

Readiness for Transition to Adult Health Care for Young Adolescents with Congenital Heart Disease

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Abstract This study evaluates transition readiness, medical condition knowledge, self-efficacy, and illness uncertainty in young adolescents (ages 12 to 15 years) with congenital heart disease (CHD), and medical, patient, and parental factors associated with transition readiness. We enrolled 82 patients with moderate or complex CHD ($n=36$, 44% male; mean age 13.6 ± 1.3 years), and their parents. Patients completed standardized self-report measures: Transition Readiness Assessment Questionnaire (TRAQ), MyHeart scale, General Self-Efficacy scale, and Children's Uncertainty in Illness Scale. Parents completed the MyHeart scale and demographic information. Many young adolescents had not discussed transfer with a health care provider ($n=20$, 24%) or parent ($n=34$, 41%). Transition readiness was higher among patients who were older, more knowledgeable about their condition, had a history of primary cardiac repair and greater self-efficacy, and was lower for boys and patients on cardiac medications. Transition readiness was unrelated to CHD diagnosis and patients' illness uncertainty. Patients' self-advocacy skills were superior to their chronic disease self-management skills. Increased parental medical condition knowledge was positively correlated with patient knowledge, and patient–parent discussion of transfer was associated with increased patient's self-management skills. Transition is not uniformly discussed with young adolescent CHD patients.

Parental involvement is correlated with increased transition readiness and patient disease self-management skills. Young adolescent transition programs should focus on education around improving patient medical condition knowledge, promote chronic disease self-management skills development, and include parental involvement.

Keywords Transition · Transition readiness · Congenital heart disease · Pediatrics · Adolescent · Health care transition

Introduction

Through advancements in medicine, over 90% of children born with congenital heart disease (CHD) survive into adulthood [1], and it is crucial for patients with moderate or complex CHD to receive life-long follow-up during adulthood as they are at high risk of cardiac complications later in life [2, 3]. Transition is defined as the “purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” [4]. The American College of Cardiology/American Heart Association (ACC/AHA) 2008 Guidelines for the management of adults with CHD state that an individual should begin the process of transition at the age of 12 years [5], and that health care providers should begin to educate adolescents between 13 and 16 years about their cardiac diagnosis and symptoms [6]. Approximately half of adolescents do not successfully transfer to adult CHD [7, 8] care resulting in suboptimal treatment and outcomes [9]. The AHA 2011 Guidelines [10] state formal transition programs should be age and developmentally appropriate; however, transition research has

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focused on transition readiness in older adolescents and adults [8, 9, 11–14]. There is limited research regarding younger adolescents (12–15 years) and how transition programs can target their unique transition needs. The objectives of this study were to evaluate transition readiness, medical condition knowledge, self-efficacy, and illness uncertainty among patients with CHD aged 12 to 15 years, and to identify socio-demographic, medical, patient, and parental factors associated with transition readiness.

Methods

Participants

Patients at a tertiary pediatric hospital were screened by electronic chart review for study eligibility. A total of 543 patients met the following study inclusion criteria: aged 12–15 years and moderate or complex CHD [15]. Patients with heart transplant, significant cognitive impairment, and/or language barriers requiring an interpreter were excluded. Patients and their parents were required to complete the study surveys in order to be included in the final analysis.

Procedure

This was a quantitative, cross-sectional study approved by the Institutional Research Ethics Board. Over a 12-month period, invitation letters with randomly assigned identification numbers were mailed from the patient's responsible cardiologist to the parents of eligible patients. The letter invited both parents and patients to participate in the study. Interested families were asked to contact the study team via e-mail, referencing their identification number. Once their interest was acknowledged, an e-mail was sent to parents with a unique link which redirected parents to Research Electronic Data Capture (REDCap), a secure, web-based application for data collection and management [16], where consent was provided and study eligibility was confirmed; this followed with sequential links to complete parent questionnaires, patient consent, and patient questionnaires. Informed consent was obtained from all individual participants included in the study, by means of completion of the online or paper-based consent form. Alternatively, if interested families were eligible but did not want to complete the study online, they had the option to consent and to complete the study questionnaires either by mail, or in-person at the hospital during a routine clinic visit.

