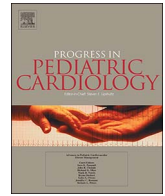




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## Review

## Young people with congenital heart disease — Transitioning to adult care

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## ABSTRACT

Congenital heart disease is the most common congenital anomaly and approximately 90% of those born with congenital heart disease today are likely to survive to adulthood. The majority require life-long specialist follow-up, requiring transition to adult-oriented services. The high frequency of patients lost to follow-up and with lapses in care is daunting and suggests that current transition preparation may be inadequate. In this review we define transition and the goals of transition and describe the concept of transition readiness. We identify barriers to effective transition, the key elements of preparation, and the importance of evaluating transition.

## 1. Introduction

The worldwide prevalence of congenital heart disease (CHD) is now estimated to be 1.35 million newborns with CHD every year [1]. With approximately 90% of children born with CHD expected to survive to adulthood, the number of adults with CHD is steadily increasing, representing an important global health issue [1,2]. While we celebrate improved survival through childhood and adolescence, the frequency of patients lost to follow-up and with lapses of medical care is daunting in adults with CHD, as high as 50% to 70%, and is associated with adverse outcomes including significant morbidity, potential mortality, and likely significantly impaired quality of life [3,4]. In survivors of tetralogy of Fallot repair, Wray and colleagues found that 24% of their patients were lost to follow-up and 48% of late deaths were in this group [5]. Disorders of psychosocial and cognitive development are key factors affecting the quality of life of individuals with CHD [6–8], and may be largely unrecognized in patients who are lost to follow-up.

Even among patients who eventually return to cardiac care, as reported by the Alliance for Adult Research in Congenital Cardiology (AARCC) with the Adult Congenital Heart Association (ACHA), 42% report a gap in care of > 3 years, 8% > 10 years [9]. The first lapse of care commonly occurred at age 19–20 years and, of great concern, the majority of subjects who reported gaps had moderate or severe complexity of CHD. In Canada, Reid and colleagues also found that one fifth of patients with complex CHD had not received any cardiology follow-up after their 18th birthday [10]. Furthermore, it is reported that the proportion of patients admitted via the Emergency Department nearly doubled surrounding the transition to adulthood [11].

Loss to follow-up and gaps in care represent a significant threat to

survival and functioning or quality of life in survivors with CHD. Given the importance of uninterrupted healthcare and the potential impact on outcomes, interventions to better prepare adolescents and emerging adults for successful transition to adulthood and to maximize lifelong physical and psychosocial outcomes in adults with CHD are imperative.

## 2. Transition Definition and Goals

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 [12]. Transfer refers to the actual point in time at which responsibility for patient care is “handed off” to the adult provider [13]. 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.” [14]. The aims of a transition program are to improve the patients' and their families' knowledge of the medical condition (and lifestyle implications); to prevent high-risk behaviors; to enhance communication skills and self-advocacy; to promote skills in decision making and self-management; to prevent patient loss to follow-up; to maintain medical insurance; to achieve educational and vocational goals; and to improve overall quality of life [13].

## 2.1. Timing of Transition

The transitional process should be individualized and is an ongoing process that should begin in early childhood and continue into

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adulthood. The timing of transition and transfer should be guided by emotional maturity and developmental level or cognitive status, as opposed to chronological age [13]. Cultural and family dynamics are also important factors to consider that will influence the individual's transition readiness and achievement of self-care. Parental anxiety can lead to overprotection and may explain parents' reluctance at times to shift greater responsibility for management to their adolescent [15]. Guidelines recommend that patients transfer from pediatric to adult care between the ages of 18 and 21 years [13]. However, assessment of transition readiness is needed to ensure the optimal and individualized timing of transfer for each patient.

### 3. Transition Readiness

Transition readiness is a complex, multi-domain concept which encompasses the entire transition process [16]. Readiness for transition requires knowledge of the medical condition and treatment including lifestyle implications and health care needs. Other domains include self-management behaviors, and perceived self-efficacy. Self-management behaviors, the patient's autonomy regarding taking medications, asking questions, making appointments, decision-making, 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, important to the development of resilience. Perceived self-efficacy supports one's willingness to accept responsibility for management of their health.

In a systematic review of transition readiness for adolescents with chronic illness, Stinson and colleagues acknowledge the key to a successful transfer is an adolescent's readiness to begin to transition [16]. Based on their review, they note the lack of a validated, patient-centered instrument to assess adolescents' acquisition of skills and knowledge remains a major limitation to a healthy transition process and transfer to adult care. In addition, they found the existing measures focus on readiness for transfer versus readiness for emerging adulthood [16].

