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ORIGINAL ARTICLE

Adolescents and young adults with congenital heart defects in transfer to adult care

Adolescentes y jóvenes portadores de cardiopatías congénitas en etapa de transferencia a la atención médica de adultos

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What do we know about the subject matter of this study?

Adolescents with chronic diseases are at greater risk of potentially serious complications of their disease because of a lack of adherence and continuity of their follow-up visits. The most critical period is the transition from pediatric to adult health care services.

What does this study contribute to what is already known?

It is the first nationwide study reporting the level of knowledge and management of the condition in adolescents and young adults with congenital heart disease. The lack of knowledge and self-management forces us to implement planned programs of transition to adult care in pediatric cardiology services.

Abstract

Congenital heart defects (CHD), the most frequent congenital malformations, have shown an increased survival and exponential growth of the adolescent and adult population living with CHD. Interventions that optimize the transition of patients from pediatric to adult health care services are essential for ensuring positive long-term outcomes. **Objective:** To describe the knowledge and management of this disease, self-efficacy, and quality of life of young people with CHD during the transition period in two hospitals in Santiago, Chile. **Patients and Method:** Non-experimental, descriptive, cross-sectional study. Patients completed: a) a survey of socio-demographic data, knowledge and management of their condition, and use of health services; b) the Health-Related Quality of Life (Con-HRQoL) Scale in patients with CHD; and c) the Generalized Self-Efficacy (GSE) Scale. **Results:** We obtained a sample of 51 patients, 53% of them were men, and the mean age was 17 ± 2.49 years. The complexity of the CHD was mild in 22%, moderate in 29%, and high in 49%. Although

Keywords:
Quality of life; self-efficacy; transition; congenital heart defects; adolescents

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patients reported high self-efficacy and good levels of quality of life, there was a lack of knowledge and self-management of their heart disease. **Conclusions:** The study showed that adolescents and young people with CHD are not prepared to achieve a successful transition to adult health care services, and there is a need for the implementation of transition programs focused on education, self-care, and self-management of the disease.

Introduction

Congenital heart diseases (CHD) are the most common congenital malformation. In Chile, the prevalence ranges from 8 to 10 per 1,000 live births, similar to international figures[1].

Major advances in pediatric cardiology and heart surgery over the past 60 years have meant an exponential growth in the population of both adolescents and adults with CHD[2]. Survival to adulthood in this population has increased from 25% to over 95% in the last 40 years[3]. This new epidemiological profile requires a focus on the successful transition of adolescents with CHD from pediatric services to adult medical care. In our country, there are no transition services for adolescent with CHD.

On the one hand, the health care transition is the progressive process of planned movement of adolescents and young adults with chronic physical conditions from a child-oriented health care system to an adult one, considering physical and psychosocial factors[4]. Transfer, on the other hand, is an event consisting of the movement of patients and medical records from a pediatric to an adult follow-up center.

The lack of follow-up during the transfer period has proven to put patients at risk of complications of their disease, comorbidities, and need for emergency care due to decompensations[5]. On the one hand, international studies conducted with CHD populations have shown a loss to follow-up of up to 50% in the transfer period, with up to 7% of patients not receiving any type of medical care after their transfer from pediatric services[2]. On the other hand, in adolescents with chronic diseases, it has been described that a better knowledge of their condition and/or disease is associated with greater personal development skills, such as self-efficacy, which, at the same time, is related to better self-management and improved levels of well-being, and quality of life[6].

The objective of this research is to describe the knowledge and management of their disease, degree of self-efficacy, and quality of life during the transfer period to adult medical care, in adolescents and young people with CHD with follow-up visits at two hospitals in Santiago, Chile.

Patients and Method

Non-experimental, descriptive, cross-sectional study. At the time of the study, none of the centers studied had a formal and planned process of transition from pediatric to adult health care services.

