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Quality of Life in Cardiac Patients Attending Assuit University Children Hospital

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ABSTRACT

Introduction: Quality of life (QOL) is described as an individual's perception of their current state of affairs in relation to the cultural framework. Congenital heart disease (CHD) assessment will yield important data for identifying risk groups and developing intervention strategies that concentrate on the needs of these children's health.

Aim of the study: to evaluate the quality of life in children with CHD in patients attending Assiut University Children Hospital and Cardiology Department.

Patients and methods: This study was analytic cross-sectional study, performed at Pediatric Cardiology Outpatient Clinic and Inpatient Pediatric Cardiology Unit in Assuit University Hospital over one year from 1st January 2020 to 31st December 2020 (one year study). It included 55 children (2:18 years) who were diagnosed as having heart disease.

Results: The most common type of congenital cyanotic heart disease (HD) was tetralogy of Fallot then transposition of great arteries (TGA). Acyanotic HD were divided into two groups; congenital and acquired. The most common congenital acyanotic HD was ventricular septal defect (VSD) and the most common acquired acyanotic HD was rheumatic HD. All patients were assessed by using the Arabic version of the Pediatric qualify of life inventory (PedsQL). There were many cognitive and communication problems in both cyanotic and acyanotic patients.

Conclusion: Children with congenital heart disease (either cyanotic or acyanotic) are at risk of having lower quality of life, which is a common problem in CHD children.

Keywords: Quality of life, Congenital Heart Disease, Generic Core Scales.

INTRODUCTION

Quality of life (QOL) is described as an individual's perception of their current state of affairs in relation to the cultural framework and value system in which they now reside. Health-related quality of life is described as the patient's subjective view of the effects of their sickness or its treatment, in contrast to their aims, expectations, standards, and worries. Individuals' unique physical and psychological health, amount of independence, social connections, environmental circumstances, and personal views are all included as part of the idea of QOL [(1).]

With a frequency of eight per 1000 live births, cardiac disease is the most prevalent congenital abnormality in children. Over the past few decades, a number of variables have increased and prolonged the lives of children and teenagers with congenital cardiac disease [(2)].

New surgical procedures, improvements in cardiopulmonary bypass, intensive care, pediatric heart transplantation, interventional catheterization, and an increase in the use of mechanical assist devices are some of these causes. The child and family are affected physically and psychologically by morbidity caused by the specific heart defect and by the medical and surgical care the youngster receives. Congenital heart disease has been linked to negative outcomes for children's neurodevelopment and psychological health, according to several studies [(3)] .

According to studies, parents of children with chronic diseases acted overprotectively, were less warm and close to their kids, and the severity of the chronic sickness played a significant role in the parents' more controlling and protective conduct [(4).]

QOL is an extremely complicated phenomenon with numerous contributing components. As a result, many directional assessments are needed. In order to identify the risk group and develop intervention strategies that are tailored to the needs of this group of children with congenital heart disease, it is important to assess the QOL of these children. This evaluation will serve as a guide for objectives such as developing new health policies, providing social and psychological support, choosing interventions that are individually appropriate, cutting down on hospital stays and treatment costs, and integrating patients and their relatives into the workforce to boost productivity. Consequently, further research must be done [(5)].

AIM OF THE STUDY: to evaluate the quality of life in children with CHD in patients attending Assiut University Children Hospital and Cardiology Department**.**

PATIENTS AND METHODS

This study was analytic cross-sectional study, performed at Pediatric Cardiology Outpatient Clinic and Inpatient Pediatric Cardiology Unit in Assiut University Children Hospital and Cardiology Department over one year from 1st January 2020 to 31st December 2020. Number of patients was 55. **Clinical trial number:** NCT04354844

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Inclusion criteria for patients: Any child (2:18 years) diagnosed as having heart disease and receive any type of cardiac intervention, conservative treatment, surgical repair or heart transplantation. Acceptance of caregiver to participate in the study.

Exclusion criteria for cases: Children under the age of two and anyone with any accompanying lesions (patients who had any congenital anomalies with congenital heart like Down syndrome).

Study population: we subdivided patients in 2 groups:

- **Children with cyanotic heart disease:** all school and preschool age children (2:18yrs) with cyanotic CHD.
- **Children with acyanotic heart disease:** Children (2:18years) diagnosed as acyanotic CHD, rheumatic HD and cardiomyopathy with no history of any other chronic disease.

