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Current Opinion

Units for Transitioning Pediatric Cardiology to Adult Care with Congenital Heart Disease: Why, When and How?

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Abstract

Congenital heart disease is the most common congenital malformation worldwide; today, 13 of every 1,000 live births and 6 of every 1,000 adults have congenital heart disease. Advances in pediatric cardiovascular surgery, an increasingly earlier diagnosis, and advanced postoperative care, have increased the number of survivors. Survival is > 90% in most countries in the world. And as consequence the number of adults with congenital heart disease has increased. Nowadays more adults than children are living with congenital heart disease, especially in developed countries, and in the rest of world the same situation it's happening. This growing population needs specialized and permanent care. But a great problem is the loss in the follow-up. Recently research's shows loss in follow-up >60%, or experience lapses in care after leaving pediatric cardiology. As a consequence, the population experiences relapses due to decompensation of congenital heart disease, even decades after leaving attention in pediatric cardiology. Without a doubt, the critical point of loss is the transition from pediatric to adult care (transfer stage). This point definitely requires intervention by the specialists in charge of the patient's care. As well as in years ago Adult Congenital Heart Disease Units (ACHDU) around the world were created to take care this population; In this opportunity I propose: why not create congenital heart disease transfer units now? This paper answers the questions: Why, When and How, it's really necessary to create Pediatric Congenital Heart Disease Transfer units (PCHDT units) has the main objective of decreasing patient losses to follow-up.

Keywords

Adult Congenital Heart Disease; Congenital Heart Disease Units; Follow up Patients; Transfer to Adult Care

Abbreviations

ACHDs	:	Adults Congenital Heart Disease
CHD	:	Congenital Heart Disease
ESC	:	European Society of Cardiology
ACHD units	:	Adult Congenital Heart Disease Units
PCHDT units	:	Pediatric Congenital Heart Disease Transfer Units
RV	:	Right Ventricle
PR	:	Pulmonary Regurgitation
PV	:	Pulmonary Valve

LV	:	Left Ventricle
CHF	:	Congestive Heart Failure
AHA	:	American Heart Association
ACC	:	American College of Cardiology
HF-rEF	:	Heart Failure with Reduce Ejection Fraction
HF-pEF	:	Heart Failure with Preserved Ejection Fraction
TGA	:	Transposition Great Arteries
AP	:	Anatomical and Physiological
NYHA	:	New York Heart Association

Introduction

The growing number of Adults with Congenital Heart Disease (ACHDs) is a direct consequence of the survival success of children with repaired Congenital Heart Disease (CHD) [1,2]. Developed countries (North America, Europe, Oceania and some in Asia) have experienced a dramatic change in the CHD population profile. In previous decades there were thought to be more children than adults with CHD [3,4]. It was also believed that moderate and high complexity CHD in adults was exceptional, and that the most common CHD types were the simple ones, such as bicuspid aortic valve, atrial septal defects, low-complexity Ebstein's anomaly and aortic coarctation, among others. Individuals with unrepaired moderate and high complexity CHD were not expected to survive into adulthood. However, in United States (US) and Europe with the development of pediatric cardiovascular surgery and cardiovascular intensive care units, the relationship has reversed [5,6]; there are now more adults than children with CHD, with the majority having had surgery. Consequently, ACHD units have had to be developed and cardiologists trained as specialists in ACHD. In 1959, Canada developed the world's first ACHD unit; subsequently, the United Kingdom established the first ACHD unit in Europe, followed by the US, Oceania, South America and Asia. To date, it has taken more than 40 years for Europe to have the highest number of ACHD units per 10 million inhabitants [7]. North America and Europe have defined the requirements for ACHD unit structuring and functioning. These are the recommendations of the European Society of Cardiology (ESC) Working Group on Grown-Up Congenital Heart Disease [8]:

Staff members
-Adult/pediatric cardiologist with ACHD certification, at least 2
-ACHD imaging specialist (echocardiography, cardiac resonance, tomography), at least 2
-Congenital interventional cardiologist, at least 2
-CHD surgeon, at least 2
-Anesthesiologist with CC experience, at least 2
-Invasive electrophysiologist with ACHD experience, at least 1
-Psychologist, at least 1
-Social worker, at least 1
-Cardiovascular pathologist, at least 1

Diagnostic equipment: Electrocardiogram, continuous electrocardiographic monitoring (Holter), ambulatory blood pressure or event monitoring, ergometry and cardiopulmonary stress test, echocardiography, conventional radiology, computerized axial tomography and magnetic resonance.