Study Measures

Parents completed a demographics questionnaire and responded to the following two questions regarding discussions of transfer of care: (1) Has anyone on the health care team discussed moving to adult health care with you when your child is 18 years old? (2) Have you discussed moving to adult health care with your child when they are 18 years old? Patients were asked to similar questions: (1) Has anyone on the health care team discussed moving to adult health care with you when you are 18 years old? (2) Has your parent discussed moving to adult health care with you when you are 18 years old? The questions were designed based on a mandatory age of transfer of 18 years old at the study's institution. The validated questionnaires described below were also administered.

Transition Readiness

Patients completed the Transition Readiness Assessment Questionnaire (TRAQ), a validated tool developed and evaluated in the USA [17] that measures transition readiness of youth with chronic conditions under two domains: (1) self-advocacy (e.g., communication and use of resources within the community and school), and (2) chronic disease self-management (e.g., scheduling medical appointments, asking questions of health care providers, filling prescriptions) [17]. The TRAQ was validated in youth with chronic health conditions, who had a mean self-management score of 3.01 ± 1.02 and mean self-advocacy score of 3.67 ± 0.77 [17]. The TRAQ has previously been used to assess pediatric patients with CHD, where 15–17 year olds previously scored 2.95 ± 0.98 in the self-management domain, and 3.92 ± 0.67 in the self-advocacy domain [7, 14]. The TRAQ consists of 29 questions scored on a 5-point Likert scale, ranging from 1 ('no, I do not know how') to 5 ('yes, I always do this when I need to'), with an option to select 'not needed for my care.' A total score and two domain scores (self-advocacy and self-management) were calculated for each participant. Scores range from 1 (i.e., lowest transition readiness and an inability to perform tasks deemed important for transition) and 5 (i.e., highest transition readiness and ability to perform independent transition tasks).

Medical Condition Knowledge

Patient knowledge regarding their heart condition was assessed using the MyHeart scale, a scale previously piloted to confirm face and content validity, and utilized in a study to measure knowledge of heart condition in patients with congenital heart disease aged 15–17 years by Mackie et al. [14]. This tool consists of seven combined multiple-choice

and written answer questions [14]. Accuracy of patient knowledge was determined using information abstracted from the patient's medical record. The score is presented as a percentage correct, where 0% represents no or incorrect knowledge of their own illness, while 100% represents the patient answering all questions correctly regarding their health condition. Parent knowledge of their child's heart condition was evaluated by adapting MyHeart items (e.g., "What is the name of your child's heart defect/condition?").

Illness Uncertainty

Patients completed the children's uncertainty in illness scale (CUIS), a 16 multiple-choice self-report measure [18, 19]. Illness uncertainty can be defined as the "cognitive experience elicited in situations in which the meaning of illness-related events is unclear and outcomes are unpredictable" [20]. Item responses are chosen from a 5-point Likert scale ranging from 1 (very true) to 5 (very false) and summed to produce a total score ranging from 16 to 80. Higher scores reflect higher levels of illness uncertainty (i.e., lower confidence in regard to their illness course and understanding of their disease).

Self-efficacy

Patients also completed the general self-efficacy scale (GSE) [21], which is a validated measure assessing one's "belief that one can perform a novel or difficult task, or cope with adversity." The scale includes ten questions, measured on a 4-point Likert scale ranging from 1 (not true at all) to 4 (exactly true), which are then summed and divided by the number of answered questions to produce a mean item score. Higher scores reflect higher self-efficacy.

Statistical Analysis

Data are described as means with standard deviations, or medians with inter-quartile range and frequencies as appropriate. Associations between continuous patient characteristics and scores were assessed in linear regression models and/or with Pearson correlations; results are reported as parameter estimates with 95% confidence intervals or correlation coefficients. Associations with binary outcomes were assessed using logistic regression models. Results for these analyses are reported as odds ratio with 95% confidence interval. Because of the limited sample size, we treated ordinal level variables as continuous. All statistical analyses were performed using SAS v9.4 (SAS Institute, Cary, NC).

