists and clinic staff were not informed of group allocation. Due to the nature of the intervention, participants, parents, and study nurses could not be blinded to allocation; however, participants in the usual care group were not aware that an intervention group existed, and

TABLE 1 Participant Characteristics

	Intervention Group (n = 58)	Usual Care Group (n = 63)
Age, yrs	16.9 ± 0.6	17.1 ± 0.6
Female	32 (55)	27 (43)
CHD severity		
Moderate	38 (65)	49 (78)
Coarctation of the aorta	10 (17)	11 (17)
AVSD	8 (14)	3 (5)
Tetralogy of Fallot	6 (10)	13 (21)
Other	14 (24)	22 (35)
Complex	20 (35)	14 (22)
DORV	5 (9)	2 (3)
TGA	5 (9)	6 (10)
Pulmonary atresia	3 (5)	2 (3)
Other	7 (12)	4 (6)
No. of interventions completed		
Session 1	57 (98)	NA
Session 2	54 (94)	NA
No. completing questionnaires		
1 month	56 (97)	53 (84)
6 months	49 (84)	48 (76)
12 months	51 (88)	49 (78)
18 months	47 (81)	42 (67)

Values are mean ± SD or n (%).
 AVSD = atrioventricular septal defect; CHD = congenital heart disease; DORV = double outlet right ventricle; NA = not applicable; TGA = transposition of the great arteries.

TABLE 2 Cox Regression Estimates of the Allocation Group

	Estimate	SE	p Value
Allocation group adjusted for time interaction			0.0183
Intervention	0.575	0.238	
Usual care	0.0	-	
Allocation group*excess time (interaction)	0.0857	0.0458	0.066

participants in both groups were unaware of the primary outcome (excess time to attendance at first adult appointment). Clinical outcomes were adjudicated by observers who were blinded to group allocation.

The primary outcome was analyzed with Cox proportional hazards regression by using SAS Proc SURVEYPHREG (24) with week as the cluster unit, to account for clustered randomization (because randomization was of weeks rather than individuals). Time zero was defined as the recommended date of the first adult CHD appointment (excess time = 0). For example, if the pediatric cardiologist recommended a first adult CHD appointment in 12 months, time zero was 12 months after the final pediatric appointment. The event was the first adult CHD appointment. The proportionality assumption was violated by assessment of Kaplan-Meier curves and Schoenfeld residuals; therefore, the interaction term (allocation group)*(excess time) was added to the Cox regression model. Both terms from the model, allocation group and the interaction (allocation group)*(excess time), were used to estimate the hazard ratio (HR), which was not constant over time.

To evaluate the intervention effect on secondary outcomes such as change in MyHeart scores, change