We included adolescents and young people aged between 13 and 21 years, seen between July 2018 and May 2019, with a diagnosis of CHD, and who were in follow-up at the Pediatric Cardiology Department of a university general hospital (*Red de Salud UC-Christus*), representing the pre-transfer adolescent group, and at the Adult Congenital Heart Disease Unit of a public referral hospital in Santiago, Chile (*Instituto Nacional del Tórax*), representing the group of adolescents and young people in post-transfer period. Patients who could not answer the required surveys in writing due to their cognitive conditions were excluded.

This study was approved by the Scientific Ethics Committee of the Faculty of Medicine of the Pontifical Catholic University of Chile and the Scientific Ethics Committee of the Eastern Metropolitan Health Service. Caregivers provide informed consent as well as assent in the case of minors and informed consent in young people.

The surveys were self-applied in the waiting room, after explaining to the patient and supervised by a member of the research team in case of questions.

The following instruments were applied:

a) A structured survey that included general socio-demographic data, information regarding their disease and follow-up visits, knowledge of their medical condition and treatment, and regarding the use of health services, and perception concerning health decision making. Following the clinical diagnosis, we defined the complexity of CHD, according to Bethesda criteria, as simple, moderate, or great complexity[7].

b) Con-QOL Scale for Health-Related Quality of Life (HRQOL). It was developed for children and adolescents with CHD and has been validated in Chile for application to adolescents[8]. It includes the measurement of four domains: a) symptoms (frequency and intensity), b) limitations in daily activities, c) relationships, and d) coping and managing the disease. It scores from 0 to 100, where 0 indicates the worst and 100 the best HRQOL.

c) General Self-Efficacy Scale (GSE). It measures the personal perception of one's abilities to handle different stressful situations in life[9] which was validated in Chile for application in general population over 15 years of age[10]. The scale consists of 10 questions, which score ranges from a minimum of 10 to a maximum of 40 points. These are examples of questions: 'I can always manage to solve difficult problems if I try hard enough' and 'It is easy for me to stick to my aims and accomplish my goals'". The possible answers are: 1 = not at all true, 2 = hardly true, 3 = moderately true, and 4 = exactly true. The higher the score, the greater the overall perceived self-efficacy. The authors of the scale report that there is no pre-set cut-off point and suggest dichotomizing the sample into 30 points if the sample median is close to that value, or establishing groups based on the empirical distributions of a particular reference population. The values obtained in the Chilean validation of the GSE were mean 34.18 points ± 4.84 and median 35 points (range 16-40)[10].

Statistical analysis

The data obtained were managed anonymously by the researcher in charge, who carried out the digitalization and analysis, supported by the co-investigators. In no case were data stored that would allow the identification of the research subjects.

For descriptive statistics, we used numbers and percentages for categorical or nominal variables and mean and standard deviation for the continuous ones. Pearson's chi-squared test was applied for categorical variables and comparison of averages using Student's t-test for continuous variables. A p-value < 0.05 was considered statistically significant.

Multiple linear regression analysis was used to evaluate association.

All analyses were performed using IBM SPSS Statistics® (Chicago, IL, USA) software, version 26.0.

Results

A sample of 51 adolescents and young people was included, with CHD divided into two groups, 15 adolescents in the pre-transfer period in follow-up at the Pediatric Cardiology Department of a university general hospital, and 36 adolescents and young people in the post-transfer period in follow-up at the Adult Congenital Heart Disease Unit of a public referral hospital.

Of all patients, 53% were male. The average age was 17 ± 2.49 years, 14 ± 1.41 years in the group of patients seen at the Pediatric Cardiology Department, and 18 ± 1.80 years in the group seen at Adult Congenital Heart Disease Unit. 53% of all patients were users of the public health care system, 12% of the private one, and 35% of the patients did not know their health care system. Out of the total number of adolescents and young adults, 49% (n = 25) had great complexity CHD, 29% (n = 15) moderate complexity, and 22% (n = 11) simple complexity. 82% of the patients had undergone some type of heart surgery at the pediatric age.