Results

Participants

Of the 543 patients who met inclusion criteria from a chart review and were invited to participate, 100 patients responded to the study invitation, for a response rate of 18%. Of these, 82 participants and their respective parents were included in the study data, for a completion rate of 15%. We excluded 18 participants who responded because of failure to complete both parent and participant surveys or an inclusion criteria was not met. Patient socio-demographics and medical history are summarized in Table 1. The mean age of patients was 13.6 ± 1.3 years and 36 (44%) patients were male. Cardiac interventions were performed on 72 (88%) patients, with 83% of these patients undergoing a primary repair with an interventional catheterization, surgery, or both. Only 11 (13%) patients were taking cardiac medications at the time of assessment.

Survey Responses

With regard to communication about transfer (i.e., eventual movement to adult care at 18 years), 20 patients (24%) recalled discussing this with a health care provider and 34 (41%) recalled discussing this with a parent. Similarly, 33 (40%) parents recalled discussing transfer with their child. Twenty-three parents (28%) recalled discussing transfer to adult care with their child's health care provider. Older patients were more likely to have discussed transfer with their health care team [odds ratio (OR) 1.838, 95%CI +1.184, +2.854, $p=0.007$] and their parent (OR +1.564, 95%CI +1.070, +2.288, $p=0.02$).

The mean total TRAQ score was 2.91 ± 0.82 and patients scored higher in the self-advocacy skills domain (3.41 ± 0.81) than the chronic disease self-management skills domain (1.95 ± 0.91) (Fig. 1). For all three TRAQ scores, there was a significant increase in scores with increasing patient age (Fig. 1). The mean patient MyHeart knowledge score was $71 \pm 20\%$, and scores were higher across increasing age (EST: +0.030, 95%CI -0.004, +0.063, $p=0.08$). The mean parent MyHeart knowledge score was $87 \pm 12\%$, and this was unrelated to their child's age ($p=0.33$). There was a positive association between patient and parental knowledge as measured by the MyHeart scale ($p<0.001$, $r=0.42$) (Fig. 2). The mean CUIS score for illness uncertainty was 32.9 ± 8.5 and the mean GSE score for self-efficacy was 3.0 ± 0.6 . Neither CUIS ($p=0.92$) nor GSE scores ($p=0.84$) were associated with patient age.

Table 1 Patient characteristics

Characteristic	n (% of total)
Gender (male)	36 (44%)
Age (mean ± SD)	13.6 ± 1.3
Age at assessment	
12 years	22 (27%)
13 years	13 (16%)
14 years	25 (30%)
15 years	22 (27%)
Primary diagnosis	
Septal defects (ASD ^a /VSD ^b /AVSD ^c)	24 (29%)
Right heart lesions (Ebstein’s anomaly/PAIVS ^d / PAVSD ^e /TOF ^f)	21 (26%)
Aortic defects (Coarctation ^g /truncus arteriosus)	13 (16%)
TGA ^h /DORV ⁱ	12 (15%)
Left heart lesions (HLHS ^j /aortic valve)	7 (9%)
Other	5 (6%)
Primary repair	67 (83%)
Any cardiac intervention	72 (88%)
Surgery	60 (73%)
Catheterization	48 (59%)
Cardiac medications	11 (13%)
Maximum parental education	
High school graduate	5 (6%)
Some college/university credit	18 (22%)
Trade/technical/vocational training	9 (11%)
Associate degree	3 (4%)
Bachelor’s degree	28 (34%)
Masters, PhD, or professional degree	19 (23%)
Household income	
\$0–\$19,000	2 (3%)
\$20,000–\$39,000	5 (6%)
\$40,000–\$59,000	9 (12%)
\$60,000–\$79,000	10 (13%)
\$80,000–\$99,000	12 (15%)
\$100,000–\$119,000	14 (18%)
\$120,000–\$139,000	11 (14%)
More than \$140,000	15 (19%)