The ACHD unit should ideally be located in the same building or physical space as pediatric cardiology, but ACHD care should be separate from that of the children and in a non-pediatric environment. The unit should maintain an adequate and sufficient procedural volume in order to sustain an adequate training standard. It should be led by an ACHD specialist.

The formation of an ACHD unit is a challenge for developing countries, due to its high implementation cost and a very limited number of ACHD specialists. Pediatric CHD mortality continues to be a priority in most medium and low-income countries (Eastern Europe, some Asian countries, Africa and Latin America), and therefore financial resources and objectives have been focused on developing pediatric CHD centers, increasing care during childhood. However, the constant population growth, especially in countries with a high birth rate (Latin America and Asia) results in a rapid increase in ACHDs. This has taken these countries by surprise, and they have not prepared themselves to care for this growing population. Therefore, it is also necessary to develop ACHD units concomitantly.

However, the problem really does not end there. The latest research in developed countries has shown that many ACHDs are lost to follow-up. There are big problems in even maintaining continuity of care from pediatric cardiology to adult care. Currently, the reasons for losses to follow-up in the CHD population are being researched, along with the implementation of strategies for decreasing these losses. Without a doubt, the critical point of loss is the transition from pediatric to adult care (transfer stage). This point definitely requires intervention by the specialists in charge of the patient's care. It all begins with sensitization of pediatric and adult cardiologists, who must encourage the transfer to ACHD specialists. There must be cooperation between the specialties.

The objective of this paper is to foster and encourage the formation of units for the transition or transfer of pediatric CHDs to adult CHD care. Just as ACHD units were proposed several years ago, why not create CHD transfer units now? The mortality of ACHDs decreased substantially with the

implementation of ACHD units. Mylotte D et al., they showed a reduced mortality in adults referred to specialized ACHD centers, in Quebec population [9]. The proposal to create Pediatric Congenital Heart Disease Transfer units (PCHDT units) has the main objective of decreasing patient losses to follow-up.

Why?

CHD are the most common congenital malformation worldwide; today, 13 of every 1,000 live births and 6 of every 1,000 adults have CHD [10]. In the 70s, in the US, Joseph K Perloff had already described the changing population of congenital heart disease. During the 70s, 3,718,000 births were recorded in the US, of which 28,000 had CHD (0.8%), but only 50% were able to survive beyond their first year of life. From 1940-1959, survival at one year of age for high, medium and low complexity defects was 20%, 60% and 95%, respectively; likewise, from 1980-1989, survival was 85%, 90% and 95%, respectively [11]. Currently, survival for children with CHD is >90% in most countries in the world. Advances in pediatric cardiovascular surgery, an increasingly earlier diagnosis, and advanced postoperative care turn the child with CHD into a postoperative CHD adult. Consequently, the new profile of the adult with cardiovascular disease has changed over the last few years, especially in developed countries. The residuals, sequelae and complications of repaired CHDs cause serious cardiovascular disorders throughout life, and even take decades to appear, with long asymptomatic periods. This has taught us that only simple CHDs (2001 Bethesda classification) [12] should be considered cured. However, more than 85% of CHDs are of medium or high complexity, and in these cases successful cardiovascular surgery in childhood should not be considered curative. These types of procedures improve a hemodynamic situation which is incompatible with life, producing an almost normal situation which allows survival during childhood. Nevertheless, the postoperative changes required to improve the original situation produce, in turn, other anatomic and hemodynamic changes in the heart which manifest early or late.

