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Effect of Adult Congenital Heart Disease in adults on Psychological Wellbeing and Quality of Life in Egypt

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ABSTRACT

Background: Complex congenital heart disease (CHD) had very poor prognosis just a few decades ago. Nowadays, more than 90% of them, survive into adulthood, yet the complete "correction" or "repair" of CHD is not the rule and many of those patients undergo palliative interventions or surgeries. Many psychiatric and mental disorders could be seen in this group of patients. Furthermore, this could affect quality of life (QOL).

Objectives: Find out how prevalent anxiety and depression are among adult congenital heart disease (ACHD) patients and understand how it affects their lifestyle quality.

Patients and Methods: Observational case-control, cross-sectional study on 300 Adults with CHD vs 300 controls. Controls and patients were asked to fill three questionnaires to determine the prevalence of anxiety, depression, and QOL.

Results: Cases had higher anxiety and depression scores than controls and had poorer QOL than controls.

Conclusion: Congenital heart conditions adversely affect the QOL compared to a matched control group. Additionally, this cohort of patients suffers psychological distress, with more anxiety and depression in comparison to the control group. These results emphasize the drastic impact of CHD on the overall well-being of affected individuals, stressing upon the importance of holistic care that addresses both the physical and psychological aspects of their health.

Keywords: Congenital heart disease, Depression, Anxiety, Quality of life, Stress levels.

INTRODUCTION

Complex congenital heart disease (CHD) had high rates of mortality in the first few years of life until around 1940. Nowadays, more than 90% of them reach maturity. These significant advancements are mainly due to scientific breakthroughs in congenital cardiology, cardiac surgery, critical care, and pharmacology [1].

One significant study came to the conclusion that the age distribution at death is changing from bimodal to unimodal. In other words, the number of adults with CHD has surpassed that of children[2] . Despite a sharp decline in CHD mortality, a sizable portion of morbidity is still underreported. It is important to realize that complete repair with anatomical and physiological repair that results in a normal life expectancy and no need for additional care, is not the rule [1].Many psychiatric and mental disorders can be seen in patients with CHD. For instance, many studies suggested that adults with CHD are more prone to depression. Depression in this cohort of patients could be as high as 30% in some studies. Generally, the co-existence of chronic medical conditions and depression is well established [3].

Additionally, patients with single-ventricle physiology are reported to have a lifetime anxiety diagnosis rate that is five times higher and a lifetime attention deficient hyperactive disorder (ADHD) diagnosis rate that is almost six times higher, both of which can have an impact on academic performance and social functioning. [4].

The QOL of adult CHD patients can also be impacted by mental conditions such as anxiety and mood disorders, according to research. The employment and social lives of patients may be affected because of these diseases. As a result, psychiatric disorders screening may help the patient's condition. [5].

Quality of life in patients with severe forms of the illness is usually more impaired compared to those with mild and moderate forms of the illness [6,7].

Healthcare systems in most countries are challenged by a considerable financial strain owing to the growing ACHD population [8,9], this is mainly due to late disease complications and the necessity of lifetime follow-up. It is thus crucial to estimate the cost of hospitalization for ACHD patients [10,11] .

AIM OF WORK

To determine the prevalence of anxiety and depression in adult congenital heart disease (ACHD) patients and to understand its effect on the QOL.

PATIENTS AND METHODS

We conducted this observational case-control, cross-sectional study on CHD patients presenting for elective assessment in the Demerdash Congenital and Structural Heart Disease Unit, Cardiology Department, Ain Shams University. We included 300 patients and 300 controls.

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Inclusion criteria:

- We studied patients above 19 years old with CHD presenting to Demerdash Hospital between September 2022 till March 2023 as cases.
- Controls were age and sex-matched subjects.

Exclusion criteria:

- Patients below 19 years.
- Presence of a pre-existing diagnosis of a mental illness.
- previous history of psychiatric illness or taking psychotropic drugs.

Full history was taken from all participants including age, sex, educational level, smoking, marital status, sleeping habits, previous diagnosis of a mental disorder or taking psychotropic drugs, previous catheterizations, and previous heart surgeries.

After history taking, three questionnaires were introduced to all participants by the investigator either in hard copy or soft copy. Patients who could not read were asked the questions in an oral form and the questionnaire was manually filled by the investigator.

The first questionnaire was the HADS (the Hospital Anxiety and Depression Scale) score, constructed from seven questions for anxiety assessment and seven questions for depression assessment. The questions are distributed through the questionnaire, yet, they were scored separately with a score that could be as low as zero or as high as 21 for each division (anxiety and depression). Results from 0 to 7 denote no anxiety or depression, results from 8 to 10 equal borderline cases, and results between 11 and 21 denote abnormal cases.

