Interventional Cardiology Journal
ISSN: 2471-8157

Open Access Research Article

Social Development and Professional Activity in Adult with Congenital Heart Disease

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ABSTRACT

Background: Patients with congenital heart disease have a limited quality of life due to their heart condition and to surgical complications and interventional therapy. Many of them require further medical care and surgery or catheterization during adulthood to treat residual lesions or complications. The objective of this study was to evaluate how congenital heart disease influences schooling and employment in adult CHD patients and analyze the quality of life of patients with various heart conditions.

Methods: We prospectively included 492 consecutive adults with CHD who were followed in CHD unity. From October 2008 to July 2019 and one hundred healthy control subjects voluntarily participated in the study and were enrolled from high schools, universities and companies in Casablanca. The assessment of socio-demographic factors was performed using a questionnaire. Were covered education level, employment status and physical activity. A Linear Analogue Scale (LAS) was employed to assess quality of life among those patients.

Results: Fifty eight percent of patients having a moderate quality of life, 19% having a poor quality of life and 23% of patients report having a good quality of life. The group of patients with a good quality of life appeared to have a higher educational level than the other groups of patients. Patients categorized as having a good quality of life more often had a university degree than patients categorized as having a moderate quality of life.

According to the classification of Bethesda heart disease was simple in 42% of our patients, moderate in 50% and complex in 8% of patients. Diagnosis of the CHD was made during adulthood in 62% of patients. Complex CHD were mainly diagnosed during childhood. Patients with an unstable heart condition and patients with a worse NYHA functional class reported a poorer quality of life, with the highest proportion in the poor quality-of-life cluster.

In terms of employment status, patients who were unemployed or disabled more frequently had moderate or poor quality of life. By contrast, students were more likely to report a good quality of life.

Received:	12-September-2023	**Manuscript No:**	IPIC-23-17830
Editor assigned:	15-September-2023	**PreQC No:**	IPIC-23-17830 (PQ)
Reviewed:	29-September-2023	**QC No:**	IIPIC-23-17830
Revised:	03-October-2023	**Manuscript No:**	IPIC-23-17830 (R)
Published:	05-October 2023	**DOI**	10.21767/2471-8157.9.8.79

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Citation: Abasse ZE, Drighil A, Ejjebli S (2023) Social Development and Professional Activity in Adult with Congenital Heart Disease. Interv Cardiol J. 9: 79.

Seventy-three percent of men and 65% of women followed for CHD were married. The marriage rate in patients with complex CHD was 37%. No physical activity was declared by 39% of our patients; 66% of patients with complex CHD had no physical activity versus 34% of patients with simple CHD 40% of patients with moderate CHD.

Conclusion: Good quality of life associated a higher educational level (university). Vocational high school was more frequently associated with patients in the moderate or poor quality-of-life. In terms of employment status, patients who were unemployed or disabled more frequently had moderate or poor quality of life. Patients with a worse NYHA functional class reported a poorer quality of life.

Keywords: Linear analogue scale; Quality of life cluster; Bethesda heart disease; Patients

INTRODUCTION

Since the 1940's when the first operation methods were developed, long-term management of patients with congenital heart diseases has come to include increasing numbers of post-operative patients. The survival figures have increased from some 10%-15% to 70%-90%. Today, there are more adults than children and adolescents living with CHD in developed countries; many of them require further medical care and surgery or catheterization during adulthood to treat residual lesions or complications, such as heart failure, arrhythmia or pulmonary hypertension. In developing countries, adult patients with CHD are mostly not operated, only few of them had surgery in childhood however, we start to see some adults being operated during childhood and others with native lesions who are still waiting for surgery [1,2].

The World Health Organization defined health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity". In fact, cardiac lesions are not always the major problem for these patients; whereas emotional, psychological and social determinants such as employment status, educational achievement and marital status have an important impact in the quality of life beside physical health. Thus quality of life can be assimilated to a multi-dimensional concept integrating emotional, physical and social well-being as perceived by the individual [3].