Regarding educational level, around half of the sample had a scientific-humanistic high school education. Table 1 describes the sociodemographic characteristics of the population.

In relation to the assessment of knowledge of their disease, most of the patients stated that they knew the name of their disease and prescribed medications. However, 83% reported that they did not know or only partially knew the adverse reactions of their drugs. Between 30 and 40% of those interviewed stated that they did not fully know the effect of tobacco, drug, and alcohol consumption on their heart disease. It is noteworthy that about one-third of the female patients reported that they did not know if it was safe to become pregnant considering their cardiovascular condition (Table 2).

Regarding the management of their disease, 84% of patients referred to participate in decisions related to their health. However, almost half of the sample reported receiving medication from their caregiver, 50% acknowledged not knowing how to reach their doctor, and 57% were unaware of their future health insurance plan (Table 3).

When analyzed by age, there were no significant differences in most questions of knowledge, disease management, and use of health services between the group of adolescents aged ≤17 and the group of those aged >17. We only observed that the older group reported better knowledge regarding the effect of their medication ($p = 0.009$) and a greater perception of their participation in health decision making ($p = 0.021$). When comparing the group of patients in the pre-transfer versus post-transfer period, no differences were observed in knowledge, disease management, and use of health services.

The average score for the GSE was 31.3 ± 4.1 points, similar to that reported in general Chilean population. The mean score for HRQOL was 72.5 ± 10.7, which is comparable to the subgroup with the best quality of life in the patient sample used for the national instrument validation.

Pearson's correlation analysis showed bilateral significance between GSE and HRQOL scores ($p = 0.012$). In other words, the greater the self-efficacy of individuals, the greater their quality of life, with a moderate strength of association ($r = 0.342$).

Multiple regression analysis showed that age was the

Table 1. Sociodemographic description of adolescents and young adults with CHD

	Total n = 51 n (%)	Pediatric Cardiology Unit n = 15 (%)	Adult CHD Unit n = 36 n (%)	p value
Gender				
Female	24 (47)	7 (47)	17 (47)	NS
Male	27 (53)	8 (53)	19 (53)	NS
Age (years)	17 ± 2.49	14 ± 1.41	18 ± 1.8	< 0.0001
CHD Complexity*				
Simple	11 (22)	2 (13)	9 (25)	NS
Moderate	15 (29)	3 (20)	12 (33)	NS
Great	25 (49)	10 (67)	15 (42)	NS
Current Educational Level				
Special Ed.	3 (6)	0	3 (8)	NS
Primary Ed.	6 (12)	6 (40)	0	0.0001
Secondary Ed.	23 (45)	8 (53)	15 (42)	NS
Technical Secondary Ed.	3 (6)	0	3 (8)	NS
University	7 (14)	1 (7)	6 (17)	NS
Higher Technical/Vocational Ed.	9 (17)	0	9 (25)	NS
Insurance type				
Public system	27 (53)	5 (33)	22 (61)	NS
Private system	5 (10)	5 (33)	0	0.0005
Others	1 (2)	0	1 (3)	NS
I don't know	18 (35)	5 (33)	13 (36)	NS
Marital status				
Married	1 (2)	1 (7)	0	NS
Living with partner	1 (2)	0	1 (3)	NS
Single	49 (96)	14 (93)	35 (97)	NS
Geographical Region				
Metropolitan	7 (14)	4 (27)	3 (8)	NS
Others	40 (86)	11 (73)	33 (92)	NS

p value < 0.05 was considered statistically significant. *Congenital Heart Disease Complexity acording to Bethesda Conference[7]. CHD = Congenital Heart Disease; NS = Not significant; Ed. = Education.

only significant predictor of self-efficacy (p = 0.0420) with an adjusted r^2 of 0.021. (Table 4).