METHODOLOGY

History: Sociodemographic data: age, sex, order, educational level, type of education, etc...

Clinical data: duration of the disease, causes of cardiac disease and its type (cyanotic or acyanotic), age at diagnosis, treatment modality (medical or surgical) and family history of similar disease.

Family Socioeconomic data: Parent's level of education, parent's occupation, and family residence and number of family members.

Assessment of health-related quality of life (HRQoL) using the Arabic versions of the Pediatric qualify of life inventory (PedsQL): It is a 23-item, which includes: Problems with heart (7 items), problems with treatment (3 items), problems with physical appearance (3 items), problems with treatment anxiety (4 items), problems with cognitive functioning (3 items) and problems with communication (3 items). Children were required to score each item on the PedsQL (3.0) response options using a 5-point rating scale ranging from "never" to "nearly usually," as follows: 0 if it never happens, 1 if it almost never happens, 2 if it occasionally happens, 3 if it frequently happens, and 4 if it almost always happens.

Ethical Considerations:

Approval from the Ethics of Scientific Research Committee, Faculty of Medicine Assiut University was obtained. Verbal and written consents were obtained from all the caregivers of the patients. Privacy and confidentiality of all obtained information was observed without intervention in the prescribed treatment. This work has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for studies involving humans.

Statistical analysis

The mean and standard deviation values were calculated for each group in each test. Data were explored for normality using Kolmogorov-Smirnov and Shapiro-Wilk tests and showed non-parametric (not normal) distribution.

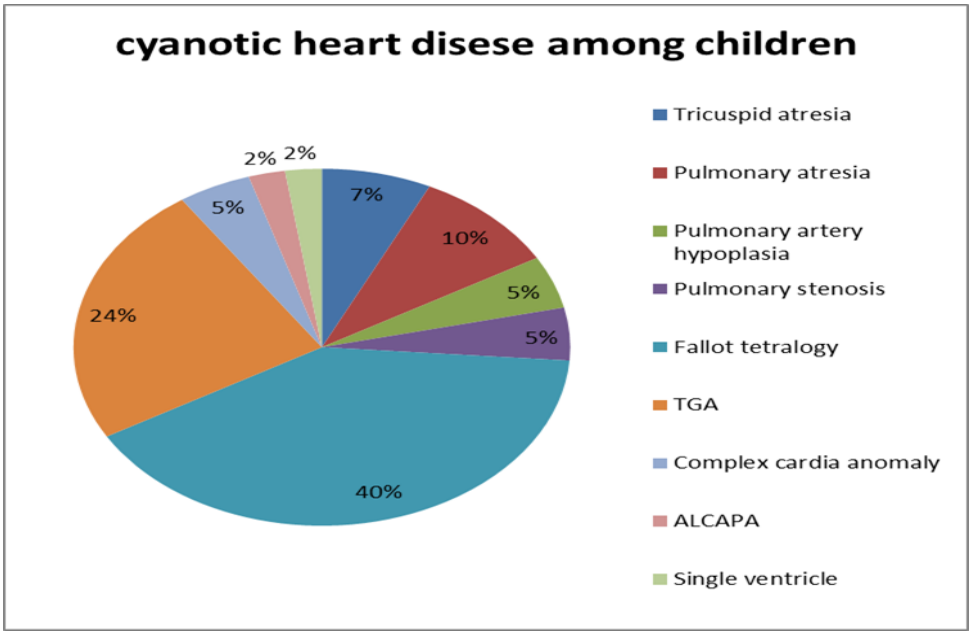
Categorical variables were described by number and percent (N,%), where continuous variables described by mean and standard deviation (Mean, SD). Chi-square test used to compare between categorical variables where compare between continuous variables by Mann Whitney was used to compare between two groups in non-related samples for non-parametric (not normal distribution) variables. The significance level was set at P value <0.05.

