Transition Readiness in Adolescents and Young Adults with Heart Disease: Can We Improve Quality of Life?

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Objectives We previously reported common knowledge deficits and lack of transition readiness in 13- 25-year-olds with congenital or acquired heart disease. The aims of this study were to re-evaluate transition readiness in this cohort at follow-up and to examine the relationship between changes in transition readiness and quality of life (QOL).

Study design In this prospective cohort study, patients completed the Transition Readiness Assessment and the Pediatric Quality of Life Inventory using an e-tablet, web-based format at a routine follow-up visit. Changes from initial to follow-up scores were evaluated.

Results Sixty-five percent of patients (106 of 164) completed follow-up assessments at a median age of 18.7 years (IQR, 16.5-21.2 years) at a median follow-up of 1 year. The average perceived knowledge deficit score (percent of items with no knowledge) at follow-up was 18.0 ± 15.2%, which decreased from 24.7 ± 16.5% ($P < .0001$). On a 100-point scale, the mean score for self-efficacy increased from 71.4 ± 17.0 to 76.7 ± 18.2 ($P = .0004$) and for self-management increased from 47.9 ± 18.4 to 52.0 ± 20.7 ($P = .004$). Although physical QOL did not change, the mean psychosocial QOL score increased significantly ($P = .02$). A decrease in the knowledge deficit score at follow-up was significantly associated with an increased psychosocial QOL score ($P = .03$). An increase in the self-efficacy score was associated with an increase in psychosocial QOL score ($P = .04$), especially social QOL ($P = .02$).

Conclusions Although deficits in knowledge and self-management skills persist, transition readiness assessment and recognition of deficits can improve transition readiness with improved psychosocial QOL. *(J Pediatr 2019;212:73-8)*.

The number of adults with congenital heart disease (CHD) in the US is increasing exponentially and now exceeds 1.5 million.[1] Children and adults with CHD are at increased risk for impaired psychosocial adjustment and quality of life (QOL).[2,3] Lapse of medical care is common in adults with CHD, as high as 50%-70%, and is associated with adverse outcomes, including significant morbidity and potential mortality, and likely contributes to significantly impaired QOL.[4,5] In a review by Moceri et al, they concluded that the quality of a formal transition process during adolescence will determine future outcomes in patients with CHD, including the quality of future medical follow-up and potential psychosocial outcomes in adult life.[6]

Transition has been defined as the process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood to maximize lifelong functioning and potential.[7,8] Knowledge and understanding of their CHD and its lifestyle implications, an important component of transition preparation, may influence QOL outcomes including psychosocial QOL,[9,10] which is often unrelated to the severity of disease.[11,12] We previously reported that transition knowledge deficits are common in adolescents and young adults with heart disease and are associated with decreased self-efficacy and self-management behaviors.[9] Other investigators have also identified important knowledge gaps in the population with CHD, including an understanding of the reasons for follow-up, symptoms that reflect deterioration of their heart disease, the effects of competitive sports, appropriate contraceptive methods, and the risks of pregnancy.[13,14] Furthermore, Thomet et al found that self-efficacy was an important predictor of patient-reported outcomes in adults with CHD, including their QOL and symptoms of anxiety and depression.[15] The aims of this study were to evaluate changes in transition readiness (knowledge deficits, perceived self-efficacy, self-management behaviors) over time in the original cohort and to examine the relationship between changes in transition readiness and QOL outcomes at follow-up.

QOL	Quality of life
CHD	Congenital heart disease
PedsQL	Pediatric Quality of Life Inventory

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Methods

As previously reported, a convenience sample of adolescents and young adults, aged 13-25 years, and parents of children aged 13-18 years were recruited from the University of Michigan Congenital Heart Center. The study was approved by the institutional review board and informed consent was obtained from study participants. Eligible patients had a previous diagnosis of CHD or heart transplantation. Patients with significant neurocognitive impairment that precluded their ability to complete the survey or those being evaluated for an acute problem were excluded. The initial consent rate was 91%. Follow-up surveys were completed by 106 patients, approximately two-thirds (65%) of the initial cohort.