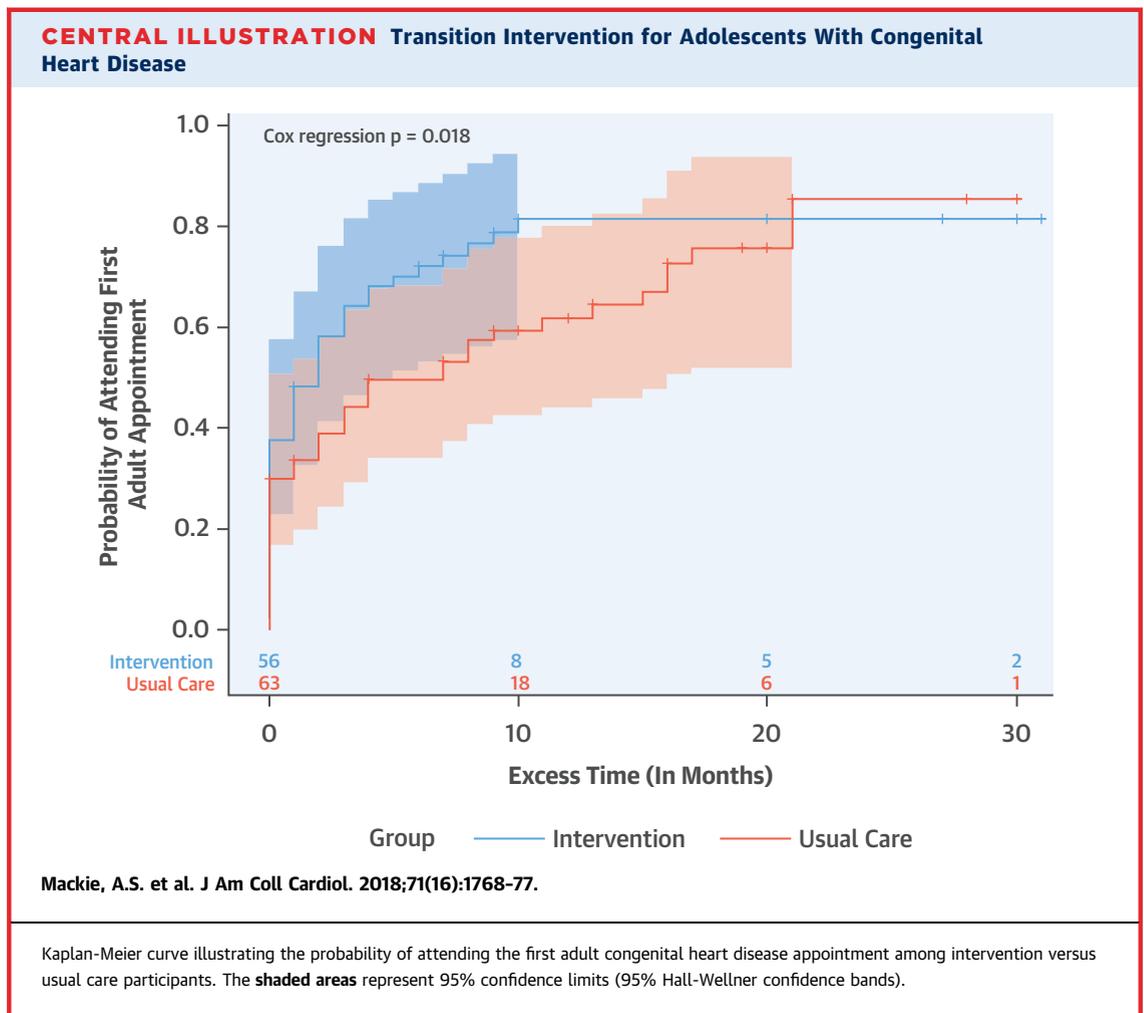
in TRAQ scores, and change in the Williams' score, linear mixed models adjusted for cluster randomization and baseline scores were used. Descriptive statistics are presented using proportions for binary variables and mean ± SD for continuous variables. Comparisons between the 2 groups were performed with a Student's *t*-test or Mann-Whitney *U* test for means and chi-square tests for proportions. All statistical analyses were conducted by using SAS version 9.4 (SAS Institute, Inc., Cary, North Carolina) and IBM SPSS statistics version 24 (IBM SPSS Statistics, IBM Corporation, Armonk, New York).

RESULTS

Of 173 potentially eligible patients approached by the study team, 125 (72%) were enrolled. Four participants withdrew from the study: 3 in the intervention group and 1 in usual care. The remaining 121 participants were analyzed: 58 in the intervention group and 63 in usual care. Participant flow through the study is illustrated in Figure 1, and participant characteristics are summarized in Table 1. Mean duration of session 1 interventions was 77 ± 15 min, and mean duration of session 2 intervention was 66 ± 11 min.

PRIMARY ENDPOINT. A recommended time interval to the first adult CHD appointment from the participant's pediatric cardiologist was available for 108 (89%) of 121 participants. Median excess time was 7.0 months (95% limits: 2.1, 11.9 months) in the usual care group and 2.0 months (95% limits: 0.7, 3.3 months) in the intervention group. The proportion seen within 3 months of the recommended time interval (excess time ≤ 3 months) was 51% in the usual care group versus 68% in the intervention group (p = 0.059). In the Cox model with allocation group by time interaction, the HR between subjects from the usual care group and the intervention group depends on time as $HR = e^{0.575 + 0.0857t} = 1.778 * e^{0.0857t}$, where *t* is excess time in months. As excess time increased, the HR increased as well (Table 2).