Statistical analysis was performed with IBM® SPSS® Statistics Version 26 for Windo

RESULTS

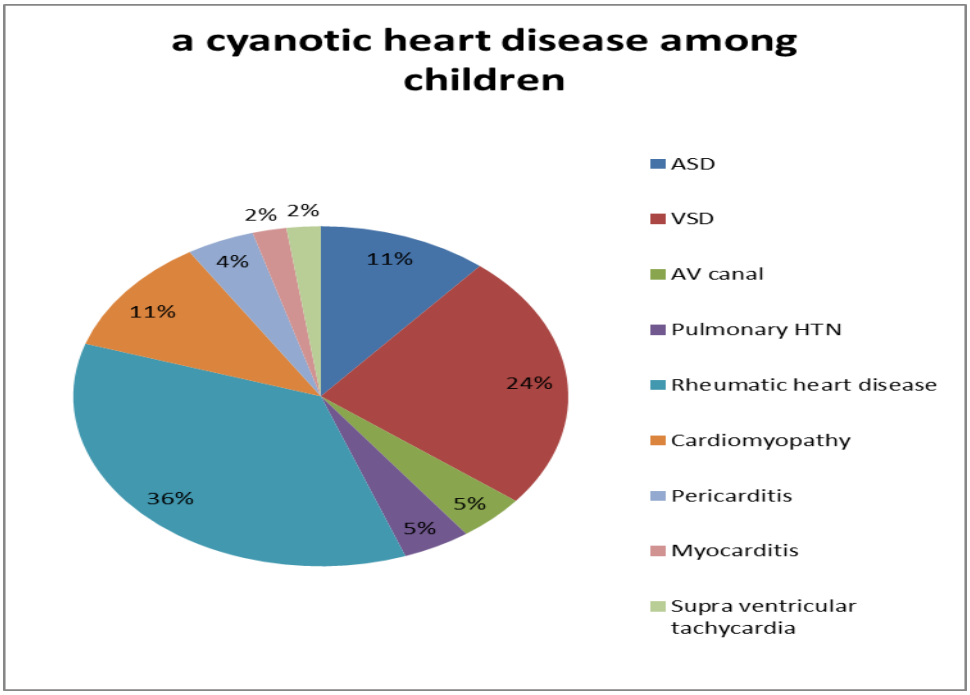
The most common type of congenital cyanotic HD was tetralogy of Fallot that represented 40% of all cyanotic cases (Figure 1).

Also, study showed that median age of diagnosis was 2.6 years in cyanotic group. It also showed that almost all cases received both medical and surgical treatment by percentage of 97.8%.



TGA transposition of great arteries.
ALCPA apparent left coronary pulmonary artery.
Figure 1: type of cyanotic heart disease among the studied children

Acyanotic HD were divided into two groups congenital and acquired. The most common congenital acyanotic HD was VSD that represents 24.4%. And the most common acquired acyanotic HD was rheumatic HD that represent 35.6% (Figure 2). Most cases (71.1%) received medical treatment only and 28.9% received both medical and surgical treatment.



ASD atrial septal defect
VSD ventricular septal defect
AV atrioventricular canal

Figure 2: Figure 1 type of acyanotic heart disease among the studied children

Patients with acyanotic group most commonly had chest pain or tightness, sometimes during exercise. Most of children with cyanotic and acyanotic HD were almost always catching cold easily. Children with acyanotic HD were almost always had attacks of tachycardia. Nearly all children in both groups always had tendency to rest more than their friends. All children with cyanotic HD had increasing blue color of their lips when running but in acyanotic HD 48.5% of children were sometimes getting blue lips during running (Table 1).

Table 1: Descriptive heart problems in children with cyanotic and acyanotic heart disease

Heart Problems and Treatment	Cyanotic heart disease (n=22)		Acyanotic heart disease (n=33)		P. value
	No.	%	No.	%	
1. Getting out of breath while doing active play or exercise					
Sometimes	3	13.6	7	21.2	0.451
Often	8	36.4	15	45.5	
Almost Always	11	50.0	11	33.3	
2. Chest pain or tightness while doing active play or exercise					
Never	2	9.1	2	6.1	0.222
Almost Never	7	31.8	4	12.1	
Sometimes	9	40.9	17	51.5	
Often	4	18.2	6	18.2	
Almost Always	0	0.0	4	12.1	
3. Catching colds easily					
Never	0	0.0	1	3.0	0.093
Almost Never	1	4.5	0	0.0	
Sometimes	2	9.1	11	33.3	
Often	8	36.4	5	15.2	
Almost Always	11	50.0	16	48.5	
4. Fast heartbeat					
Never	2	9.1	0	0.0	**<0.001****
Almost Never	3	13.6	1	3.0	
Sometimes	10	45.5	10	30.3	
Often	6	27.3	2	6.1	
Almost Always	1	4.5	20	60.6	
5. Waking up at night with trouble breathing					
Never	2	9.1	8	24.2	0.193
Almost Never	1	4.5	4	12.1	
Sometimes	16	72.7	13	39.4	
Often	2	9.1	6	18.2	
Almost Always	1	4.5	2	6.1	
6. Having to rest more than his/her friends					
Never	0	0.0	1	3.0	0.471
Almost Never	0	0.0	2	6.1	
Sometimes	3	13.6	8	24.2	
Often	7	31.8	7	21.2	
Almost Always	12	54.5	15	45.5	
7. His/her lips turning blue when running					
Almost Never	0	0.0	1	3.0	**<0.001****
Sometimes	0	0.0	16	48.5	
Often	0	0.0	9	27.3	
Almost Always	22	100.0	7	21.2	