Example: Pulmonary atresia with an intact septum, without sinusoids, coronary abnormalities or associated lesions, and with an appropriate Right Ventricle (RV). Without repair, neonatal mortality is >50% in the first 15 days and more than 85% in the first six months. The immediate options during this stage are percutaneous valvulotomy with radiofrequency or surgical valvulotomy. A stent in the ductus arteriosus or a systemic-pulmonary fistula may be temporarily placed. If percutaneous or surgical valvulotomy is chosen, the newborn will survive and improve his/her hemodynamic condition from being cyanotic and hypoxemic to having an almost normal arterial saturation, generally >85%. The hemodynamic consequence is post-valvuloplasty Pulmonary Regurgitation (PR) (sequela) and some degree of residual valvular stenosis (residual). In this case, the progression of the CHD will follow its natural course with trophic changes in the RV (hypertrophy, dilatation) which will affect the functional class. The child should be followed by the pediatric cardiology service. He/she may need a second percutaneous pulmonary valvuloplasty if the predominant residual lesion is stenosis, or surgical implantation of a biological Pulmonary Valve (PV) if the sequela is (PR). This can usually occur during adolescence. Once this stage is passed, the heart disease follows its natural course (calcification and stenosis of the biological PV, increased PR, or a combination of both lesions) along with changes in the RV which manifest as dilatation, hypertrophy, arrhythmias and ventricular dysfunction. Finally, a third re-intervention will be necessary in adulthood (percutaneous PV valve-in-valve implant or surgical PV replacement).

Recognizing these special needs in each stage of life and in each particular case requires a specific type of specialist. In adults, a new profile of cardiologist, duly trained and educated in the ACHD specialty, with the necessary knowledge to know when to make each particular decision, is essential. Complicating the perspective even more, care does not end here; even the deterioration of the re-interventions could continue throughout adulthood. Now the care priorities are not just about cardiovascular health; they also include lifestyle, reproduction and fertility counseling, career selection, and family and psychosocial support, among others. In conclusion, patients with CHD should never be discharged from the cardiology service; follow-up and treatment should be life-long.

The same cardiovascular disease in adults with or without CHD has a different origin and progression; the diagnostic approach and treatment must be different, even though we are dealing with the same disease.

Example: Congestive Heart Failure (CHF). The American Heart Association (AHA) and the American College of Cardiology (ACC) define CHF as a clinical syndrome manifested by dyspnea, fatigue and systemic congestion symptoms resulting from a structural and functional inability of the heart to maintain a minute volume sufficient for the metabolic and hemodynamic demands [13]. CHF is classified as Heart Failure with reduced Ejection Fraction (HF-rEF) or Heart Failure with preserved Ejection Fraction (HF-pEF) (EF higher or lower than 40 - 45% of the sub aortic Left Ventricle (LV)). This definition may only be applied to hearts with two differentiated

ventricles, and only as long as the ventricle being studied has a left morphology. However, in complex CHDs, the systemic ventricle may have a left, right or indeterminate morphology (Transposition of the Great Arteries [TGA] repaired with an atrial switch will have a systemic ventricle with a right morphology), and thus this definition might not be applicable, even when speaking of the same disease.

In general, hospitalizations for CHF in ACHDs are double those adults without CHD. The growing ACHD population has increased the number of CHF hospitalizations over the last decade. In complex CHD, chronic CHF accounts for 42% of deaths. The Dutch national registry, 'CONCOR', showed that the incidence of first hospitalization for CHF was 1.2 for every 1,000 admitted patients, with five times the mortality of non-admitted patients. Out of 24,865 patients admitted for CHF, the mortality was 2.8% per year. Chronic CHF caused 26% of the deaths, and sudden death caused 19%. The mean age of death due to chronic CHF was 51.0 years (range: 20.3 - 91.2 years). In the US, 20% of admissions for CHD are due to decompensated CHF; univentricular hearts (Fontan) account for 40%, congenitally corrected transposition of the great arteries for 32% and TGA corrected with an atrial switch for 22% of cases [14]. In adults without CHD, the prevalence of HF is approximately 1-2% of the adult population in developed countries, rising to ≥10% among people >70 years of age. Among people >65 years of age presenting to primary care with dyspnea on exertion, one in six will have unrecognized HF (mainly HFpEF). The lifetime risk of HF at age 55 years is 33% for men and 28% for women. The proportion of patients with HFpEF ranges from 22 to 73% [15]. This clearly shows that HF presents at an earlier age in ACHDs.

