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Assessment of Transition Readiness in Adolescents and Young Adults with Heart Disease

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Objectives To evaluate transition readiness, including perceived knowledge deficits, self-efficacy, and self-management behaviors, in 13- to 25-year-olds with congenital heart disease or heart transplant and to examine the relationships between transition readiness assessment, information seeking behavior, and quality of life (QOL).

Study design In this cross-sectional study, patients (n = 164) completed the Transition Readiness Assessment and the Pediatric Quality of Life Inventory using an e-tablet, web-based format at a routine clinic visit.

Results Median patient age was 18.1 years (range 13.0-25.5). Average perceived knowledge deficit score (% of items with no knowledge) was 25.7% (range 0%-75%). On a 100-point scale, the mean score was 72.0 ± 17.2 for self-efficacy and 49.7 ± 17.5 for self-management. Knowledge deficits were negatively correlated with self-efficacy ($r = -0.45$, $P < .0001$) and self-management ($r = -0.36$, $P < .0001$). Overall, 66% of patients requested information (73% $\geq$ 18 years old). Higher psychosocial QOL scores were correlated with lower knowledge deficit scores ($r = -0.21$, $P = .01$) and higher perceived self-efficacy scores ($r = 0.41$, $P < .0001$).

Conclusions Transition knowledge deficits are common and associated with decreased self-efficacy and self-management skills in adolescents and young adults with heart disease. Greater transition knowledge and perceived self-efficacy are associated with better psychosocial QOL. Routine assessment of transition readiness is recommended to facilitate recognition of deficits and interventions to promote successful transition outcomes. *(J Pediatr 2015;167:1233-8)*.

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As a result of tremendous improvements in diagnosis and treatment of congenital heart disease (CHD), currently 85%-90% of children born with CHD survive to adulthood.[1] The estimated number of adults with CHD in the US now exceeds 1 million.[2] 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 quality of life (QOL).[3,4] Patients with lapses of care are more likely to require urgent cardiac intervention at presentation.[3] Gurvitz et al[5] found that the proportion of patients with CHD admitted through the emergency department nearly doubled surrounding the transition to adulthood, age >17 years. Even though the lack of insurance is a barrier to receiving ongoing care in some patients, a more common factor is a lack of knowledge regarding the importance of follow-up.[3,6] Among adolescents and young adults with CHD, significant gaps in knowledge of their disease, treatment, and preventive measures have been identified.[7,8]

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.[9] As stated in the American Academy of Pediatrics Policy statement, the goal of transition in healthcare is “to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.”[10] Given the heterogeneity of the population with CHD and the complexity of their medical conditions, as well as variation in cognitive, developmental, and psychosocial factors, an individualized CHD based model is proposed to guide transition assessment and counseling interventions. There is a critical need to evaluate transition readiness including identification of the specific needs of patients to better prepare them for transition to adulthood and self-management of their healthcare needs.[11] Currently, there are few formal transition programs for patients with CHD in the US, and no published metric for assessment of transition readiness in this patient population.

The aims of this study were to evaluate transition readiness (knowledge deficits, perceived self-efficacy, self-management behaviors) in patients 13-25 years of age with CHD or heart transplant, including the field-testing of a Transition

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

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Readiness Assessment measure administered by an e-tablet, to examine the relationship between assessment of transition readiness and information-seeking behavior, and to examine the relationship between transition readiness and perceived psychosocial QOL.

Methods

A convenience sample of adolescents and young adults, age 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 transplant. Patients with significant neurocognitive impairment that precluded their ability to complete the survey or those being evaluated for an acute problem were excluded.

Consenting patients completed the CHD Transition Readiness Assessment using an e-tablet, web-based format while waiting to see their cardiologist at the time of a routine scheduled clinic follow-up. This format was chosen to increase ease of use and acceptability in this patient population and allowed automatic downloading of the data using Qualtrics (Qualtrics, Provo, Utah). 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 Pediatric Quality of Life Inventory (PedsQL)[12] was also administered by the e-tablet to assess the subject's QOL by self-report and as perceived by their parents for adolescent patients. Following completion of the questionnaires, subjects (and parents) were given a "Request for Information" checklist (paper form) to indicate their interest in receiving information on topics that paralleled those queried in the assessment. This completed checklist was then made available to the clinician.

The initial development of the Transition Readiness Assessment was based on extensive review of the transition literature in adolescents and adults with chronic childhood conditions as well as specific literature related to knowledge gaps and problems in the adult CHD population. Experts in the field of transition were interviewed and existing transition assessments/checklists were reviewed. In addition, discussions with cardiology healthcare providers and feedback from patients with CHD formed the basis for the initial item generation. Identified domains or scales included perceived knowledge, self-efficacy, and self-management behaviors. Self-management behaviors, the patient's autonomy regarding taking medications, asking questions, making appointments, etc, are primarily related to a person's self-efficacy, a person's belief about his or her ability and capacity to accomplish a task or execute those behaviors. The University of North Carolina Self-management and Transition from Pediatric to Adult-Focused Health Care with Treatment (STARx) questionnaire[13] for patients with kidney disease included items related to self-efficacy and self-management, which were incorporated and/or modified for inclusion in the CHD Transition Readiness Scale with selected knowledge items modified from the University of North Carolina TR_xANSITION Scale.[14] The number of items in each scale varies, with more items if the subject is female (pregnancy and contraception) and/or is taking medications. For the perceived knowledge domain (16-28 items), respondents are asked if they have knowledge (eg, Do you know the name of your heart condition, what symptoms your doctor needs to know about). 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). In an effort to assess the reliability of their reporting, actual knowledge was queried on 4 selected items (diagnosis, medication, exercise, and need for follow-up) that was verified in the medical record if the respondent indicated that they knew the information. Overall, 86%-90% of items assessing actual knowledge were answered correctly, suggesting that patients' perceived knowledge is a fairly accurate reflection of their actual knowledge, with somewhat lower agreement related to appropriate exercise. 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?). As the number of items may vary, 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. Internal consistency reliability was acceptable with Cronbach alpha of 0.69 for self-management (with exclusion of 1 item) and 0.70 for self-efficacy. Instrument validity was supported by confirming the expected relationship between knowledge, self-efficacy, and self-management scores and age and severity of disease. Responsiveness was reflected in changes in scores over time with receipt of information.[15]

The Request for Information checklist was also developed for this study and inquires about the patient/parent's interest in information on any of 13 topics addressed in the Transition Readiness Assessment. The information requested was compared with the deficits identified in the Transition Readiness Assessment. It is recognized that information may be sought from other resources, especially in younger patients who may prefer to seek information from their parents.

The 23-item PedsQL 4.0 Generic Core Scales encompassing Physical Functioning, Emotional Functioning, Social Functioning, and School/Work Functioning was administered to measure psychosocial QOL.[12] The PedsQL scales are composed of parallel child self-report and parent proxy-report formats. Items are reverse-scored and linearly transformed to a 0-100 scale, 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