Denominators were not always 82, given information was not always available

^aAtrial septal defect (patients recommended to transfer)

^bVentricular septal defect

^cAtrioventricular septal defect

^dPulmonary atresia with intact ventricular septum

^ePulmonary atresia and ventricular septal defect

^fTetralogy of Fallot

^gCoarctation of aorta

^hTransposition of the great arteries

ⁱDouble outlet right ventricle

^jHypoplastic left heart syndrome

Factors Correlated with Transition Readiness

Significant correlations were found between socio-demographic, medical, patient, and parental factors with patients’ transition readiness scores (TRAQ total score) (Table 2). The data are presented as an estimate in the amount of change and direction of the TRAQ score associated with a change in units of the predictor variable. An increase in TRAQ total score was significantly correlated with age (EST: +0.17, 95%CI +0.03, +0.31, *p*=0.02) (Fig. 1), patient medical condition knowledge (EST +0.91, 95%CI +0.04, +1.79, *p*=0.04), and patient’s self-efficacy (EST: +0.54, 95%CI +0.26, +0.83, *p*<0.001). There was no significant difference in TRAQ total score according to CHD diagnosis category (Table 1), parents’ education or income level or the patient’s level of illness uncertainty.

Certain factors had a significant correlation with an increase specifically in the TRAQ self-management scores (Table 2). These included age (EST: +0.25, 95%CI +0.10, +0.40, *p*<0.001) (Fig. 1) and history of primary repair (by surgery and/or interventional catheterization) (EST: +0.52, 95%CI +−0.01, +1.03, *p*=0.05). TRAQ self-management scores were higher when parents recalled speaking to their child about transfer (EST: +0.50, 95%CI +0.07, +0.93, *p*=0.02), and when parents recalled a health care team member speaking to them about transfer (EST: +0.68, 95%CI +0.31, +1.05, *p*<0.001). Self-management scores were higher when the patient recalled their parent speaking to them about transfer (EST: +0.38, 95%CI −0.01, +0.78, *p*=0.06), and when the patient recalled their health care team speaking to them about transfer (EST: +0.38, 95%CI: −0.08, +0.84, *p*=0.11). Male gender was associated with a decrease in TRAQ self-management scores (EST: −0.40, 95%CI −0.79, −0.01, *p*=0.05).

Associations found with TRAQ self-advocacy domain can be found in Table 2; these included age (EST: +0.16, 95%CI +0.02, +0.29, *p*=0.03) (Fig. 1), patient medical condition knowledge (EST: +0.91, 95%CI +0.03, +1.78, *p*=0.04), and patient self-efficacy (EST: +0.65, 95%CI +0.38, +0.93, *p*<0.001). These factors were also found to have a significant association with TRAQ total scores (Table 2). A decrease in TRAQ self-advocacy scores was significantly associated with patients who were currently taking cardiac medications (EST: −0.52, 95%CI −1.02, −0.01, *p*=0.04).