Because of a lack of an integrated national health care system, as well as a lack of a national disease based registry for congenital heart disease, studying national trends and characteristics of patients with congenital heart disease in developing countries remains a great challenge. Employment prospects are a major concern for patients and their parents. Paid employment is important in daily life, not only in terms of earnings and social status, but also for its social support and social distraction [4]. Because of the defect, the environment of social growth may be changed, owing to the attitude of parents, peers and teachers. The patients are easily over protected and separation from the parents in adolescence may therefore be delayed. This deviation in social relations may also be influenced by the emotional trauma described in children with congenital heart disease. The objective of this study was to evaluate how congenital heart disease influences schooling and employment in adult CHD patients and analyze quality of life of patients with various heart conditions [5].

MATERIAL AND METHODS

Study Population

We included 492 adults with CHD who were followed in the cardiology department from October 2008 to July 2019. Patients were included from a database of 3219 patients followed for congenital heart disease [6].

The inclusion criteria were as follows: Structural congenital heart disease, as confirmed by echocardiogram, cardiac catheterization or surgery; ability to give their consent and respond to questionnaires and age ≥ 18 years. Patients were excluded if they were judged to have learning disabilities during the clinical interview. The study protocol conformed to the ethical guidelines of the 1975 Declaration of Helsinki. One hundred healthy control subjects voluntarily participated in the study and were enrolled from high schools, universities and companies in Casablanca. Informed consent was obtained and instructions on filling out the questionnaire were provided to medical staff, patients and control subjects [7].

Variables and Measurements

From the database and the clinical interviews, we collected demographic data (age, sex), marital status, medical history, complications. The complexity of CHD was classified as simple, moderate or complex, according to the Bethesda criteria [8].

The assessment of socio-demographic factors was performed using a validated questionnaire. Were covered education level (achieved secondary education or not), employment status and physical activity (categorized into four levels: No physical activity; mild physical activity 20 minutes no more than once a week; moderate physical activity 20 minutes twice a week; and intense physical activity (20 minutes, at least three times a week) [9,10].

A Linear Analogue Scale (LAS) was employed to assess quality of life. The LAS consisted of a vertically oriented, 10-centimeter line, graded with indicators ranging from 0 (worst imaginable quality of life) to 100 (best imaginable) defining

from 0 to 30 a poor quality of life, from 31 to 60 a moderate quality of life and from 61 to 100 a good quality of life. Statistical analysis was performed with SPSS 17.0.1 (SPSS, Inc., Chi-cago, Illinois).

RESULTS

The median age of our patients is 31 years 18-85 years, with a female predominance of 60%; in the control group the median age was 23 years 17-65 years (Table 1).

Table 1: Demographic and clinical characteristics of CHD patients.

Median age	31 years (18-85 years)	Total number=492
	Percentage	Number: n
	Gender	
Men	40.2%	n=196
Women	59.8%	n=296
	Type CHD	
Left to right shunt	70.5%	n=344
Obstructive CHD	27.9%	n=132
right to left shunt	25.4%	n=123
Medical treatment	22.8%	n=108
Diuretics	19.2%	n=94
Aldosterone antagonist	10.2 %	n=49
ACEI/ARAII	16.8%	n=78
Beta blockers	21.2%	n=103
Anticoagulants	23.2%	n=113
Antiplatelets	25.2%	n=123
	Surgical treatment	
Operated	63%	n=309
Non operated	37%	n=182
Cardiac interventionnal catheterization	14.4%	n=70

According to the classi ication of Bethesda heart disease was simple in 42% of our patients, moderate in 50% and complex in 8% of patients. Diagnosis of the CHD was made during adulthood in 62% of patients. Complex CHD were mainly diagnosed during childhood (Figure 1).

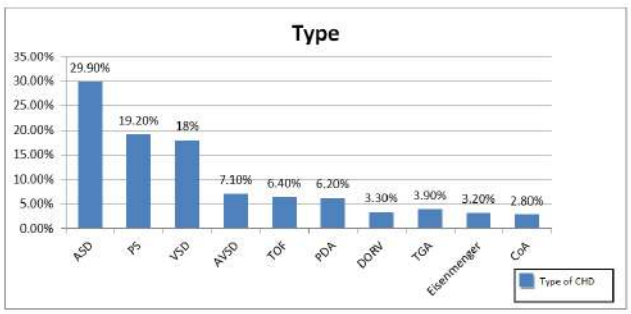

Figure 1: Distribution of congenital heart disease in the study population.