The Central Illustration illustrates the probability of attending the first adult CHD appointment as a function of excess time. At the recommended time of first adult CHD appointment (i.e., excess time = 0),



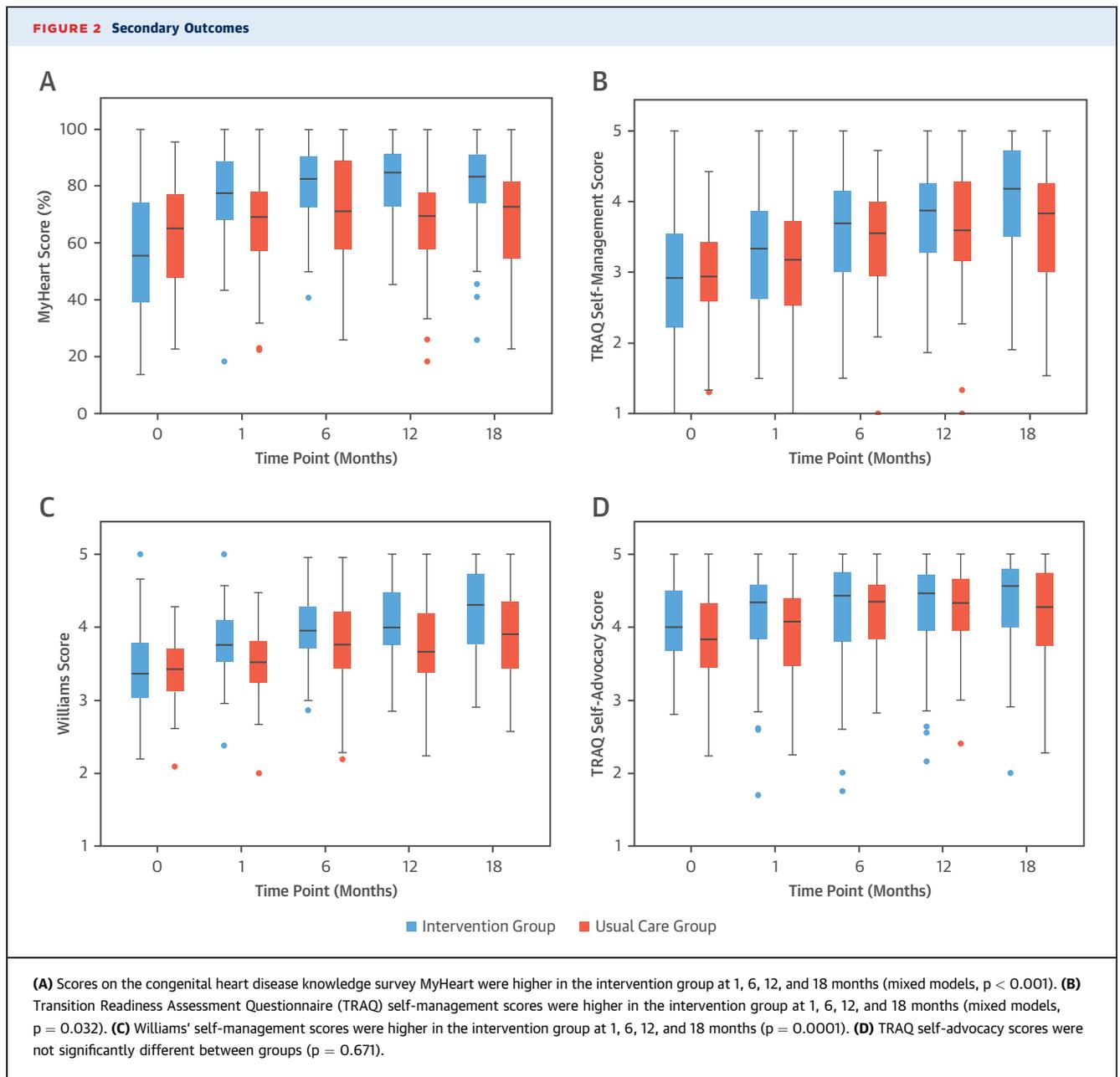
intervention participants were 1.8 times more likely to have their adult CHD appointment within 1 month relative to those in usual care (95% CI: 1.1 to 2.9; Cox regression, $p = 0.018$). This hazard increased with time; at an excess time of 6 months, intervention participants were 3.0 times more likely to have an appointment within 1 month (i.e., within an excess time of 7 months; 95% CI: 1.1 to 8.3). Complete failure to return during follow-up occurred in 16 (28%) of 58 intervention participants versus 21 (33%) of 63 usual care participants ($p = 0.56$).