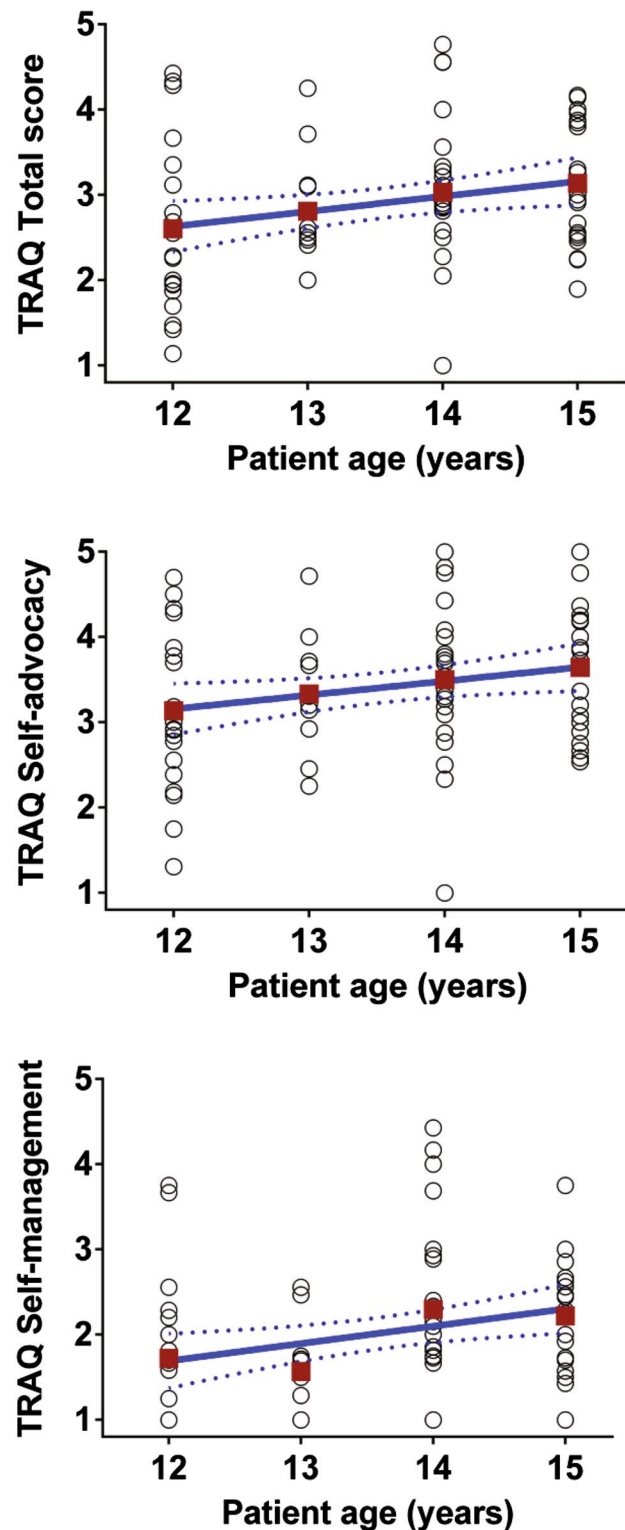
Discussion

The first objective of this study was to determine the transition readiness of young CHD adolescents. We noted that, despite current recommendations [10] for transition, health care providers and parents have not regularly

Fig. 1 Increasing age was significantly associated with increasing transition readiness scores for TRAQ total score, self-advocacy, and self-management domains. Total TRAQ score was estimated to increase by 0.17 TRAQ score points for each increasing year of age (EST: +0.17, 95%CI +0.03, +0.31, $p=0.02$). Self-advocacy TRAQ score was estimated to increase by 0.16 TRAQ score points for each year increase (EST: +0.16, 95%CI +0.02, +0.29, $p=0.03$). Self-management TRAQ score was estimated to increase by 0.25 TRAQ score points for each year increase (EST: +0.25, 95%CI +0.10, +0.40, $p=0.001$). Young adolescents scored higher in self-advocacy skills domain (mean: 3.41 ± 0.81) than the chronic disease self-management domain (mean: 1.95 ± 0.91)

discussed health care transfer with young adolescents (ages 12–15 years). Young CHD adolescents have better self-advocacy skills compared to their chronic disease self-management skills. The second objective determined numerous factors which showed correlations with the transition readiness of young CHD adolescents. Higher transition readiness was correlated with increasing age, and better medical condition knowledge. No significant association was noted with disease severity or uncertainty of medical condition. Lower transition readiness was noted for young adolescent males, and those continuing to take cardiac medications. This study highlights the potential important role of parents in transition, as demonstrated with the association between parental medical condition knowledge and patient knowledge, and also higher transition readiness scores in patient–parent dyads that had previously discussed the idea of transfer of medical care at age 18 years.