The clinical signs and symptoms, such as progressive dyspnea, peripheral edema and deteriorating functional class, although present in both groups, do not have the same validity in ACHDs. Many of these patients interpret the current functional class deterioration as normal and related to the CHD itself (masking phenomenon). Current pharmacological therapies are effective in patients with HF-rEF (EF ≤35%) who have a biventricular circulation and a LV as the sub-aortic ventricle. However, these treatments are not yet fully validated or effective in ACHD. The same scenario is more complicated because HF presents differently in hearts with univentricular physiology [16-18].

Currently, the ACHD population is greater than that of children with CHD, especially in developed countries. There are 1.4 million ACHDs in the US vs. one million children with CHD and 2.3 million ACHDs in Europe vs. 1.9 million children with CHD. The estimates of ACHD prevalence in most Latin American countries are extrapolated from systematic reviews. Assuming a CHD prevalence in the adult population of approximately 3,000 per million adults, there are an estimated 261,000 ACHDs in Central America and almost 1.2 million in South America. The ACHD population will continue to increase, with a 5-6% annual growth rate, and it is estimated that there will be 11% more per year in 2030 [19]. At present, the global population is 6.8 billion, with 4.4 billion adults, and the ACHD population has a prevalence of 0.15-0.3%. Therefore, it is estimated that there are 15 to 20 million ACHDs throughout the world; however, 30-60% are lost to follow-up. Other studies in Canada, Germany, the United Kingdom and the US have demonstrated that 21% to 76% of adolescents with CHD are either lost to follow-up or experience lapses in care after leaving pediatric cardiology [20].

The ACHD population which is lost to follow-up, later on relapses due to decompensation of the congenital disease. The main causes are: arrhythmia, heart failure, syncope, aortic dissection and endocarditis; followed by thromboembolism, bleeding (noncerebral), sudden cardiac death and pulmonary arterial hypertension [21].

When?

During childhood, patients are seen by pediatric cardiologists; many have even had a prenatal diagnosis, forming a strong bond between the pediatric cardiologist and the parents. The parents are the ones directly responsible for the care of children with CHD; they are responsible for keeping medical appointments and are the primary caregivers. For most pediatric cardiovascular centers, there are no major constraints to care. In general, care is provided well in most countries around the world, protecting the success of the initial CHD surgical repair.

The real problem begins in adolescence; the transition from pediatric to adult care constitutes a critically vulnerable period for adolescents. The physical and psychological changes in this stage of life produce episodes of emotional stress for adolescents, and many are tired of medical appointments, lengthy medical treatments, and routine and repetitive medical tests. Some long and bothersome exams, such as blood tests and imaging like cardiac resonance, tomography and echocardiography, cause them some anxiety. In other cases, more invasive procedures (heart catheterization, electrophysiological studies) end up bothering and tiring them.

Adolescents want to live life like everybody else; they want to feel free. They are young and do not understand the real significance of their CHD. Many of them minimize or brush off their symptoms and try to do what the rest of the people their age can do (participate in sports without restriction, party, drink alcohol and smoke, among other things). Frequently, they skip their medications and do not keep their medical

appointments. In this period, losses to follow-up reach over 70%. Wacker et al., in the German heart center in Munich, evaluated the rate and outcomes of adults with CHD lost to follow-up. Patients were selected from the CHD program registry (n >10,500). Loss to follow-up was defined as patients' failing to return to their center for follow-up visits for >5 years. The investigators found that >76% of patients were lost to follow-up [22].

The main obstacles to proper transfer lie in the patient, the family, the pediatric cardiologist and the adult cardiologist. Often, the patients have significant gaps in knowledge about their disease, and during this period they are emotionally immature or depend emotionally on their parents or caregivers, which keeps them from assuming responsibility for self-care. The families tend to be excessively protective and may distrust their child's new group of physicians; they tend to be demanding and overprotective. The pediatric cardiologists usually develop bonds of friendship and affection with the patients and their families, and distrust adult cardiologists. Adult cardiologists, in turn, are not cognizant of the severity of the disease. This results in loss of management and follow-up.

The new 2018 AHA/ACC-ACHD guidelines recommend that, ideally, the transition process begin at 12 years of age, although it is not a written rule [23].