SECONDARY ENDPOINTS. MyHeart knowledge scores were similar between the intervention and control groups at baseline (mean: $55 \pm 22\%$ vs. $62 \pm 19\%$, respectively; Mann-Whitney U test, $p = 0.63$). However, MyHeart scores were higher (i.e., better knowledge) in the intervention group compared with the usual care group at 1, 6, 12, and 18 months (mixed models, $p < 0.001$) (Figure 2A).

TRAQ self-management scores were similar between the intervention and control groups at baseline

(mean: 2.9 ± 0.7 vs. 2.9 ± 0.9 , respectively; Student's t -test, $p = 0.68$). Self-management scores increased over time in both groups. However, self-management scores were higher in the intervention group compared with the control group at 1, 6, 12, and 18 months (mixed models, $p = 0.03$) (Figure 2B). Williams' self-management scores were similar between the intervention and control groups at baseline (mean: 3.4 ± 0.6 vs. 3.4 ± 0.4 ; Student's t -test, $p = 0.85$). At 1, 6, 12, and 18 months, Williams' scores were higher in the intervention group compared with the control group ($p = 0.0001$) (Figure 2C).

TRAQ self-advocacy scores were similar between the intervention and control groups at baseline (mean: 4.0 ± 0.6 vs. 3.9 ± 0.7 , respectively; Mann-Whitney U test, $p = 0.37$) (Figure 2D). Self-advocacy scores increased over time in both groups; the differences between the scores in the intervention group and the control group were not statistically significant at 1, 6, 12, or 18 months (mixed models, $p = 0.67$).



Self-advocacy, defined as “skills for communication with the health care team and items related to managing activities of daily living and use of school and community resources” (14), was assessed by the participant’s cardiologist at his or her first cardiology follow-up appointment after enrollment. Cardiologists, blinded to group allocation, reported that participants (rather than their parents) in the intervention group were more likely to answer their questions (44 of 47 [94%]) compared with participants in the usual care group (31 of 46 [67%]) ($p = 0.0007$). Additional details about cardiologists’

perceptions of patient self-management skills are provided in [Table 3](#).

The incidence of cardiac re-interventions (surgery or interventional catheterization) was low and did not differ between study groups. Within 12 months of enrollment, there were 17 hospitalizations among 14 study participants (12%) and 14 interventional cardiac procedures among 12 participants (10%). Within 24 months of enrollment, there were 22 hospitalizations among 17 study participants (14%), and 19 interventional cardiac procedures among 15 participants (12%).

TABLE 3 Self-Management as Reported by Cardiologists

	Intervention Group (n = 47)	Usual Care Group (n = 46)	p Value
Who attended clinic?			0.11
Patient only	3 (6)	8 (17)	
Patient with parent	40 (85)	35 (76)	
Patient with significant other	1 (2)	0 (0)	
Patient with other relative or friend	1 (2)	1 (2)	
Patient with significant other and relative or friend	2 (4)	0 (0)	
Incomplete data	0 (0)	2 (4)	
Who answered the majority of your questions in clinic?			0.006
Patient	44 (94)	31 (67)	
Parent	1 (2)	7 (15)	
Significant other	0 (0)	0 (0)	
Other relative or friend	0 (0)	1 (2)	
Patient and parent	2 (4)	5 (11)	
Incomplete data	0 (0)	2 (4)	
Did the patient use an electronic or written record of their health history to help them discuss their condition with you?			0.64
Yes	5 (11)	2 (4)	
No	40 (85)	42 (91)	
Incomplete data	2 (4)	2 (4)	
Did the patient ask you any questions relevant to their cardiac condition?			0.66
Yes	35 (74)	31 (67)	
No	11 (23)	13 (28)	
Incomplete data	1 (2)	2 (4)	
Based on your interaction with your patient today, how prepared is he or she for independently taking responsibility for their health?			0.53
0 (Not prepared at all)	1	0	
1	0	3	
2	3	5	
3	16	13	
4	17	18	
5 (Completely prepared)	9	6	
Incomplete data	1	1	

Values are n (%) unless otherwise indicated.