Discussion

Based on these results, there is little knowledge of patients with CHD about their disease and pharmacotherapy, both in pre-transfer and post-transfer groups of adolescents and young people. This may occur due to the lack of a planned process of transition of adolescents from pediatric to adult health care in the centers studied.

A risk factor for loss of adherence to treatment could be that about one-third of the sample does not know or knows only partially the effect of the drugs they use, with the consequences that this has on their clinical evolution. However, even more worrying is the level of ignorance about the adverse effects of their drugs, which can be potentially harmful to their health.

Women in the sample showed a high degree of ignorance regarding the safety of carrying out pregnancy with their cardiovascular condition. In the population of women with CHD, pregnancy contraindications are limited to a small group of cases, however, the recommendation is that pregnancies should be planned and with a previous assessment of their cardiovascular condition[11]. The lack of knowledge of patients in this area exposes them to unnecessary risks in the case of unplanned pregnancies in at-risk populations. This also occurs in women who, without having a contraindication for normal pregnancy or delivery, are faced with a pregnancy that can be highly stressful due to the perceived fear of their cardiovascular condition, with possible unnecessary and risky obstetric interventions (rest indication, pre-term inductions, elective cesarean

Table 2. Level of knowledge of their disease in adolescents and young adults with CHD

	Total (n = 51) n (%)
Do you know the name of your heart condition?	
Yes	40 (78)
No	11 (22)
Do you know the name of your medications?	
Yes	25 (86)
Partially	4 (14)
Do you know what the medications you use are for?	
Yes	20 (69)
No	3 (10)
Partially	6 (21)
Do you know the adverse reactions of your medications?	5 (17)
Yes	20 (69)
No	4 (14)
Partially	
Do you know if it is safe to get pregnant?	
Agree	14 (59)
Moderately agree	2 (8)
Disagree	8 (33)
Do you know the effect of tobacco on your heart disease?	
Agree	33 (65)
Moderately agree	12 (23)
Disagree	6 (12)
Do you know the effect of illicit drugs on your heart disease?	
Agree	34 (67)
Moderately agree	8 (15)
Disagree	9 (18)
Do you know the effect of alcohol on your heart disease?	
Agree	31 (61)
Moderately agree	7 (14)
Disagree	13 (25)

CHD = Congenital Heart Disease.

Table 3. Management of their disease in adolescents and young adults with CHD

	Total (n = 51) n (%)
Do you participate in decision-making regarding your health?	
Yes	43 (84)
No	8 (16)
Who administers your medications?	
Me	16 (55)
Caregiver	13 (45)
Do you know wich medical facility should you go in an emergency?	
Yes	33 (65)
I need to learn more	18 (35)
Do you know how to contact your physician?	
Yes	25 (49)
No	26 (51)
Do you know if you should keep your health insurance plan for life?	
Yes	29 (57)
No	22 (43)

CHD = Congenital Heart Disease.

section), which in most patients are not clinically justified by their heart disease.

There is a poor self-management of the current disease, where only half of the total sample is personally administering their drugs, evidencing the permanent presence of a caregiver-patient dyad that has extended its pediatric operating pattern, without a change in the assignment of care responsibilities according to the maturation of the adolescent. In addition, there is a low degree of knowledge of the clinical and administrative functioning of health services, highlighting that most patients declare not knowing how to contact their physician or schedule a follow-up visit. 35% of adolescents and young people with CHD report not

Table 4. Multiple regression correlation analysis between specific variables and General Self-Efficacy Scale Score

Variables	B	SE B	p
CHD Complexity	-0.281	0.682	0.682
Age	-0.542	0.259	**0.042**
Educational Level	0.489	0.296	0.105
Gender	-0.574	1.152	0.621
R^2	0.021		-
F	1.288		0.28

p value < 0.05 was considered statistically significant. CHD = Congenital Heart Disease; B = Coefficient; SE B = Standard error of coefficient; R^2 = Adjusted coefficient of determination; F = F Index.

knowing where to go in case of an emergency, which could represent a delay in the need for this type of care.