Consenting patients completed the CHD Transition Readiness Assessment and Pediatric Quality of Life Inventory (PedsQL)[16] using an e-tablet, web-based format while waiting to see their cardiologist at the time of a routine scheduled clinic visit and again at a routine follow-up visit. Parents of patients less than 18 years of age also independently completed the CHD Transition Readiness Assessment reporting their perceptions of their child's transition readiness (knowledge and behaviors) on a parallel version of the measure. The PedsQL[16] was also administered via the e-tablet to assess parental perceptions of the adolescent subject's QOL. After completion of the questionnaires, subjects (and parents) were given a request for information checklist (a paper form) to indicate their interest in receiving information as well as receipt of information at or since the prior visit. The request for information checklist was then made available to the clinician. In response, verbal with or without written information could be provided by the cardiologist, nurse practitioner, social worker, or a referral made to other resources (adult CHD clinic, high-risk obstetrics/gynecology clinic, community health, iHeartChange website, other).

The Transition Readiness Assessment was developed specifically for youth and emerging adults with CHD and includes items most relevant for this patient population. Domains include perceived knowledge, self-efficacy, and self-management behaviors by patient self-report as well as a parent proxy report in patients <18 years of age. As previously reported, the initial psychometric evaluation demonstrated acceptable internal consistency reliability, construct validity, and responsiveness reflected in changes in scores over time with receipt of information.[9,17] Perceived knowledge deficit is scored as a percentage of knowledge deficits identified, ie, the proportion of items where patients responded they did not know or were unsure of the information queried. The reliability of responses was previously evaluated by queries of actual knowledge and found to be acceptable at 86%-90%, lowest related to exercise recommendations. A 5-point Likert scale is used to score self-management ranging from never to almost always (eg, How often did you take your medicines on your own?) and to score self-efficacy ranging from very hard to very easy (eg, How easy or hard is it for you to take your medicines without being reminded?). Self-management and self-efficacy questionnaire items are shown in **Table I**. Because the number of items may vary (not all patients are on medications), the total score is divided by the number of items. Scores are linearly transformed to a 0- to 100-point scale with higher scores indicating greater self-management and self-efficacy.

The request for information checklist inquires about the patient/parent's interest in information on any of 13 topics addressed in the transition readiness assessment. Both the information requested and information received (by patient report) were compared with the information deficits identified in the transition readiness assessment. It is recognized that information may be sought from other resources, especially for younger patients, who may prefer to seek information from their parents. Furthermore, response to information requests may have prompted referral to the adult CHD clinic or other resources, rather than education and counseling at the time of the visit.

Table I. Self-management and self-efficacy assessment*

Self-management
1. How often did you understand what your doctor told you?
2. How often did you use the Internet, books, or other guides to find out more about your heart?
3. How often did you take your medicines on your own?
4. How often did you ask your doctor or nurse questions about your heart, medicines, or medical care?
5. How often did you make your own appointments?
6. How often did you need someone to remind you to take your medicines?
7. How often did you forget to take your medicines?
8. How often did you use things like pillboxes, schedules, or alarms to help remind you to take your medicine?
Self-efficacy
1. How easy or hard is it for you to talk to others (friends, family, etc) about your condition?
2. How easy or hard is it for you to talk to your doctor or nurse?
3. How easy or hard is it for you to make a plan with your doctor to care for your health?
4. How easy or hard is it for you to call your doctor/nurse when you have a new problem or question?
5. How easy or hard is it for you to see your doctor by yourself?
6. How easy or hard is it for you to take your medicines without being reminded?
7. How easy or hard is it for you to take care of yourself?

*A 5-point Likert scale is used to score self-management ranging from never to almost always and to score self-efficacy ranging from very hard to very easy.

The 23-item PedsQL 4.0 generic core scales encompassing physical functioning, emotional functioning, social functioning, and school/work functioning was administered to measure physical and psychosocial QOL.[16] The PedsQL scales are composed of parallel child self-report and parent proxy report formats. Items are reverse scored and linearly transformed to a scale of 0-100, so that higher scores indicate better QOL. To create a psychosocial health summary score, the mean is computed as the sum of the items divided by the number of items in the emotional, social, and school/work functioning scales. The reliability and validity of the PedsQL generic core scales has been demonstrated in healthy and patient populations including the population with CHD.[3,16]