DISCUSSION

This randomized controlled trial showed that a nurse-led educational intervention directed at older adolescents with CHD reduced the likelihood of a delay in obtaining adult CHD care after graduation from pediatric cardiology. This intervention further resulted in greater CHD knowledge and self-management skills that were sustained up to 18 months' post-intervention. The intervention required nursing time to prepare for and deliver the 1-on-1 meetings with participants but was of relatively low cost and is reproducible by other clinical programs.

Adolescent survivors of CHD are at risk of substantial cardiac morbidity (25,26) and mortality

(27,28) in the early-to-mid adult years and most require lifelong follow-up with a cardiologist with specialized training and expertise in CHD (29). However, lack of knowledge about their CHD is common among adolescents and young adults (5,30-32). For example, a misperception of being cured or no longer needing cardiology follow-up has been documented by several investigators (4,33), and a lapse in cardiology care occurs in 21% to 76% of adolescents and young adults (3-9). Knowledge gaps also negatively affect adolescents' comfort with communicating with health care providers (34). Despite these challenges, a minority of pediatric cardiology programs provide a transition program for adolescent patients (35). Only 1 study reported an acceptable rate of loss to follow-up (7%), and this finding occurred in the context of a small, densely populated country (Belgium) with government-funded health care and with pediatric and adult CHD programs located in the same building (36).

Our team previously showed that a single nurse-led educational session improved CHD knowledge and self-management skills among adolescents with moderate or complex CHD (CHAPTER 1 [Congenital Heart Adolescents Participating in Transition Evaluation Research] study) (23). However, this single-center study followed up participants for only 6 months and did not evaluate lapses in cardiology follow-up. The CHAPTER 2 study improved on the methods used in the CHAPTER 1 study (15,23) by using a larger sample size and following up participants for 18 months rather than 6 months. The CHAPTER 2 study was conducted at 2 sites to improve external validity. Most importantly, the novel primary outcome of the present study was excess time to first adult cardiology appointment. Given the potential negative impact of lapses in cardiology care (4,7,10), efforts to avoid or minimize care lapses should be a priority of pediatric and adult CHD programs alike.

The present study also sought the perspective of the patient's cardiologist regarding readiness for transfer (Table 3). Although cardiologists' own perceptions are not a validated assessment of patient readiness for transfer to adult CHD care, these cardiologists who were unaware of group allocation reported that a significantly higher proportion of intervention participants answered their questions (in contrast to parents answering questions) relative to those in the usual care group. This finding is consistent with the findings of Clarizia et al. (34), who reported that adolescents who were more knowledgeable about their CHD felt more comfortable communicating with health care providers.

The adult CHD programs participating in this study contacted all study participants directly to schedule the first adult appointment, rather than relying on the participants' initiative to arrange their own first adult appointment. Staff members who scheduled adult clinic appointments were not aware of group allocation, and participants in both groups were unaware of the primary outcome and, therefore, could not have consciously influenced the study findings. We hypothesize that participants in the intervention group had greater awareness of the need for lifelong CHD follow-up (assessed in the MyHeart score) and were more likely to reply to support staff to confirm and/or attend their first adult appointment. It is possible that the study intervention would have had a greater impact if participants, rather than the adult programs, were responsible for initiating the contact required to schedule the first adult appointment.

TRAQ self-management and self-advocacy scores improved over time in both the intervention and usual care groups, as did MyHeart scores. This outcome is not surprising, given that TRAQ scores increase with increasing age in late adolescence and early adulthood (14). However, this finding highlights the importance of a control group. In the absence of control subjects, investigators may erroneously conclude that increasing scores over time are the result of an intervention, rather than the "natural history" of these scores.

