



Review

Transition from adolescence to adulthood in congenital heart disease—Many roads lead to Rome



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ABSTRACT

More than 90% of children born with heart defects reach adulthood. They continue to require specialized medical care. In most countries, their care has to be transferred from the pediatric care environment to specialized adult clinics. This transfer of care usually occurs at a time when adolescents become young adults. Supporting adolescents and emerging adults with congenital heart disease through transition has been recognized as an important task of their treating teams in recent years. An environment where adolescents feel welcome and where education and patient participation are fostered is crucial. For an optimal transition process, patients, their families and all health care providers need to be involved. Different models for transition programs have emerged, depending on local policies and resources. The authors offer insight into established transition programs in Bern and Zurich, Switzerland. Advantages and challenges of different models of care and transition programs are presented.

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1. Introduction

Only a few decades ago, the outlook of a child born with congenital heart disease (CHD) was bleak. This has changed dramatically. Nowadays, more than 90% of infants born with a heart defect are expected to reach adult life [1]. Current mortality in childhood due to CHD is fortunately low and mortality has shifted to adulthood [2]. Nonetheless, the majority of patients who underwent surgical repair in childhood are not cured and at risk of cardiovascular complications and premature death [3]. As a consequence, the emphasis of medical care in CHD shifts from improving infant survival to reducing morbidity and mortality and improving quality of life throughout the whole life span [4,5]. Patients with CHD require lifelong specialist care, and recent data suggest that adults continuously followed at specialist centers have improved outcomes compared to CHD adults with non-specialized medical follow-up or even lapses in their care [4,6].

While some CHD patients are followed throughout life by their pediatric cardiologists, in most patients, care is handed over from pediatric cardiology to a team of adult CHD specialists once patients reach adult age. If this handover is not well structured, 50–60% of adolescents may not see a CHD specialist in adult life in a timely manner for a variety of reasons and can have lapses in care for several years [7,8]. When these “lost” patients are re-admitted or present to a specialized adult CHD program, they are more likely to have hemodynamic deterioration or cardiac problems requiring urgent cardiac interventions [9]. Avoiding

gaps and, even more important, complete loss to specialist follow-up care, is one important way to reduce morbidity and maybe even mortality in CHD patients [4]. In 2011, the American Heart Association published a scientific statement about reaching adulthood with CHD with key elements for successful transition from a pediatric environment to an adult-centered consultation [10]. The handover of care from pediatric to adult medicine should not be limited to ensuring uninterrupted medical follow-up but should also encompass aspects of age and developmentally appropriate patient education and aim to support the adolescent's ability to assume adult roles and functioning [11].

In this review, we summarize current definitions and practices of transition in CHD and share the experiences from two tertiary Swiss centers with different approaches to this process. In both centers, there is a transfer of care from a pediatric to an adult care team. In one center, pediatric and adult cardiologist work near each other in the same building and the transition clinics are led by an advanced practice nurse (APN) acting as a transition coordinator. In the second center, pediatric and adult cardiology programs are located in different hospitals, and the process of transition is mainly coordinated by the treating pediatric and adult cardiologists and supported by dedicated nurses. Both models have been adapted to the local conditions and needs and have evolved over time.

1.1. Concept and definition of transition

We all go through many transition phases in life, such as changing school or employment, entering menopause, or being hospitalized for heart failure. Adolescence itself is a transition phase. In general terms, transition can be described as the state between two stable conditions

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or as “a process or movement from one period of life, place or physical state to another” [12]. A part of this transition process can be the planned act of changing from one system to another (e.g., moving out of the parents' house or changing from the pediatric cardiologist to the adult CHD specialist). This change is called transfer [13]. Transition and transfer are not synonymous terms. A transfer is a facultative part of the transition process. Even adolescents with continuous medical follow-up with their pediatric cardiologist (i.e., without a transfer of care from the pediatric to the adult medical facilities) will have to go through a transition process in order to assume adult responsibilities.

The transition process in CHD starts during the teenage years, a vulnerable time in most individuals, characterized by the emancipation of the adolescent from the parents. In all patients with a chronic disorder, a structured transition program should not only be focused on the adolescent but should also include parents and caregivers. Given the multiple aspects of a transition process, it must be individualized and tailored to the patient and her or his family's needs. Many experts encourage initiating the transition process in children with chronic disorders at an early age of 12–14 years [10,11]. The transition process is not completed after the eventual transfer of the adolescent from pediatric to adult medical care but continues until the patient has all tools in his or her hands to assume full responsibility. In some patients, this may be far beyond their 20th birthday.

1.2. The different players and their contributions to the transition process in CHD

The transition process has many stakeholders and goes beyond a classic patient–doctor relationship. The main players in this process are the adolescent, the parents or guardians, and the health care providers on the pediatric and adult sides, as outlined in a recent review by Kovacs and McCrindle [14]. Health care providers include nurses cardiologists, general practitioners, but also non-medical staff as, e.g., social workers or psychologists. All stakeholders can facilitate or hamper the transition process.