Data are reported as frequency (%) for categorical variables and mean ± SD or median with IQR or a full range, as appropriate, for continuous variables. Patient characteristics at the initial visit were compared between patients who completed the follow-up surveys vs those who did not, using the χ^2 test or Wilcoxon rank-sum test. Changes in transition readiness scores and PedsQL scale scores from initial to follow-up assessments were assessed by one sample *t* test and effect size (ie, change in the transition readiness score from the initial assessment to follow-up divided by the SD of the transition readiness score at the initial assessment). Transition readiness scores at the follow-up assessment were compared between patients who reported receipt of information on specific topics and those who did not receive information, using a 2-sample *t* test. In addition, patients lost to follow-up or having a gap in care for >2-3 years were compared with those with follow-up, in terms of initial transition readiness scores and patient characteristics, using the Fisher exact test, 2-sample *t* test, or Wilcoxon rank-sum test, as appropriate.

The Pearson correlation coefficient was used to examine the relationship between the change in each Transition Readiness score and PedsQL scores. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, North Carolina), with a statistical significance level of .05 using 2-sided tests.

Results

Follow-up transition readiness and PedsQL surveys were completed by 106 patients (65%) at a median age of 18.7 years (IQR, 16.5- 21.2 years). Follow-up assessments were not available for 38 patients (23%) who returned for follow-up early, 2 patients moved/changed practitioners (1%), 5 patients (3%) declined to participate, and 1 patient died. In addition, follow-up assessment was not available in 9 patients (5%) who had gaps of care >2-3 years, including 2 returning after presenting to the emergency department and 2 who remain lost to follow-up at 3 years after their initial assessment. Patient characteristics are described in **Table II**. The median duration of follow-up was 1 year (IQR, 0.98-1.11 years). Cardiac diagnoses ranged from mild to severe, with complex heart defects including single ventricle in approximately one-third of subjects. Patient characteristics were similar between patients who completed the follow-up surveys vs those who did not, with the exception that patients who completed the follow-up surveys were more likely to be taking medications at initial visit compared with those who did not have follow-up assessments (50% vs 23%; $P = .001$).

Table II. Patient and clinical characteristics in patients who had a follow-up assessment (N = 106)

Age at initial survey, years	17.7 (13.1-24.7)
<18	58 (54.7)
≥18	48 (45.3)
Female sex	37 (34.9)
Caucasian race	97 (91.5)
Taking any medication at initial survey	53 (50.0)
Diagnosis	
Single ventricle	22 (20.8)
Other complex	16 (15.1)
Transposition of the great arteries	8 (7.5)
Tetralogy of Fallot repair	13 (12.3)
Left heart surgery	19 (17.9)
Heart transplant	5 (4.7)
Other (ventricular septal defect, right heart lesions, aortic coarctation, etc)	23 (21.7)
Duration of follow-up, years	1.02 (0.50-2.07)

Data are presented as number (%) or median (range).

The average perceived knowledge deficit score (percent of items with no knowledge) at follow-up was 18.0 ± 15.2%, decreased from 24.7 ± 16.5% ($P < .0001$; **Table III**). Overall knowledge deficit scores most improved/decreased in patients with knowledge deficits who reported receipt of information regarding medications (13.9% vs 30.0%; $P = .002$), symptoms to call for (13.9% vs 27.1%; $P = .02$), and information on how to contact the heart doctor (14.2% vs 23.8%; $P = .02$). Female patients who received information regarding pregnancy also tended to have lower knowledge deficit scores (21.3% vs 32.9%; $P = .07$) at follow-up. Overall, 71% of patients requested information on the request for information checklist at follow-up. As reported at initial assessment,[9] information regarding pregnancy/contraception and symptoms for which to call remained common requests by 46% and 29%, respectively. Requests for health insurance increased slightly from 25% at initial assessment to 31% of respondents at follow-up, which might be expected with increasing age. Of interest, 22 patients (21%) requested information on stress management at follow-up. The reported receipt of information varied by type of information ranging from 69% to 31% and was lowest for pregnancy/contraceptive information.