Campbell et al. (12) recently published a systematic review of transition interventions from pediatric to adult services. Although they considered a broad range of chronic health conditions, only 4 studies met their inclusion criteria, including the CHAPTER 1 study. All studies focused on the patient, rather than on health care providers or systems. The other 3 interventions included a cognitive-behavioral program, a web-based and text-message delivered skill-based intervention, and standardized telephone communications combined with paper and USB-based copies of medical records. The review's authors concluded that, given the lack of rigorous literature in the field of transition interventions, there is considerable opportunity for further studies, particularly those having longer periods of follow-up and including clinical outcomes.

The nurse-led intervention in the present study was time-intensive, requiring time with participants and time to review cardiology records in advance of the sessions. It is difficult to "weigh" this time against the benefits gained in terms of earlier first adult CHD appointment, improved CHD knowledge, and

improved self-management scores. Interventions were deliberately delivered by cardiology nurses who are an integral part of most cardiac programs and less costly than nurse practitioners. This approach increases study generalizability to other sites.

STUDY LIMITATIONS. There may have been participant bias, with participants having more (or less) knowledge and self-management skills relative to the general population of adolescents with CHD; however, we do not have substantial reason to assume such selection bias. Despite efforts to maintain intervention fidelity, the nature of the nurse-led intervention is such that some between-nurse and between-participant variability is inevitable. Cardiologists and other clinic staff were not informed of group allocation but may have inadvertently found out whether a given participant was in the intervention group; if so, this knowledge would likely have resulted in underestimation of the impact of the intervention relative to the usual care group. Complete failure to return occurred among 28% of intervention participants and 33% of usual care participants. Reasons for this finding are unknown but may include inadequate duration of the follow-up period, relocation to another region, or that participants were unaffected by the intervention with complete loss to follow-up. However, this binary outcome is an oversimplification of the data because it does not account for the time-to-event nature of the primary outcome. In other words, not all participants in the 2 groups were followed up for the same amount of time, and not all participants have the same recommended time to first adult CHD appointment. The primary outcome was excess time to the event (the first adult CHD appointment) but not the event itself. There is relatively little validation of the MyHeart and Williams' questionnaires used in this study, although the TRAQ is considered the best-validated transition readiness instrument (37). The clinical impact of a 5-month reduction in median excess time is unknown. The long-term clinical impact of improved CHD knowledge and self-management skills is similarly unknown, although professional consensus is that these factors are vital for optimizing patient engagement with the health care system and health outcomes.

With regard to clinical implementation of study findings, it would be important to determine whether sessions could be abbreviated with the same positive outcomes and whether they could be provided at 2 consecutive cardiology clinic appointments separated by >2 months. Integration of health counseling within the regular-scheduled clinical visits might

also be more realistic given challenges regarding insurance reimbursement in the United States.

CONCLUSIONS

We showed that a nurse-led transition intervention for older adolescents, which focused on education about their CHD and development of self-management skills, reduced the likelihood of a delay in obtaining adult CHD care after graduating from a tertiary care pediatric cardiac program; it also resulted in improved CHD knowledge and self-management skills that were sustained 18 months later. The nurse-led intervention is feasible and can be duplicated in other CHD programs. A structured intervention program should be provided to all adolescents with CHD to prepare them for long-term care.

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PERSPECTIVES

COMPETENCY IN PATIENT CARE AND

PROCEDURAL SKILLS: Adolescents with CHD benefit from a transition intervention program that incorporates education and self-management. Pediatric and adult CHD programs should provide structured transition interventions to older adolescents in the course of routine patient care.

TRANSLATIONAL OUTLOOK: Key developmental changes distinguish younger (13 to 14 years old) from older adolescents. Older patients should participate in plans for transfer of care to adult cardiologists, whereas younger adolescents must develop knowledge of their condition to build confidence and enhance their ability to communicate with health care providers. Further studies are needed to develop optimum transition intervention programs for younger adolescents that address these objectives.

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