CHD left to right shunt is the most common entity 70%. Atrial septal defect was the most frequent CHD 30% with 83% who were ostium secondum. Sixty three percent of the total patients were operated. Medical treatment was prescribed in 23% of cases. Cardiac interventional catheterization was performed in 14 of patients [11].

Many complications were reported in our patients among them we found: Supra ventricular rhythm disorders in 21% of cases; heart failure 34% of cases; pulmonary hypertension in 20%; ventricular arrhythmias in 7% of cases and infective endocarditis in 8% of cases. No case of resuscitated death was reported [12].

Education and Employment

The education rate: Twenty five percent (n=123) of all patients passed the baccalaureate; 34% of them had a simple CHD, 22% had a moderate CHD and 12% of them had a complex CHD. The success rate in school was higher in patients without congenital heart disease complications (34%*vs.* 14%) (p=0.007). In the control group we had 87% who were schooled of which 60% pursued their schooling at that time [13].

The employment rate: Forty eight percent of our patients had an employment; among them 60% with simple CHD, 44% had a moderate CHD and 16% had a severe CHD. In the control group 86% had a job (p=0.014).

Marital Status

Seventy-three percent of men and 65% of women followed for CHD were married. The marriage rate in patients with complex CHD was 37%. Seventy one percent of married women have one child or more [14]. Ninty two percent of single patients live with their parents; at opposite, 40% of the control group were married and 22% were living alone (p=0.027).

Physical Activity

No physical activity was declared by 39% of our patients; 66% of patients with complex CHD had no physical activity versus 34% of patients with simple CHD 40% of patients with moderate CHD. Among patients who declared no physical activity, sport had been contra-indicated by practitioners in 25%.

Quality of Life

Based on the Linear Analogue Scale LAS, 58% of our patients had a moderate quality of life, 19% had a poor quality of life and 23% of patients had a good quality of life [15].

The group of patients with a good quality of life appeared to have a higher educational level than the other groups of patients. Patients categorized as having a good quality of life more often had a university degree than patients categorized as having a moderate quality of life [16]. Eighty four percent of patients with complex CHD had a poor quality of life and 70% of patients with moderate and simple CHD had a good quality of life [17].

Among patients who underwent surgery or interventional catheterization, 61% of operated patients had a good quality of life. Fifty two percent of non-operated patients had also a good quality of life (p=0.07). In terms of employment status, patients who were unemployed or disabled more frequently had moderate or poor quality of life. By contrast, students were more likely to report a good quality of life [18]. Patients with an unstable heart condition and patients with a worse NYHA functional class reported a poorer quality of life, with the highest proportion in the poor quality-of-life cluster (**Table 2**).

Table 2: Congenital heart disease related complications.

	All patients (n=492)	Simple CHD 41% (n=201)	Moderate CHD 50.6% (n=248)	Complex 8.2% (n=40)
Diagnosis during childhood	62.2%	80.2%	56.7%	12.7%
		Complications		
Heart failure	34.05%	22.2%	38.2%	72.7%
Supraventricular arrythmia	20.82%	12.7%	22.6%	55.6%
Pulmonary hypertension	19.9%	16.8%	19.1%	43.7%
Endocarditis	8.54%	5.6%	9.2%	20.7%
Ventricular arrythmia	6.49%	1.4%	9.5%	14.7%

DISCUSSION

In this study, which included 492 patients who are followed in our structure for congenital heart disease, we observed that there is a clear relationship between the presence of CHD and especially its complexity and quality of life which mainly include the level of education, employment and physical activity [19].

Level of Education

According to our study, the level of education of adults followed for CHD seems low, this rate is much lower in patients with complex CHD. Also, success rate tended to decrease with the complexity of congenital heart disease [20].

van Rijen, et al. reported a lower educational attainment in young adults with CHD compared to a reference group. Absence from school because of illness, treatment or recovery and learning disabilities because of early neurologic complications could explain these poorer outcomes in patients with CHD. Moreover, low self-esteem and less motivation might contribute. Early diagnosis and treatment is associated with better neuro cognitive outcomes (**Table 3**).

Table 3: Assessment of social variables and physical activity according to severity of heart disease.