Young adolescents' TRAQ scores show similar trends to TRAQ results of older patients with CHD [14]; older adolescents ages 15 to 17 years also had higher mean TRAQ self-advocacy scores (3.92 ± 0.67) versus self-management scores (2.95 ± 0.98), as well as young adults ages 18 to 25 years (mean TRAQ self-advocacy: 4.3 ± 0.6 – 0.7 , mean TRAQ self-management: 4.0 ± 0.8) [13]. The TRAQ scores noted in older patients are higher than the scores of young adolescents [13, 14], reflecting the association with age identified in our study. Young adolescents who were more knowledgeable about their heart condition and who had higher levels of self-efficacy were found to have higher transition readiness scores, a common finding among older adolescents with CHD [6, 22]. While young adolescents report higher self-advocacy skills, their low self-management skills suggest that they are less 'ready' to accept responsibility for the management of their condition, a skill that is crucial in adulthood [13]. Previous reports on transition have shown that education and preparation is a process and that adolescents must assume responsibility for their health for the successful transfer to adult CHD care [11, 23, 24]. While many young people have a poor, but basic understanding of their heart condition [6, 25], educational interventions with older adolescents have been shown to



improve readiness [14], leading to positive effects on both cardiac knowledge and transition preparedness.

Young adolescents' type of CHD diagnosis was not significantly associated with patients' readiness for transition, a finding consistent with the literature [9, 12, 13]. While

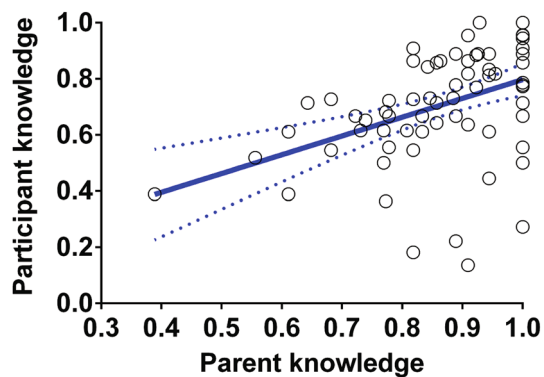


Fig. 2 The level of parent’s knowledge of their child’s heart condition had a positive association to patient’s knowledge of their own heart condition, as determined by the MyHeart scale. ($r=0.42$, $p<0.001$)

CHD type and severity may not determine whether adolescents successfully transition to adult CHD care [12], young adolescents with no prior history of primary cardiac repair, either by interventional catheterization or surgical intervention, had lower transition readiness scores compared to those with a history of definitive repair. A similar report found that older adolescents who had no prior history of heart surgery, cardiac-related hospitalization, or cardiac-related hospitalization without a procedure, had an absence of cardiology follow-up in adulthood [7, 8]. Young adults need to understand that despite the absence of symptoms, life-long follow-up may be required [26]. In addition, this study demonstrated that a patient’s lack of cardiac knowledge and self-management skills may result in loss to follow-up. Transition programs need not be disease specific, as no association was found between specific CHD diagnosis and transition readiness in young adolescents, but rather patient and family focused with an emphasis on education and preparation for self-managed care to guide successful transfer. There are conflicting reports in the literature as to whether gender influences transition readiness among CHD adolescents [7–9, 12]. In this study, young adolescent boys had lower scores in transition readiness self-management skills compared to adolescent girls. Females with special health care needs in general were found to have higher self-advocacy scores compared to males [17]. Male gender has been linked to unsuccessful transition in younger adolescents with CHD [7, 8], while successful transition among older adolescents (18–25 years) was not affected [12, 13]. Gender differences have been found to diminish around the age of transfer to adult care [9, 12], suggesting that transition readiness may be related to gender differences in developmental maturity during puberty.