**: Highly significant

Majority of children with heart disease in both groups were sometimes refusing to take heart medicine that represented 40% in cyanotic and 42% in acyanotic group, some of them forgot taking medicine (40% and 33% in cyanotic and acyanotic group) and Few children reported that medicine making them feeling sick or had side effects from medication (Table 2).

Table 2: Treatment problems in children with cyanotic and acyanotic heart disease

Treatment II (Problems with medications)	Cyanotic heart disease (n=22)		Acyanotic heart disease (n=33)		P. value
	No.	%	No.	%	
1. Refusing to take heart medicine					
Never	3	13.6	6	18.2	0.519
Almost Never	7	31.8	11	33.3	
Sometimes	9	40.9	14	42.4	
Often	1	4.5	2	6.1	
Almost Always	2	9.1	0	0.0	
2. Difficulty taking heart medicine					
Never	1	4.5	2	6.1	0.553
Almost Never	6	27.3	13	39.4	
Sometimes	12	54.5	17	51.5	
Often	2	9.1	1	3.0	
Almost Always	1	4.5	0	0.0	
3. Forgetting to take heart medicine					
Never	0	0.0	2	6.1	0.643
Almost Never	5	22.7	6	18.2	
Sometimes	9	40.9	11	33.3	
Often	1	4.5	2	6.1	
4. Heart medicine making him/her feel sick					
Never	16	72.7	19	57.6	0.452
Almost Never	5	22.7	10	30.3	
Sometimes	1	4.5	4	12.1	
5. Worry about side effects from his/her medicine					
Never	11	50.0	12	36.4	0.493
Almost Never	4	18.2	8	24.2	
Sometimes	0	0.0	1	3.0	

Some children had feelings that they are not good looking that represented 22% in cyanotic and 21%in acyanotic group. Most of them almost always are ashamed of their scars that represent 50% in cyanotic and 48% in acyanotic HD (Table 3).

Table 3: Problems with the physical appearance in children with cyanotic and acyanotic heart disease

Perceived Physical Appearance	Cyanotic heart disease (n=22)		Acyanotic heart disease (n=33)		P. value
	No.	%	No.	%	
1. Feeling that he/she is not good looking					
Never	7	31.8	13	39.4	0.844
Almost Never	10	45.5	13	39.4	
Sometimes	5	22.7	7	21.2	
2. Not liking other people to see his/her scars					
Never	2	9.1	7	21.2	0.224
Almost Never	3	13.6	3	9.1	
Sometimes	5	22.7	2	6.1	
Often	1	4.5	5	15.2	
Almost Always	11	50.0	16	48.5	
3. Being embarrassed about others seeing his/her Body (general looking)					
Never	3	13.6	2	6.1	0.176
Almost Never	2	9.1	0	0.0	
Sometimes	5	22.7	4	12.1	
Often	4	18.2	7	21.2	
Almost Always	8	36.4	20	60.6	

Most patients were sometimes had difficulty paying attention to things and surrounding environment in both groups. No one of children with cyanotic HD was always remembering what is read to him. Most patients were almost always having trouble writing school papers and solving math problems. Most of patients were almost never telling the doctor and nurses how they felt or asked them questions; that represented 36.4% in both groups. Most of children in both groups never explained their heart problem to other people; that represented 50% in cyanotic and 45% in acyanotic group (Table 4).