The second questionnaire is the Arabic version of General Health Questionnaire 28 (GHQ 28). It is a simple questionnaire used to assess functional psychiatric disorders. The GHQ-28 is feasible to be used in different cultures and is accessible in 38 languages [12]. We used the translated and validated Arabic version with a cut-off value of 7 in the Egyptian score, where results of 7 or higher indicate a high level of psychological distress while results below 7 indicate a low level of psychological distress.

The third questionnaire was the SF-36 (36-Item Short Form Survey) health survey, which is a widely used, thoroughly studied, self-reported indicator of health. It consists of 36 questions that address eight different areas of health:

1) Physical activity limitation.
2) Negative impact on social activity restrictions brought on by mental or physical issues.
3) Restrictions on routine daily activities brought on by physical health issues.
4) Pain in the body.
5) General mental health (ease of mind and psychological suffering).
6) Restrictions on routine job duties brought on by emotional reasons.
7) Vitality (vigour and exhaustion).
8) Perceptions of general health [13].

On the premise that each question has equal weight, each scale is instantly converted into a 0-100 scale. The more disabled you are, the lower your score; the less disabled you are, the higher your score. Maximum disability is equal to a score of 0, and no disability is equal to a score of 100. The QOL of an individual or population is frequently assessed using the SF-36.

Ethical Approval

Approval from the Ethical Committee at Ain Shams University was granted prior to the protocol's launch. This study was done according to the ethical standards specified in the 1964 Helsinki Declaration. The participants gave informed complete permission.

Statistical analysis

The statistical software for social sciences, version 23.0 (SPSS Inc., Chicago, Illinois, USA) was used to examine the data that were acquired.

When the distribution of the quantitative data was parametric (normal), it was provided as mean, standard deviation, and ranges; however, when the distribution was non-normal, it was shown as median and interquartile range.

Probability (P-value)

–Statistical significance was determined with a P-value less than or equal to 0.05, while a P-value below 0.01 determined highly significant correlations.

– On the other hand, P-value above 0.05 was considered insignificant

RESULTS

With a mean age of 26.64 and ages ranging from 19 to 63, the research group included 300 individuals. 132 men (44%) and 168 women (56%) made up the study group. The age and sex of the control group were matched.

214 patients were single (71.3%), and 212 patients (70.7%) had secondary education, followed by tertiary (22.3%), primary (2.7%), and post-secondary (4.3%). Employment-wise, 33.3% were employed, and 66.7% were not employed. In this study group, 50 patients were smokers (16.7%), and 174 patients (58.0%) reported disturbed sleep patterns.

222 patients (74.0%) had undergone catheterization previously, 34 patients (11.3%) had undergone surgery, while 38 patients (12.7%) had experienced both procedures. Regarding catheterization, 200 patients (76.9%) had percutaneous interventions while 60 patients (23.1%) had diagnostic catheterization (Table 1).

Table (1) shows the study group's previous interventions.

		Study group N = 300	
		N	%
Previous intervention	**Catheterization**	222	74%
	Surgery	34	11.30%
	Both	38	12.70%
	None	6	2.00%
Catheterization	**Therapeutic**	200	76.90%
	Diagnostic	60	23.10%
Number of cath. Lab interventions or surgeries	**Median (IQR)**	1(1-2)	
	Range	0-4	

Atrial septal defect was the most common diagnosis in 44.5%, followed by patent ductus arteriosus (PDA) in 17.7%, and ventricular septal defect (VSD) in t 16.4%. Other diagnoses included coarctation of the aorta (7.7%), pulmonary stenosis (Ps) (4.3%), tetralogy of Fallot (TOF) (3.0%), subaortic membrane (SAM) (2.0%), and various other rare conditions.

In the context of the study involving 300 participants, the GHQ-28 (General Health Questionnaire-28) questionnaire was employed to assess psychological well-being. Results revealed that two-thirds of the participants (67.3%) of participants had a positive outcome and scored 7 or higher indicating potential psychological distress (2).

Table (2) shows values of GHQ-28 (General Health Questionnaire 28) score among cases, with cut off value of ≥7

		Study Group (N=300)	
		N	%
GHQ-28	**Higher level of distress**	202	67.30%
	Lower levels of distress	98	32.70%

Regarding the results of the HADS assessment, anxiety scores indicated that anxiety was more prevalent in the cases vs controls, where 48.3% of the cases vs 22.7% of the controls, by Chi- Square test, the difference reached statistical significance (P<0.001).