Parental and familial involvement is an integral part of successful transition [26, 27], and parents who instill feelings of safety and act as resources for their child during the

transition process enable positive outcomes for transfer to adult CHD care [11, 28]. Yet, some adolescent reports of overprotective parents [13], and parents who take responsibility for all or most of their child’s care activities [6], appear to impede a child’s ability to develop independence and self-management skills. While socio-demographic characteristics of parents were not associated with transition readiness of their children [12], greater medical condition knowledge [22] and discussion of health care transfer between parent and child were among the factors that were associated with increased medical knowledge and transition readiness of adolescents. Therefore, parents can play an important role in helping their children with transition. However, young adolescents requiring continued drug therapy for their cardiac condition showed lower levels of transition readiness. A previous study found that 45% of parents administered their child’s medication [6]. Parental support is important for child development and transition preparation of young adolescents, but young adolescents must actively participate in their own care while gaining their independence. Transition preparation must include both parent and patient [29]. Although CHD adolescents demonstrate the ability to function independently, they may lack the specific skills to manage the complex medical needs associated with their condition, jeopardizing their independence. Health care providers should involve the entire family during the transition process to ensure that support and management of care is appropriately allocated among family members.

Limitations

The cross-sectional design limited data collection to one time-point, and so it is not clear how transition readiness evolves during adolescent development up until the time of transition. The population sample was limited to one tertiary pediatric center, and therefore may limit the generalizability of this study, further study would involve patients from multiple centers. Young adolescents’ varying developmental stages may impact their level of knowledge and responsibility. The TRAQ has not been validated for adolescents younger than 16 years of age [17] and requires further validation to support these findings. While parents were included in this study, further research is needed to determine the role of parents in transition preparation and the associated needs of the adolescents and their parents [30]. The MyHeart questionnaire has previously been piloted for adolescents [14], but the adapted parental form used in this study has not previously been assessed. Long-term follow-up of adolescents from an early age is warranted to determine how transition readiness relates to successful transition for ACHD care.

Table 2 Transition readiness (TRAQ) scores associations with patient characteristics

Factors associated with...	Total TRAQ score	Self-management domain	Self-advocacy domain
Age (increasing per 1 year)	EST: +0.17	EST: +0.25	EST: +0.16
	LCL: +0.03	LCL: +0.10	LCL: +0.02
	UCL: +0.31	UCL: +0.40	UCL: +0.29
	<i>p</i> =0.02	<i>p</i> =0.001	<i>p</i> =0.03
Male gender	EST: −0.11	EST: −0.40	EST: −0.08
	LCL: −0.47	LCL: −0.79	LCL: −0.44
	UCL: +0.25	UCL: −0.01	UCL: +0.27
	<i>p</i> =0.55	<i>p</i> =0.05	<i>p</i> =0.65
Household income (per category)	EST: 0.02	EST: −0.02	EST: +0.03
	LCL: −0.07	LCL: −0.12	LCL: −0.07
	UCL: +0.77	UCL: +0.09	UCL: +0.12
	<i>p</i> =0.65	<i>p</i> =0.55	<i>p</i> =0.56
Combined parent education (per category)	EST: +0.02	EST: +0.02	EST: +0.03
	LCL: −0.04	LCL: −0.04	LCL: −0.03
	UCL: +0.07	UCL: +0.08	UCL: +0.08
	<i>p</i> =0.53	<i>p</i> =0.77	<i>p</i> =0.33
Highest parental education level (per category)	EST: +0.04	EST: +0.008	EST: +0.07
	LCL: −0.07	LCL: −0.11	LCL: −0.04
	UCL: +0.15	UCL: +0.13	UCL: +0.17
	<i>p</i> =0.48	<i>p</i> =0.89	<i>p</i> =0.22
Primary defect repair by surgery or catheterization	EST: +0.39	EST: +0.52	EST: +0.40
	LCL: −0.07	LCL: +0.01	LCL: −0.06
	UCL: +0.85	UCL: +1.03	UCL: +0.86
	<i>p</i> =0.09	<i>p</i> =0.05	<i>p</i> =0.09
Any cardiac medications at time of study	EST: −0.41	EST: +0.27	EST: −0.52
	LCL: −0.92	LCL: −0.30	LCL: −1.02
	UCL: +0.10	UCL: +0.85	UCL: −0.01
	<i>p</i> =0.11	<i>p</i> =0.35	<i>p</i> =0.04
Number of previous surgeries (increasing per 1 surgery)	EST: +0.001	EST: +0.15	EST: +0.01
	LCL: −0.19	LCL: −0.06	LCL: −0.18
	UCL: +0.19	UCL: +0.36	UCL: +0.20
	<i>p</i> =0.99	<i>p</i> =0.15	<i>p</i> =0.90
Medical condition knowledge (MyHeart) (per 0.1 point)	EST: +0.91	EST: +0.25	EST: +0.91
	LCL: +0.04	LCL: −0.76	LCL: +0.03
	UCL: +1.79	UCL: +1.27	UCL: +1.78
	<i>p</i> =0.04	<i>p</i> =0.63	<i>p</i> =0.04
Self-efficacy (GSE) (per 1 unit)	EST: +0.54	EST: +0.16	EST: +0.65
	LCL: +0.26	LCL: −0.19	LCL: +0.38
	UCL: +0.83	UCL: +0.50	UCL: +0.93
	<i>p</i> <0.001	<i>p</i> =0.38	<i>p</i> <0.001
Illness uncertainty (CUIS) (per 5 units)	EST: −0.07	EST: +0.01	EST: −0.06
	LCL: −0.18	LCL: −0.11	LCL: −0.16
	UCL: +0.03	UCL: +0.13	UCL: +0.04
	<i>p</i> =0.17	<i>p</i> =0.82	<i>p</i> =0.26
Patient recalled parent spoke to them about transfer	EST: +0.30	EST: +0.38	EST: +0.21
	LCL: −0.06	LCL: −0.01	LCL: −0.15
	UCL: +0.65	UCL: +0.78	UCL: +0.56
	<i>p</i> =0.10	<i>p</i> =0.06	<i>p</i> =0.26