Table 4: Cognitive and communication problems in children with cyanotic and acyanotic heart disease

Cognitive And Communication Problems	Cyanotic heart disease (n=22)		Acyanotic heart disease (n=33)		P. value
	No.	%	No.	%	
1. Figuring out what to do when something bothers him/her					
Never	6	27.3	8	24.2	0.163
Almost Never	7	31.8	8	24.2	
Sometimes	6	27.3	3	9.1	
Often	2	9.1	9	27.3	
Almost Always	1	4.5	5	15.2	
2. Difficulty paying attention to things					
Never	2	9.1	1	3.0	0.569
Almost Never	6	27.3	7	21.2	
Sometimes	8	36.4	9	27.3	
Often	3	13.6	8	24.2	
Almost Always	3	13.6	8	24.2	
3. Remembering what is read to him/her					
Never	5	22.7	7	21.2	0.142
Almost Never	7	31.8	6	18.2	
Sometimes	9	40.9	9	27.3	
Often	1	4.5	9	27.3	
Almost Always	0	0.0	2	6.1	
4. Trouble writing school papers or reports					
Almost Never	2	9.1	2	6.1	0.667
Sometimes	4	18.2	7	21.2	
Often	6	27.3	5	15.2	
Almost Always	10	45.5	19	57.6	
5. Trouble solving math problems					
Never	1	4.5	0	0.0	0.216
Almost Never	3	13.6	3	9.1	
Sometimes	2	9.1	9	27.3	
Often	7	31.8	5	15.2	
Almost Always	9	40.9	16	48.5	
6. Telling the doctors and nurses how he/she feels					
Never	8	36.4	11	33.3	0.820
Almost Never	8	36.4	12	36.4	
Sometimes	4	18.2	6	18.2	
Often	2	9.1	2	6.1	
Almost Always	0	0.0	2	6.1	
7. Asking the doctors or nurses questions					
Never	10	45.5	14	42.4	0.572
Almost Never	7	31.8	6	18.2	
Sometimes	4	18.2	9	27.3	
Often	0	0.0	2	6.1	
Almost Always	1	4.5	2	6.1	
8. Explaining his/her heart problem to other people					
Never	11	50.0	15	45.5	0.517
Almost Never	3	13.6	10	30.3	
Sometimes	7	31.8	7	21.2	
Almost Always	1	4.5	1	3.0	

There was no significant difference between most items of QOL questionnaire and the type of congenital heart disease of the studied participants, except for that as regard to son questionnaire, patients with acyanotic heart disease had higher cognitive problems than patients with cyanotic heart disease. Regarding parent questionnaire, patients with cyanotic heart disease had higher heart and treatment problems than patients with acyanotic heart disease (Table 5).

Table 5: Comparison between cyanotic heart disease and acyanotic heart disease groups according to scores

	Son				Parent			
	Total (N=55)	**Cyanotic Heart Disease (N=22)**	**Acyanotic Heart Disease (N=33)**	**P. Value**	**Total (N=90)**	**Cyanotic Heart Disease (N=45)**	**Acyanotic Heart Disease (N=45)**	**P. Value**
Heart Problems and Treatment								
Mean±SD	19.29±3.03	19.77±2.49	18.97±3.35	0.341	20.82±2.6	21.42±2.18	20.22±2.86	0.28*
Treatment II								
Mean±SD	4.91±.15	5.14±1.43	4.76±0.31	0.528	5.15±0.51	5.49±0.68	4.8±0.31	0.194
Perceived Physical Appearance								
Mean±SD	6.51±1.64	6.18±1.52	6.73±1.74	0.458	6.39±1.55	6.07±1.3	6.71±1.77	0.233
Treatment Anxiety								
Mean±SD	11.09±0.15	11.41±2.56	10.88±0.52	0.546	11.64±2.77	11.69±2.65	11.6±2.91	0.880
Cognitive Problems								
Mean±SD	11.64±2.55	10.55±2.56	12.36±2.3	0.008*	11.72±2.42	11.6±2.72	11.84±2.11	0.635
Communication								
Mean±SD	3.02±0.43	2.82±0.38	3.15±0.49	0.623	2.63±0.25	2.51±0.83	2.76±0.53	0.514
Grand total								
Mean±SD	56.45±7.25	55.86±6.38	56.85±7.84	**0.625**	58.3±6.9	58.78±6.87	57.82±6.98	

*: Significant, **: Highly significant

DISCUSSION

The present study reported that tetralogy of Fallot (TOF) is the most common cyanotic CHD, which was documented in 40% of the children with cyanotic congenital heart disease (CCHD), followed by transposition of great arteries (TGA) documented in 24.4%. Ventricular septal defect (VSD) was the most common congenital acyanotic heart disease documented in 24.4% and rheumatic heart disease was the most common acquired acyanotic heart disease documented in 35.6%.

