

More Than Just the Heart Transition and Psychosocial Issues in Adult Congenital Heart Disease



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KEYWORDS

• Adult congenital heart disease • Transition • Depression • Anxiety • Psychosocial

KEY POINTS

- There is increasing recognition of the importance of a thoughtful and coordinated process of transition from pediatric to adult congenital heart disease (CHD) care.
- Approximately 1 in 3 North American adults with CHD face additional challenges associated with clinically significant depression or anxiety.
- Psychosocial outcomes of European studies seem more favorable, although reasons for international differences are currently unknown.
- It is time to move beyond description and begin developing and evaluating interventions targeting the psychosocial needs of adults living with CHD.

INTRODUCTION

As a result of significant advancements in the diagnosis and management of congenital heart disease (CHD), almost 90% are now expected to reach adulthood.¹ In North America, there are now more adults than children living with CHD.² Despite this success story of modern medicine, most adults with CHD of moderate or great complexity are not cured and are at significant risk of heart failure, arrhythmias, additional surgeries and interventional procedures, and premature mortality.^{3–8} For these reasons, lifelong surveillance by CHD specialists is important.⁹ Adults with CHD thus face 2 sets of challenges: (1) the transition from pediatric to adult care and (2) the psychosocial implications of coping with a chronic and often life-shortening medical condition. These challenges, along with proposed clinical management strategies, are the focus of this article.

TRANSITION FROM PEDIATRIC TO ADULT CARE

Among all subgroups of patients with pediatric-onset health conditions, there is growing recognition of the importance of addressing the unique needs of adolescents and young adults making the transition from pediatric to adult health care services. The Society of Adolescent Medicine defined transition as “a purposeful, planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems.”¹⁰ Similarly, the American Academy of Pediatrics defined the goal of transition as “to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the

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individual moves from adolescence to adulthood."¹¹ Although young patients are the primary focus of transition, the list of key stakeholders also includes parents/guardians, pediatric care providers, and adult care providers.¹²

In 2011, the American Heart Association published a scientific statement describing best practices for the transition of adolescents with CHD from pediatric to adult care.¹³ Guidelines recommend a flexible age of transfer between the ages of 18 and 21 years, although in some countries the age of transfer is mandated by the health care system (eg, at 18 years in Canada). The preparation of patients (and their parents) for the transfer from pediatric to adult CHD care should be a routine component of adolescent care. Unfortunately, a survey of almost 2000 young adults with a variety of health conditions revealed that only 55% recalled discussing with their health care providers how their needs would change as they aged.¹⁴

Absences from and lapses in specialized CHD care are unfortunately common. In a multisite American study that included almost 1000 adults with CHD, 42% of patients had a lapse in care of 3 years or longer.¹⁵ A Canadian study revealed that only 47% of a cohort of 360 patients aged 19 to 21 years had received care in a specialized adult CHD center.¹⁶ A German study of more than 10,500 patients revealed that 76% had not received specialized adult ACHD care within a 5-year period.¹⁷ Findings were more positive in a Belgium study in which only 7% of adults with CHD were not receiving specialized CHD care, although this study occurred at a hospital in which the pediatric and adult CHD programs were physically colocated in the same building.¹⁸ Absences from specialized care are not restricted to the adult care setting. Quebec researchers queried a provincial database to investigate the proportion of children and young adults with CHD receiving outpatient cardiology care.¹⁹ Results indicated that 28% of patients had not received outpatient care after the age of 6 years; 47% had not received outpatient care after the age of 13 years, and 61% had not received outpatient care after turning 18.

When patients do re-establish specialized CHD care following a lapse in care, they are often found to be on suboptimal medication regimens,²⁰ to be less likely to have undergone surgical interventions expected for their form of CHD,²¹ to be at high risk of late complications,²² and to require urgent cardiac intervention.²³ The consistent finding, therefore, is that lapses in specialized CHD follow-up are associated with suboptimal medical care. Discussions regarding the importance of life-long care should be initiated with both patients and

parents in the pediatric setting and emphasized before and after transfer of care.

Transition is not merely the transfer of patients and their medical records from pediatric to adult institutions. Rather, transition refers to an extended process that begins in early adolescence (ideally by the age of 12) and continues following transfer to adult care. Although transition is often focused on the needs of adolescents with special health care needs, young adults between the ages of 18 and 25 years are "emerging adults,"²⁴ who are taking increased responsibility and becoming independent decision-makers.²⁵ Both patient and parent reports suggest that many young people with CHD are insufficiently prepared for the transition to adult care and to assume control of their health care management.^{26,27} Qualitative research has highlighted many challenges of transitional age youth with CHD, including managing interpersonal frustrations and learning how to develop strategies to coexist with the disease.²⁸ Unfortunately, a survey of European and American pediatric cardiology programs revealed that most programs do not provide structured preparation for transitioning patients and their family.²⁹

Clinical Strategies to Optimize Transition

There are multiple review articles describing the importance of a thoughtful approach to transition as well as several empirical articles describing perspectives on transition according to the patients and other key stakeholders. What is most needed now is guidance for practical strategies to address the needs of transitioning patients, particularly in the context of health care systems with limited resources (both personnel and finances). Descriptions of an outpatient nurse-led transition clinic from Stockholm, Sweden and a transition task force from Toronto, Canada may provide guidance to other programs wishing to establish transition initiatives.^{30,31} With regard to transfer from pediatric to adult care, pediatric CHD programs are encouraged to develop a policy by which their team's approach to transfer is clearly communicated to patients, parents, and other health care providers.³²

Patient education and the fostering of self-management skills are hallmarks of the transition process and key components of a comprehensive transition program.^{9,12,13,33} Not surprisingly, participation in a structured education program has been linked with improved knowledge among adolescents and adults with CHD.³⁴ In a clinical trial, a 1-hour nurse-led session significantly improved cardiac knowledge and self-management skills.³⁵ Education for adolescents and adults with CHD can be provided in inpatient and

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