In terms of HADS depression scores 33.0% of the cases vs 18.0% of the controls were classified as "Depressed." Similarly, the difference between cases and controls regarding depression scores reached statistical significance (P<0.001), emphasizing variations in psychological well-being between the two groups. Assessing SF-36 scores; the control group demonstrated a markedly higher score than the study group (Table 3).

Table (3) shows SF-36 (36-Item Short Form Survey) scores in cases vs controls.

		Study Group (N=300)		Control Group (N=300)		P-value
		N	%	N	%	
SF-36 Score	**Mean ±SD**	45.45±11.12		66.0±11.13		<0.001**
	Range	11.6 – 91.20		30.44 – 92.10		

**: Highly significant

DISCUSSION

We conducted this study to explore ACHD patients and how this affects psychological well-being and QOL. Determining the magnitude of the problem is crucial for better allocation of all available resources (medical and financial) in this growing population.

The 300 cases we evaluated had an average age of 26.64 years (10.42), ranged in age from 19 to 63 years, and had a pretty evenly split gender of 44.0% men and 56.0% females. similarly, **Khajali** and colleagues studied 101 patients, with a mean age of approximately 31.05 years. Female participants were more represented in the study population with 63 females compared to 38 males [5].

In our study, the prevalence of smoking among cases was 16.7%, while the majority were non-smokers (83.3%). According to a study done in 2022 by **Baroutidou *et al.***, only 8% of Greek patients with CHD acknowledged smoking [14].

Similarly, **Engelfriet** and colleagues revealed that 9.3% (n= 314) were current smokers and 4.2% (n= 142) of the patients had smoked in the past [15]. Although the

prevalence of smoking is almost the same in both Egypt and Greece, the higher smoking prevalence in ACHD patients in Egypt could point to a lack of comprehensive cardiac rehabilitation, health education and counselling in this group of patients.

The GHQ-28 results in this current study, show a noteworthy prevalence of psychological distress, affecting two-thirds of the study population. Similar findings were made in 2002 by **Cox** and colleagues, who discovered a statistically significant difference in the mean GHQ between the case group and comparison group with CHD, as well as considerable distress in the case group [16]. This could be related to a variety of factors, including their medical condition, past interventions, or other life circumstances. This emphasizes how crucial it is to take into account the psychological health of people with congenital cardiac disorders as well as the possible need for specialized psychological care and therapies.

Regarding the results of the HADS score in our study, the results reveal significant differences in the mental health profiles between the two groups. Diagnosis of anxiety and depression (with a score between 11 and 21 for each) was higher in the cases than the control group, this difference reached statistical significance both for anxiety and depression. Similarly, **Lebherz *et al.*** concluded that the prevalence of anxiety was higher than expected from reference values (12.7% ACHD vs. 5.6% control) [17]. However, their study revealed that the prevalence of depression in ACHD was comparable to the German normal population (5.9% ACHD vs. 5.4% control). The statistically significant differences in anxiety and depression scores underscore the importance of addressing the psychological well-being of individuals with congenital heart diseases and the potential need for targeted mental health support and interventions within this population.

The SF-36 scores serve as a critical measure of health-related QOL. In our study, cases had a notably lower mean SF-36 score of 45.45 (±11.12), indicating lower QOL, in contrast to the control group, which had a significantly higher mean score of 66.0 (±11.13). We conclude a substantial and statistically significant difference in mean SF-36 scores between the two groups.

In a study done by **Khajali** and colleagues, they revealed that adults with CHD suffered an impaired QOL, which was independent of the varying demographic and socio-economic influences [5]. The mere presence of the illness and its consequences could alter their QOL.

This disparity underscores the considerable impact of congenital heart diseases on the QOL of affected individuals, highlighting the need for targeted interventions and support to enhance their well-being and overall health outcomes. The wide range of SF-36 scores in both groups indicates substantial variability in individual experiences within each group, emphasizing the importance of personalized care and the consideration of various factors that may influence QOL in individuals with congenital heart disease.

CONCLUSION

Congenital heart conditions adversely affect the QOL compared to a matched control group. Additionally, this cohort suffers adverse psychological effects, with more prevalence of anxiety and depression. These findings emphasize the drastic impact of CHD on the overall well-being of affected individuals, stressing on the importance of holistic care that addresses both the physical and psychological aspects of their health.

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