Stewart and colleagues [17] evaluated transition readiness in young adolescents with CHD (ages 12 to 15 years) using the Transition Readiness Assessment Questionnaire (TRAQ), widely used and considered the best-validated generic transition-readiness tool evaluated in the USA, 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) [18,19]. Transition readiness was higher among patients who were older, more knowledgeable about their condition, had a history of primary cardiac repair, and had greater self-efficacy, and was lower for boys and patients on cardiac medications [17]. Transition readiness was unrelated to CHD diagnosis. Parental involvement was correlated with increased transition readiness and patient disease self-management skills. An important limitation, as the authors note, is that the TRAQ has not been validated for adolescents younger than 16 years of age [17]. In another study [20] using the TRAQ in 18–25 year olds with CHD, transition readiness did not differ as a function of disease category (moderate CHD versus complex CHD versus Heart Transplant) or where patients were being followed (pediatric vs. adult CHD clinic). The authors note that the similarity of scores among 18 to 25-year olds followed in a pediatric versus adult CHD clinic implies that the pediatric CHD providers in this study are not more likely to transfer patients who are more “ready” for adult care. Rather, there are likely system factors that determine in which clinic a patient is followed [20]. They further suggest that the TRAQ has limitations in the CHD population since ceiling effects were observed and a response of “not needed for my care” to 5 or more of the 29 TRAQ items was provided by 75% of participants [20].

Uzark and colleagues [21] evaluated 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 cardiac specific Transition Readiness Assessment measure administered with an e-tablet, web-based format. Transition knowledge deficits were common and associated with decreased self-efficacy and self-management skills in adolescents and young adults with heart disease. Perceived self-efficacy scores were higher in patients  $\geq 18$  years of age and were lower in patients with single ventricle than in patients with 2-ventricle heart defects [21]. The mean score for self-management behaviors was only 49.7 on a 100-point scale, higher in young adults, though only 54.2. As expected, higher perceived self-efficacy scores were associated with higher self-management scores. Greater transition knowledge and perceived self-efficacy were also associated with better psychosocial quality of life [21]. With respect to the Transition Readiness Assessment measure, preliminary data supported the instrument validity by confirming the expected relationship between knowledge, self-efficacy, and self-management scores and age [21]. Responsiveness was reflected in changes in scores over time with receipt of information [22].

#### 3.1. Knowledge Gaps Identified

Overall, the most common perceived knowledge deficits identified by Uzark et al. [21] were related to health insurance (74%), pregnancy (70%), contraception (42%), how to contact your doctor (37%), and symptoms to call for (30%). Although the frequency of several specific knowledge deficits was significantly lower in young adults than in adolescents, the proportion of young adults (18–25 years) with these specific knowledge deficits still ranged from 23%–65%. Similar knowledge gaps in adults with CHD have been identified by others including reasons for follow-up and symptoms of deterioration of their heart disease [23]. Van Deyk et al. [24] found that adolescents with CHD had poor knowledge regarding their heart condition including the name of their heart defect, reasons for follow-up, the effects of competitive sports, symptoms that reflect deterioration of their heart disease, appropriate contraceptive methods, and the risks of pregnancy. Many young adults with CHD also have misconceptions about safe, desirable levels of physical activity, and have lower activity levels than recommended for their cardiac conditions [25,26]. After completion of a transition readiness assessment, Uzark et al. [22] reported that overall 66% of 13–25 year olds requested information from a checklist, 73% of patients  $\geq 18$  years of age. Interestingly, nearly 1 in 5 (18.3%) requested information regarding stress management. As reported by Clarizia and colleagues [27], children and adolescents more knowledgeable about their diagnosis demonstrate a better understanding about their transition to adult care (100% versus 7%, respectively) and are more likely to communicate directly with their providers than those who are less or not knowledgeable (88% versus 33%, respectively). Importantly, Ronning et al. [28] reported that patients identify lack of knowledge about their heart disease as a barrier to taking a more active role in decisions about their treatment and care.

#### 3.2. Self-efficacy and Self-management

Self-efficacy or confidence in their ability to care for themselves is key to promoting self-management behaviors, crucial to successful transitioning. While self-management includes medical management such as scheduling appointments, asking questions of health care providers, and filling prescriptions, it also extends to other activities of daily living that may be affected by the presence of CHD. A study of adolescents with CHD showed that belief in self-efficacy was more important than severity of CHD in determining exercise and sports participation [29]. More recently, Banks and colleagues [30] also found that overall self-efficacy was associated with higher moderate to vigorous physical activity among all CHD groups.

While self-efficacy significantly contributes to improved self-care, low levels of self-care are common among adults with CHD as reported

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