The lack of knowledge could be explained by a paternalistic model of pediatric care, where both parents and health personnel give little information to adolescents and young people, with the caregiver assuming the main role in managing the disease until a very advanced patient's age[12].

On the positive side, the high perception of participation of adolescents and young people with CHD in decision making regarding their health stands out. The general self-efficacy perceived by the patients is similar to that reported in the healthy population[10], showing that the studied population presents an acceptable level in this domain regarding the management of general life situations, which is not necessarily related to the management of their health condition. International studies have shown that the presence of high self-efficacy in adolescents with CHD is related to successful transfer to adult health services[6].

The good level of self-efficacy in this study could be explained by several reasons. First, the characteristics of omnipotence and invulnerability, typical of the adolescent stage; second, a possible separation in the perception of these patients between their daily life and their health condition, in other words, they perceive themselves as self-effective in daily aspects of their life, without considering aspects related to their health condition in the answers; or third, the permanent presence of an overprotective parent who solves all their limitations and difficulties. However, these assumptions cannot be drawn from this study and require another type of methodology for this purpose.

Regarding the HRQOL, the score of our sample is similar to the score of patients who reported a 'Very Good' or 'Good' self-perception of health in the Chilean validation population, showing that our sample reports having levels of HRQOL within the high range, compared with the national reference adolescent population with CHD[8].

This study shows that the higher self-efficacy of individuals, the higher their stated quality of life, which is consistent with what has been published in international studies[6]. We can also observe that self-efficacy correlates significantly with patient age, presenting higher self-efficacy in older patients. However, the coefficient of determination adjusted for self-efficacy was low, showing that there could be other variables that explain self-efficacy and that have not been included in this model.

We found that an adequate level of self-efficacy allows assuming that adolescents and young people with CHD have a high potential for self-management of their disease[10]. However, they show little knowledge of their disease and the use of health services. These findings are relevant for public policy in our country, since they highlight the need for implementing planned programs for transitioning adolescents with CHD from pediatric to adult health care services, focused on the delivery of information about their disease and management, prevention of risk behaviors, and education regarding the use of health services.

It must be understood that the transition is a planned process, which should begin at the pediatric age and extend until after the transfer, ending when the patient has developed the necessary skills to be independent regarding their health condition, with all that this implies.

Concerning the limitations of the study, the sample only includes two hospitals in the Santiago Metropolitan Region, therefore, the results cannot be extrapolated to the total population of adolescents and young people carrying CHD. Moreover, this is a selected sample of patients who adhere to follow-up visits, thus it could be assumed that the population that does not adhere to follow-up has even worse knowledge of their health condition and management of their disease, to the extent of losing follow-up. The sample size is also a limitation, especially of patients in the pre-transfer period, which limits the significance of the statistical analysis.

Despite these limitations, the results of this study contribute to our understanding of the current situation of adolescents and young people with CHD in the transfer period. Future multicenter studies representative of the different regions of the country are needed for obtaining results that can be generalized to the entire population of adolescents and young people with CHD in the period of transition to adult health care.

Conclusions

This study shows that in this population of adolescents and young people with CHD, there is a lack of preparation for the transfer to adult health care, which is consistent with what is described in studies on adolescent carriers of chronic diseases in the transition process[12].

Given the change in the epidemiological profile currently faced regarding chronic childhood pathologies, the transition process has become a major issue both nationally and internationally. There is an urgent need for implementing transition programs and services for adolescents and young people with CHD, focused on self-care and self-management of their condition, that provide support to families, health services, and the community, which will influence the successful transition to adult health care[13].

We expect to contribute to the understanding of the current situation of adolescents and young people in this critical period, serving as a starting point and basis for future research on the issue.

There is a need for qualitative studies that deepen the perception of patients and their caregivers regarding their strengths and needs at this stage.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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