My expert opinion is that the first thing that should be done is to prepare and educate the parents at the time of CHD diagnosis, even in the fetal stage, especially in complex defects. A pediatric cardiologist is aware of the path and outcome the CHD he/she has just diagnosed will have, and knows the surgical stages the newborn must go through to repair his/her CHD (Example: Hypoplastic right ventricle, which must be turned into a univentricular heart, going through the stages of systemic-pulmonary fistula, bidirectional cavopulmonary shunt - Glenn, and total cavopulmonary shunt - Fontan). A simple message such as explaining to the parents that the child they are going to have, or have just had, has a CHD which will not be cured with surgery, but which will be improved to allow the child to live, and that he/she will need strict lifelong management and follow-up. This is where we begin to educate in the transfer process. As a result, educated parents pass on care education to their children.

Each medical appointment is an opportunity to educate on self-care and disease management and to involve the child in the care of his/her CHD, where recognizing signs and symptoms of decompensation is essential. Transfer should be supported with education on CHD, through key information in clear language without technical medical terms which are difficult for the family and patient. In some cases, they are unable to learn the name of the CHD for which they had surgery (Example: Supracardiac total anomalous venous pulmonary connection to a vertical vein); it is enough to remind them of a key word (I had surgery for a pulmonary vein malformation). The information in the patient's chart is necessary and must always be on hand.

This task is the responsibility of the pediatric cardiologists assigned to forming the PCHDT units. They must work in a multidisciplinary team as the same way that ACHD units. Pediatric cardiologist should recognize that they are professionally prepared to provide medical management during childhood, since in adulthood many of the problems faced by ACHDs are beyond their understanding and management, especially the concomitant diseases in adulthood which tend to appear frequently. Teamwork is really necessary.

For most Western countries, discharge of CHD patients to adult cardiology begins when they reach the legal age, around 18 years, which is when health insurance classifies them as adults. It occurs earlier in clinical practice, depending on institutional policies. For hospitalization, admissions to pediatric cardiology tend to be restricted to patients up to 14-15 years of age in the vast majority of hospitals in America, with older patients being referred to adult hospitalization.

Yet, the scenario is even more complex, because there are forced transfers: adults who debut with a newly diagnosed CHD, or one which has never been diagnosed, arriving in the emergency room in a decompensated state (pregnant with pulmonary arterial hypertension and CHD, sustained arrhythmias and CHD). These cases are evidence of failed follow-up and long periods without follow-up in CHD services. Frequently, patients report, "I didn't know that I needed to continue seeing the doctor; I felt fine and did not follow-up with the doctor; they discharged me when I was 18 years old."

How?

PCHDT units: this transfer model is proposed, under the direction of pediatric transition or transfer cardiologists, who would be directly responsible. Their job would be to educate, care for and transfer patients in a timely and efficient manner, working together with ACHD cardiologists (Figure 1). The best way to make the transfer is in adolescence and in a compensated clinical state, avoiding abrupt changes of attending physicians. For patients who arrive in adult cardiology as either new or repaired CHDs, the adult cardiologists are responsible for promptly referring them to the ACHD unit.