With respect to self-efficacy, the mean score at follow-up increased from 71.4 ± 17.0 to 76.7 ± 18.2 ($P = .0004$) and for self-management increased from 47.9 ± 18.4 to 52.0 ± 20.7 ($P = .0004$). Perceived self-efficacy scores improved with receipt of information related to how to contact the heart doctor (76.4 vs 66.1; $P = .05$) and how to communicate with the healthcare team (78.7 vs 68.2; $P = .046$). Overall, even though self-management scores

Table III. Change in transition readiness scores from initial assessment to follow-up assessment

Transition readiness scores	n	Initial	Follow-up	Change	*P* value*	Effect size†
Perceived knowledge deficit score, %	106	24.7 ± 16.5	18.0 ± 15.2	−6.8 ± 11.6	<.0001	0.41
Using the 12 core‡ items	106	21.9 ± 15.2	14.5 ± 12.7	−7.4 ± 12.0	<.0001	0.49
Self-management score	105	51.9 ± 18.0	56.0 ± 19.0	4.1 ± 12.1	.001	0.23
Using the 4 core‡ items	105	47.9 ± 18.4	52.0 ± 20.7	4.0 ± 14.2	.004	0.22
Self-efficacy score	105	71.7 ± 16.2	76.4 ± 17.9	4.7 ± 13.3	.0004	0.29
Using the 6 core‡ items	105	71.4 ± 17.0	76.7 ± 18.2	5.3 ± 14.7	.0004	0.31

Data are presented as mean ± SD.
*P-value from one sample *t* test.
†Effect size was calculated as change (Follow-up–Initial) divided by SD at initial. Effect sizes were designated as small (0.10-0.29), medium (0.30-0.49), and large (>0.50).
‡Core items exclude items related to medications and pregnancy, which were not applicable for all patients.

improved, the effect size was small, and scores remained low and were not associated with receipt of specific information.

There were no significant differences in change in transition readiness scores between adolescents <18 years old and young adults ≥18 years (data not shown). There were also no significant differences in the initial baseline transition readiness scores for knowledge deficit, perceived self-efficacy, or self-management between patients with gaps in care or lost to follow-up (n = 9) and patients who were retained in follow-up. The mean self-management score at the initial assessment for patients lost to follow-up was only 42.7 ± 13.4 vs 50.1 ± 17.7 in the rest of the initial cohort. Patients lost to follow-up tended to be older (median age 21.0 years vs 17.9 years; $P = .05$).

Although there was no significant change in physical QOL at follow-up (from 82.0 ± 14.5 to 81.0 ± 16.0; $P = .30$), the mean psychosocial QOL score increased from 80.2 ± 13.3 to 82.5 ± 12.0 ($P = .02$). As shown in Table IV, a decrease in the knowledge deficit score at follow-up was significantly associated with an increased psychosocial QOL score ($P = .03$). An increase in the self-efficacy score was also associated with an increase in psychosocial QOL score ($P = .04$), especially social QOL ($P = .02$). There was no significant correlation between psychosocial functioning scores and self-management.

Table IV. Association between change in transition readiness scores and change in PedsQL score

Changes in PedsQL score	Change in perceived knowledge deficit		Change in self-management		Change in self-efficacy	
	r	*P* value	*r*	*P* value	*r*	*P* value
Total score	−0.16	.10	−0.13	.20	0.11	.27
Physical functioning score	−0.01	.92	−0.05	.62	−0.09	.38
Psychosocial summary Score	−0.21	**.03**	−0.12	.22	0.20	**.04**
Emotional functioning score	−0.20	**.04**	−0.13	.21	0.10	.31
Social functioning score	−0.08	.41	0.02	.88	0.23	**.02**
School functioning score	−0.16	.12	−0.11	.29	0.14	.16

Data are presented as Pearson correlation coefficient (*r*) and *P* value.
Bold indicates $P < .05$.