In agreement with the present study, some authors reported in their study that the incidence of congenital heart disease, diagnosed in children born at Jordan University Hospital over seven-year period, was in cyanotic heart disease 11% of all congenital heart diseases; the most common of which were tetralogy of Fallot. The most common diagnosis acyanotic heart disease was ventricular septal defect (43%), followed by atrial septal defect (20%) of total CHD cases [(6)].

On the other hand, **Khasawneh *et al.*** [(7)] revealed that patent ductus arteriosus (PDA) was the most prevalent diagnosis accounting for 43% followed by VSD and atrial septal defect (ASD). The high PDA prevalence in this study could be explained by the fact that 70% of examined CHD infants were premature.

TOF was the most common cyanotic CHD followed by transposition of great arteries (TGA). As reported by both pediatrics and their parents, we found no significant difference among both studied groups (cyanotic versus acyanotic heart disease) for the heart problems except in question about "Fast heartbeat " which showed that acyanotic heart disease patients suffered from fast heart rate (HR) more often than cyanotic heart disease patients, also question about " His/her lips turning blue when running", which shows that cyanotic heart disease patients suffered from this problem more than acyanotic heart disease patients ($P<0.001$).

Regarding the difference in heart rate between both studied groups, the present study disagrees with the study of **Aletti *et al.*** [(8)], which aimed to assess heart rate variability (HRV) in children with congenital heart malformation taking into account the effects of cyanotic and acyanotic defects, and comparing pathologic children with age matched controls. The authors found that low frequency (LF) power and total power of HRV were significantly higher in children with CHD than in healthy controls, independently of cyanosis. Non-linear indices were also significantly higher in pathologic subjects. These results suggested that children with a congenital heart condition display more complex HRV

and sympathetic over activity, which may be aimed at compensating for hemodynamic alterations.

Regarding the bluish discoloration of the lips, the present study agrees with the study of **Ercan *et al*.,** who reported that the dark purple coloration of the lips, nail base, tongue, and oral mucosa (central cyanosis) became more bluish with exercise always among patients with cyanotic congenital heart disease [(9)].

Also, regarding the physical appearance, cognitive and communication skills, there were many problems in both cyanotic and acyanotic heart diseases

In summary, we concluded that children with congenital heart disease (either cyanotic or acyanotic) are at risk of having lower quality of life, which is a common problem in CHD children.

In agreement with our study, the study of **Eagleson *et al*.**[(10)], which aimed to determine whether, in children with congenital heart disease (CHD), disease severity is associated with health-related quality of life (HRQOL) and impact on the family on 31 children with hypoplasia of the left ventricle (HLV) and 29 with TOF. According to the authors, there were no appreciable differences in kid reporting across any HRQOL dimensions. However, parent-proxy reporting shows that children with HLV had significantly poorer scores on the symptom scales (P 0.0001). Parents of the HLV population reported more cognitive issues (P = 0.02) and perceived treatment anxiety (P = 0.01).

But in contrast to our study the authors reported no difference between both studied groups regarding their physical appearance. Also, the present study disagrees with the study of **Maya *et al*.** [(11)], which reported that cyanotic CHD children significantly showed lower cognitive scores than acyanotic children in gross motor ($p = 0.034$) and in receptive language ($p = 0.048$), which had effect on early learning composite score ($p = 0.014$). The same authors reported that regarding the quality-of-life assessment from parent's report, in general, the cyanotic children showed lower scores in all the trajectories than children with congenital acyanotic heart disease. Significant differences were found in heart problem and therapy ($p = 0.042$), treatment anxiety ($p = 0.016$), cognitive problems ($p = 0.038$), and communication ($p = 0.022$).

Interestingly, severity of congenital heart disease does not always predict quality-of-life. For example, **Ternestedt *et al.***, found, in a long-term follow-up study that self-reported QOL was better among patients with tetralogy of Fallot than among patients with an atrial septal defect [(12)].

CONCLUSION

Congenital heart disease patients experience physical, mental, and social effects as a result of their condition. Children with CHD frequently have a lower quality of life, which emphasises the necessity of long-term monitoring. QOL evaluation is a recognised indication of subjective health.

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