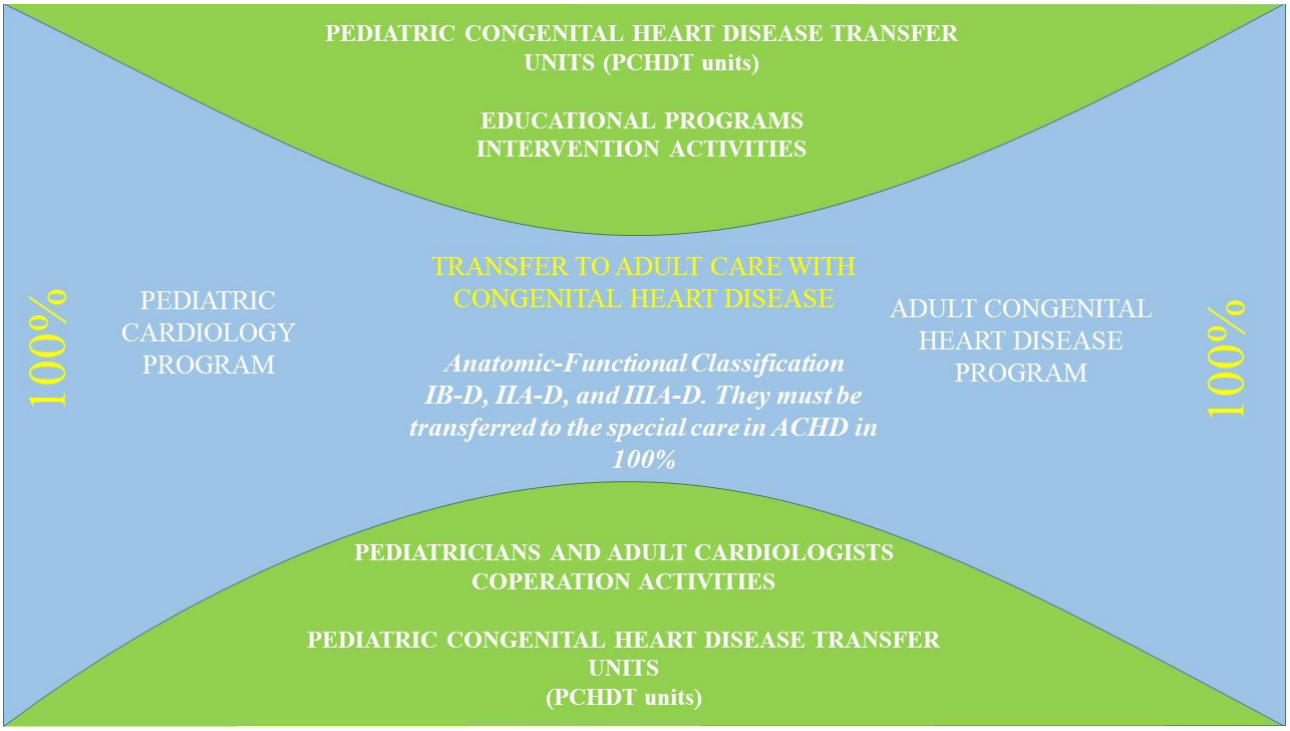

Figure 1: PCHDT units.

The 2001 Bethesda classification established CHD complexity (simple, medium and high) in adults, both for repaired as well as unrepaired CHD. Up until a few years ago, the experts recommended that adults classified in the simple category could be managed by general cardiologists, adults in the moderate category could be managed together with an ACHD cardiologist, and high complexity adults could only be managed by ACHD cardiologists. However, this concept is now questioned; over a certain period of time, as the population ages and more adults with CHD reach the fifth or sixth decade of life, more is known about the natural history of many CHDs, especially the complex ones. Innovative surgical techniques (cone surgery in the repair of Ebstein's anomaly, the Nikaidoh procedure for the repair of a double outlet RV with pulmonary stenosis, or hybrid procedures for the repair of hypoplastic LV) will bring new discoveries about clinical behavior in the various stages of life.

Recently, the new 2018 AHA/ACC - ACHD guidelines have developed an interesting Anatomical and Physiological (AP) classification [23,24] which integrates the anatomical or morphological part of the repaired or unrepaired CHD with the New York Heart Association (NYHA) functional class and nine clinical variables (hypoxemia; pulmonary hypertension/pulmonary arterial hypertension; hemodynamically significant shunt; venous and arterial stenosis; exercise capacity; end-organ dysfunction; concomitant acquired valve disease; arrhythmia; and aortopathy) which, if present, add severity to the CHD. The classification establishes four physiological stages (Table 1). These guidelines recommend that adults in AP classifications IB-D, IIA-D, and IIIA-D should be managed in collaboration with an ACHD cardiologist, with only those classified as IA being left to the care of general cardiologists.

The application of these recommendations shows us that almost 100% of ACHDs should be transferred to specialized care. In my expert opinion, this classification should be applied beginning in adolescence, categorizing patients in risk groups, with special attention given to those in physiological stage D (where the most serious CHDs are found). The NYHA functional classification was developed for non-congenital and biventricular hearts. It cannot be deliberately applied to complex CHDs (univentricular hearts). Likewise, the modified Ross functional classification developed for the pediatric population is imprecise in adolescents [25]. Thus, my expert recommendation is to try to apply the AP-2018 AHA/ACC-ACHD to adolescents with CHD, in order to have greater objectivity in the classification of the severity of CHD.