	All patients	Simple CHD	Moderate CHD	Severe CHD
		Level of education		
Passed the baccalaureate	25.93%	34.2 %	22.1%	11.7%
		Employment		
Employed	47.84%	60.4%	43.8%	15.6%
		Marital status		
Married	64.37%	72.2%	65.2%	37.2%
One children or more	60.44%	68.7%	60.1%	28.7%
		Physical activity		
No physical activity	39.66%	34.1%	40.2%	65.8%

These results confirm the studies that associate the CHD patients with good quality of life to higher educational levels. Indeed, a high educational level, by facilitating the access to information and giving an adequate environment, makes the patient able to understand his disease and being aware of the importance of following the medical instructions and benefiting from the available resources, like social services, to have the best quality of life possible in his condition. In the other hand, a CHD can also directly affect the patient education through absence from school because of illness, recurrent hospitalizations and long recovery from different invasive procedures.

Job

According to our study less than half of the adults followed for CHD have a constant job and for the control group 86% of patients had a constant job and/or pursued their schooling at that time. This joins a large multicenter study by Zomer AC, Vaartjes I, Uiterwaal CS, which states that a poorer socio demographic outcome was observed in young adults with CHD (particularly those with severe CHD) compared with a reference group. Better employment status was also observed in patients with mild versus severe defects (76% *vs.* 57%) in a study by Kam-phuisetal.

A recent multicentre study compared a large sample of adult patients with various types of CHD with a reference group. The results demonstrated that young CHD patients (aged<40 years) had lower outcomes in educational attainment and employment compared with the reference group. And this difference was observed not only for moderate-to-severe defects but also for mild defects. A latter study by Kamphuis and Ternestedt found even a clear difference between mild and severe defects, with better employment status for those with mild defects which was similar to our findings.

Marriage

In our study, the presence of congenital heart disease does not represent a real obstacle to marriage and this can be explained by the culture, religion and life style prevailing in our country. In fact, 64% of our patients were married.

On the contrary, other studies show that the prevalence of patients living with their parents is higher. This could be explained by the early diagnosis and therefore a more important dependence on parents. This dependence is not totally related to the degree of disability, but has been influenced by the social environment. The main problem is of course that the parents themselves have actively formed the close relationship during childhood. This seems to alter social progress after adolescence more than the default itself.

For a CHD patient, the eventual risks of pregnancy and delivery, in addition to the fear and the guilt of passing their heart condition to the offspring and also the bad general health condition that will compromise the parenting role are enough reasons to avoid marriage and having kids.

Quality of Life

Sixty three percent of the patients group were operated; in our study, no significant difference in quality of life between patients who were operated and not operated was observed. The results of a study by Ladak LA, Hasan BS, Gullick J, Gallagher R highlight that even after surgical intervention, children and young adult patients with complex CHD had worse cardiac-related HRQOL compared with those with moderate and mild CHD.

In our study, only 22.3% affirmed having a good quality of life. Previous studies have found that the quality of life of CHD patients is basically equivalent to that of the general population. Conversely, factors contributing to a poor quality of life are having pain, experiencing frequent or continued fatigue and losing control over one's body functions.

Some controversial studies have indicated that patients quality of life can be better than that of healthy peers. Given the fact that congenital heart disease can be considered to be a chronic condition in many patients, it appear normal that they report such a bad quality of life. This might be explained by two notions: Disability paradox and sense of coherence. The disability paradox refers to the observation that individuals with disabilities may perceive a high quality of life if they acknowledge their impairment; if they preserve control over their body, mind and life; if they remain able to perform expected roles; and if they feel satisfied when comparing themselves and their capabilities with those of others in similar situations.

We believe that patients with an unstable medical condition and with a reduced functional status had a poorer quality of life.

CONCLUSION

The number of studies on quality of life in children and adolescents with congenital heart disease has increased in recent years because of increased survival in this population. A lot of studies show conflicting results and actually, there is a tendency to investigate factors such as parental styles, social support, environment and coping strategies to better understand the quality of life in these patients with CHD. All of these variables that interact in the perception of quality of life are difficult to grasp or to analyse by a single measuring instrument.

The objectives of the management of CHD have widened in view of the development of surgical techniques and the codification of treatments. This management is no longer only to increase life expectancy but also to improve the quality of life. And this by creating transition centers whose goal is to provide uninterrupted health care and include age-appropriate education in many areas (physical, social, family relationships, emotional, educational, vocation, medical). Parents should play an important role in these centers.

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