Discussion

In adolescents and young adults with heart disease, transition knowledge deficits are common and associated with decreased self-efficacy and self-management skills.[9] In this follow-up study, significant improvements in transition readiness, including knowledge of the heart condition and lifestyle implications, perceived self-efficacy, and self-management skills, were observed. Furthermore, improvements in knowledge and self-efficacy were modestly associated with improved psychosocial QOL. Adequate measurement of transition readiness is necessary to determine areas to target for intervention towards improving outcomes.[18] Consistent with our findings, Valente et al found an improvement in knowledge in older patients who were surveyed at their first presentation to an adult CHD clinic and after an educational intervention including completion of a personal health information "passport" and an introduction to web-based resources.[19] Specific knowledge improved in patients who requested additional information. QOL was not measured in that study, but the investigators suggest that knowledge related to topics such as exercise, symptoms of problems, birth control options, and pregnancy safety may be uniquely important to the QOL for an adult with CHD, consistent with our findings. Ronning et al reported insufficient knowledge was a barrier to taking a more active role in decisions about treatment and care.[20]

In addition to an improvement in knowledge, participants reassessed in our study also perceived greater self-efficacy, or confidence in their ability to care for themselves, at follow-up. Stewart et al reported that transition readiness was higher among patients with CHD who were more knowledgeable about their condition and had greater self-efficacy.[21] Consistent with our findings, Thomet et al found that self-efficacy was a predictor of patient-reported outcomes including QOL in adults with CHD.[15] Greater self-efficacy was also associated with less anxiety and depression. They found no association between self-efficacy and CHD complexity or between self-efficacy and health behaviors, in contrast with our earlier findings.[9]

With respect to self-management behaviors, although we observed an improvement at follow-up, potentially reflecting advancing age, self-management scores remained low and were not significantly associated with QOL at follow-up. It has been previously suggested that parental anxiety and overprotectiveness may result in parents' reluctance to shift greater responsibility for self-management to adolescents and emerging adults.[22,23] In the presence of parent management, the lack of self-management may not impact QOL. The quality of the parent–child relationship may be key to successful transition.[24,25] Parents need to be educated about their adolescent's needs, especially related to support of self-management behaviors.

Transition readiness assessment served as an intervention with respect to identifying patient-specific informational needs and prompting request for and receipt of information in many patients. It is recognized, however, that cognitive challenges in this patient population may influence the timing and content of transition preparation education. Furthermore, even though patients who requested and received information on how to communicate with the healthcare team perceived greater self-efficacy, many patients did not request or receive information and many do not favor face-to-face communication with clinicians. Because neurocognitive impairments, including information processing speed, memory, and attention deficits, are more common in adolescents and young adults with CHD,[26,27] these patients may benefit more from visual patient education material including web-based programs to enhance self-management than from verbal communication of information in the clinic setting. In addition, the transition to adulthood with CHD can be stressful and resources are needed to provide support from families, peers, and the community, all of which will influence successful transition to adulthood.

We were not able to identify differences in transition readiness between patients who were lost to follow-up and those who received follow-up. The number of patients lost to follow-up was relatively small and the follow-up duration fairly short. Mackie et al found that a history of ≥1 missed cardiology appointments predicted loss to follow-up for ≥3 years, as did a lack of awareness of the need for follow-up.[28] Given our extensive efforts to reconnect with patients who cancel or do not return for scheduled appointments, including attempts to contact the patient/parent, primary care physician, and involvement of our social worker, significant gaps in care and potential loss to follow-up in 5% of the cohort remains concerning and warrants further study. Schoormans et al identified psychological predictors of future healthcare use in adults with CHD and hypothesize that reducing the negative impact of CHD and informing patients about strategies to manage their CHD will modify their future healthcare use.[29] Well-informed patients are expected to recognize the importance of uninterrupted healthcare and, thus, problems can be detected and managed sooner, ultimately leading to improved overall physical and psychosocial functioning and QOL.

As a single-center study, a potential limitation of the study is a lack of broad geographic and racial diversity. Data regarding parental educational level and socioeconomic status were also not available. Information provided to patients was not documented consistently, was subject to patient recall, and may have been sought/received from other sources such as a parent, the Internet, or sources other than the cardiology healthcare provider. The neurocognitive functioning of patients was unknown. We did not collect data on parental attitudes and beliefs, parenting behaviors or social support which may significantly influence transition readiness as previously reported.[9]

Routine assessment of transition readiness with patient and provider recognition of transition knowledge and behavior deficits can prompt education and interventions to promote successful transition to adulthood and maximize psychosocial QOL. Future efforts are needed to involve parents in transition planning and to meet the neurodevelopmental needs of patients. Longitudinal studies are needed to evaluate the impact of transition readiness and interventions on outcomes in adults with CHD. ■

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