In several European and North American hospitals, pediatric cardiology and ACHD are found in the same physical plant or building, although separate, especially if they share joint

A	- NYHA Functional Class (FC) I symptoms - No hemodynamic or anatomic sequelae - No arrhythmias - Normal exercise capacity - Normal renal/hepatic/pulmonary function
B	- NYHA FC II symptoms - Mild hemodynamic sequelae (mild aortic enlargement, mild ventricular enlargement, mild ventricular dysfunction) - Mild valvular disease - Trivial or small shunt (not hemodynamically significant) - Arrhythmia not requiring treatment - Abnormal objective cardiac limitation to exercise
C	- NYHA FC III symptoms - Significant (moderate or greater) valvular disease; moderate or greater ventricular dysfunction (systemic, pulmonary, or both) - Moderate aortic enlargement - Venous or arterial stenosis - Moderate aortic enlargement - Venous or arterial stenosis - Mild or moderate hypoxemia/cyanosis - Hemodynamically significant shunt - Arrhythmias controlled with treatment - Pulmonary hypertension (less than severe) - End-organ dysfunction responsive to therapy
D	- NYHA FC IV symptoms - Severe aortic enlargement - Arrhythmias refractory to treatment - Severe hypoxemia (almost always associated with cyanosis) - Severe pulmonary hypertension - Eisenmenger syndrome - Refractory end-organ dysfunction

Table 1: Adaptated from Stout KK, et al. [23].

academic and medical activities. At least once a month, a transfer meeting is held in which the pediatric transfer cardiologist presents the patients to the ACHD specialized adult cardiologists, providing a summary of the disease and current and future problems to be considered. A visit is arranged with the family, the pediatric transfer cardiologist and the ACHD cardiologist, presenting the new attending physician, and the following visit in the ACHD unit is scheduled, with the patient thus being turned over to adult care. This model not only generates trust in the family and patient, it also avoids loss to follow-up. The transfer age will be determined according to the center's policies. Preparation for definitive transfer includes a prior assessment of the patients' knowledge of the congenital disease, identifying gaps, educating and preparing for self-care and management of their own problems.

The key transfer elements may be divided into three aspects:

1. Assessment of knowledge about the disease: name of the congenital defect (even if it is not exact, it should at least be an approximate), surgical or hemodynamic repair procedures carried out (remembering the year in which these were performed is key), current medications and existing residual lesions.

2. Understanding that follow-up is life-long: in this section, the patients should know which surgical, hemodynamic or invasive procedures still need to be performed in the short, medium and long-term. They should be aware of the adult diseases which could negatively affect CHD progression. Warnings in the event of non-cardiac surgeries, especially surgical emergencies, should be explained and taught (Example: An acute appendicitis episode, which could happen to anyone. Although the CHD has not killed the patient, this could do so if urgent surgery is not performed. The scenario becomes complex if the patient is a repaired ACHD who takes anticoagulants for some reason, has pulmonary arterial hypertension or sustained arrhythmias, or has devices such as stents or a pacemaker). Choosing an appropriate center is essential.

3. Education regarding a healthy lifestyle: according to the CHD, residuals, sequelae and complications present. The patients should know about sports and the prevention of alcohol and tobacco use. They should recognize signs of decompensation, according to the CHD, as well as be aware of how to prevent depression and anxiety. They should receive reproductive counseling, with effective birth control methods and a classification of pregnancy risk for women.

Conclusion

Congenital heart disease is the most common congenital abnormality. Currently, there are more children than adults living with CHD, the majority having medium and high complexity lesions. Congenital heart disease is not cured with surgery, it is repaired, they continue to evolve throughout the lifespan, and the hemodynamic consequences may take years to appear. Therefore, individuals with CHD should never be discharged, and they require life-long follow-up. Loss to follow-up is >70%, and occurs mainly during adolescence. Transfer from pediatric care to ACHD care is a critical and important point in follow-up. The proposal to form PCHDT units, under the direction of pediatric transition cardiologists, is a strategy designed to avoid losing patients to follow-up. The joint work between pediatric cardiologists, adult cardiologists and ACHD cardiologists should be continuous and cooperative, in order to provide care to patients with CHD in all stages of life.

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