Table 2 (continued)

Factors associated with...	Total TRAQ score	Self-management domain	Self-advocacy domain
Patient recalled health care team spoke to them about transfer	EST: +0.34 LCL: -0.06 UCL: +0.74 <i>p</i> =0.10	EST: +0.38 LCL: -0.08 UCL: +0.84 <i>p</i> =0.11	EST: +0.36 LCL: -0.04 UCL: +0.76 <i>p</i> =0.08
Parent medical condition knowledge (MyHeart) (per 0.1 point)	EST: -0.74 LCL: -2.15 UCL: +0.68 <i>p</i> =0.31	EST: -0.93 LCL: -2.69 UCL: +0.84 <i>p</i> =0.30	EST: -0.25 LCL: -1.67 + 1.17 <i>p</i> =0.73
Parent recalled speaking to patient about transfer	EST: +0.28 LCL: -0.11 UCL: +0.66 <i>p</i> =0.16	EST: +0.68 LCL: +0.31 UCL: +1.05 <i>p</i> <0.001	EST: +0.20 LCL: -0.15 UCL: +0.56 <i>p</i> =0.26
Parent recalled health care team spoke to them about transfer	EST: +0.32 LCL: -0.03 UCL: +0.68 <i>p</i> =0.07	EST: +0.50 LCL: +0.07 UCL: +0.93 <i>p</i> =0.02	EST: +0.25 LCL: -0.14 UCL: +0.64 <i>p</i> =0.20

Variables are binary unless otherwise indicated

Conclusion

It is important for pediatric health care providers to provide resources and accessible programs that prepare and support young CHD adolescents and their families for transition. The results of this study provide important findings to add to our current understanding of the transition readiness of young CHD adolescents. Specifically, this study identified the correlation between a patient’s medical condition knowledge and better transition readiness. As well, this study identified an important role for parental involvement, where transition readiness and self-management skills were correlated to be better with parent knowledge and involvement. Based on the results of this study, transition programs for young adolescents should focus on medical condition education of the patient and their families, providing training for patients to develop chronic disease self-management skills, and incorporate parental involvement.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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