1.2.1. The adolescent

In adolescence, many changes take place at the same time. It is the time of physical, cognitive, emotional, and social development as well as gaining more and more autonomy. The body changes, first hair of beard, and the body odor modifies; it is the beginning to see life not exclusively as black or white but also with its gray scales. Emotions are growing and getting more intense, and peers are becoming increasingly important [15]. Youngsters with CHD do not only have to find their way through adolescence; they also need to learn how to live a healthy and responsible life as an adult with a cardiac defect.

Despite being challenged by adolescence, for most teenagers with CHD the move from pediatric to adult medical care is not a major concern. As shown by Moons and colleagues, they can leave familiar surroundings easily behind them and experience the change from pediatric to adult health care as a normal event [16]. Most have a positive “wait and see” attitude towards the transfer. Usually, they are unaware of what is being expected of them on the adult health care side. As a consequence, adolescents with CHD wish to be better informed about the upcoming changes. They want to be involved in the decision-making process, to learn more about their heart disease and to have the possibility to talk alone to their health care provider about all kind of health-related topics [16–18]. Most adolescents wish to be actively involved in the transition process and are eager to take over responsibility for their heart condition.

1.2.2. Parents or guardians

Parents play a crucial, but easily overlooked, role in the transition process. CHD is usually diagnosed in early life, and many of these patients undergo one or several major surgeries or other kind of interventions in the first years of life. Their families are sometimes confronted

with life-threatening conditions and go through extended periods of uncertainty and fear. A child with CHD can also impact childhood and adolescence of his/her siblings, as family life is often centered on the sick child, at least at some times. These attitudes favor the tendency for overprotection among parents of children with CHD and may render it more difficult for them to let the adolescent with CHD go his/her own way. In a recent quantitative study from Canada, only half of the parents felt that their teenagers would be ready to assume full responsibility for their health at age 18 [19]. In addition, half of all parents seem also to struggle initially with saying good-bye to a familiar and family-focused pediatric health care system and getting adjusted to a new and different adult-centered environment, where parents are not expected to play the leading part [19]. On the other hand, once the transfer of care has happened, most parents agree that it was appropriate and that the adult health care system seems to be more adequate for their growing teens than the pediatric environment [18,20].

Parents may need to be encouraged or guided on how to let their children go and on how to give their teens the opportunity to make their own first steps in the adult medical world. Parents ideally allow the adolescents to develop self-advocacy by gradually reducing their own commitment. Similar to the adolescents, parents need to have an appropriate knowledge about the heart, their young person's heart defect, and its consequences. Parental lack of knowledge about the heart defect and its impact on daily life can be another source for overprotection. The fear that their child may not be ready to take over responsibility may restrain parents from encouraging them to do so. This lack of encouragement may hinder the adolescent's progress and confirm the parent's impression of the child not being ready to be its own advocate—a self-fulfilling prophecy. The more the parents are informed about CHD, the more they know about the transition process, the better their kids will do [20–22].

1.2.3. The pediatric cardiologist

Even if a patient is not going to be transferred from pediatric to adult cardiology, pediatric cardiologists have to ensure that adolescents do have a transition from a pediatric to an adult health perspective in order to assume adult roles and responsibilities. The medical knowledge and personal attitude to take over these tasks cannot be acquired instantly. It is recommended to initiate the transition process not just before patients turn 18 years old, but years in advance as soon as parents and the teenagers consider themselves ready to play their roles in this process [10,11]. Important health-related topics like contraception, medical compliance, or use of illicit drugs should already be discussed in pediatric cardiology environment.

It is equally important for pediatric cardiologists to keep an accurate view on the long-term outcome of children with complex heart defects. Most adolescents with complex lesions, e.g., with a Fontan physiology, do very well once the early surgical risks have passed. Cardiologists, parents, and teenagers are sometimes tempted to expect this high level of functioning to last “forever” and may be reluctant to discuss long-term-related health concerns that could potentially have implications on professional and other personal decisions.

Pediatric cardiologists should make sure that adolescents are transferred to cardiologists with expertise in adult CHD in order to guarantee a lifelong specialized medical follow-up. At the time of transfer to an adult team, a comprehensive summary of the medical history (including operation reports from previous heart surgeries) should be provided in paper or electronic format by the pediatric cardiologist. As cardiac complications can occur any time, a clear plan for emergency situations around the time of transfer should be established.

1.2.4. The adult congenital heart disease (ACHD) specialist

Specialists in ACHD usually have a background in adult cardiology with additional training in CHD. Some may be challenged by adolescent patients being transferred to their care with an age-specific behavior they are not familiar with. Being able to communicate with adolescents

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