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ORGINAL ARTICLE

ASSESSMENT OF QUALITY OF LIFE IN CONGENITAL HEART DISEASE AMONG EGYPTIAN AND LIBYAN CHILDREN

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ABSTRACT

Background: Congenital heart diseases (CHD) is defined as a structural abnormality of the heart or intra thoracic vessels present at birth that is actually or potentially of functional significance .CHD is a lifelong disease that results from a heart defect or structural anomaly at birth. As CHD impacts the physical, nutritional, and developmental status of children health, it also may change many aspects of patients and their families' life, as social, psychological dimensions, there by impacting their quality of life. **Aim of the study** : This study aims to verify a possible effect of CHD on the quality of life of Egyptian and Libyan children and their families. **Subjects and methods**: Across sectional study was conductedamong279 children, distributed into 2 groups; 186 Egyptians, and 93Libyans, and were subjected to complete history, socioeconomic evaluation, assessment of Quality of life (QoL) of patient by pediatric cardiac quality of life inventory,and evaluation of quality of life of family by WHOQOL BREF. **Results**: Regarding QoL assessment in CHD patients, results showed that QoL of diseased children was affected in both groups.Bad parents' QoLwas higher among Egyptian CHD families than Libyan families, while bad child's QoL and bad siblings' QoL were higher among Libyan CHD children than Egyptian CHD children. Children's bad QoLwas positively correlated to parents and siblings' QoL. Also, cyanotic CHD was associated with bad QoL. **Conclusion** : CHD can affect QoL. So, it is recommended to concentrate on social and psychological aspects in CHD patient through health education and group therapy.

Keywords: Quality of Life, Congenital Heart Disease, Egyptian, Libyan

INTRODUCTION

Congenital heart disease (CHD) is usually defined as a structural abnormality of the heart or intrathoracic vessels present at birth that is actually or potentially of functional significance .CHD is a lifelong disease that results from a heart defect or structural anomaly at birth [1]. Approximately 9 people in 1000 are born with these abnormalities [2]. Incidence of significant CHD is 8 per 1000 live births, this does not include minor defects, which often present later in childhood or adult life (e.g. bicuspid aortic valves occur in 1/100 of the population) [3]. The incidence of congenital heart disease among Egyptian children has been estimated tobe5-6/1000 live birth [4].

In Libya, there is insufficient data about congenital heart disease because of the default in research activities and epidemiological studies, but the birth rate in Libya is about 27.6 /1000 population[5], while the number of the newly diagnosed congenital heart disease cases is about 2000/year [6], and the incidence of moderate to severe cases is about 4- 5/1000 life birth [7]. There are several thousand children that need heart surgery, including hundreds of new-

born. That is why, with the support of the Presidency Council and the UN's World Health Organization, Dr. Novick has launched a one-year national program, hoping to treat more than 400 Libyan children's hearts [8]. It is possible that children with chronic illness, as cardiac disease, are challenged to develop a Sense of Coherence earlier than healthy children, by experiences that derive from the disease and require a great capacity for adaptation. Growing with CHD requires attention to medical treatment and often living with some restrictions on activities that are part of any child's life. Perhaps because they do not know a different reality these children acquire a greater sense of appreciation for life and expectations consistent with their capabilities and limitations, which will influence their perception of Quality of Life (QoL) in the course of their development [9].

World Health Organization (WHO) defines (QoL)as individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It's a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment [10]. Health related quality of life refers to the impact of a specific illness, medical therapy, and/or health services policy on the ability of the patient to function in situational contexts (e.g. family, school) and to draw personal satisfaction from a physical, psychological, and social functioning perspectives [11]. Several investigators have demonstrated that children with heart disease have significantly lower QOL scores when compared with healthy peers in the same age group [12]. Numerous factors may affect health-related quality of life in children with congenital heart disease according to the stage of their growth. For example, during infancy, children are totally dependent on their parents, while as they are entering childhood, they have different needs such as relationships with other children, obtaining independence, knowledge, etc. Similarly, the features of their personality, which determine the degree of adaptation to the disease and the improvement of their quality of life, should be thoroughly considered [13]. Sustained effort and financial support are challenging and require a major commitment from the government and Ministry of Health to provide better service for this growing population [14].

SUBJECTS AND METHODS

Study design and settings: Across sectional study was conducted in Cardiology unit of Pediatrics Department, Faculty of Medicine, Zagazig University, and Cardiology Unit of Tripoli Children Hospital during the period from 2018 to 2019. The work has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for studies involving humans.

Target groups: The study included children with CHD. **Inclusion criteria**:Children aged from 6 months to 6 years at the time of study, suffering from congenital heart disease, and diagnosed by Echocardiography(simple or complex, mild, moderate, or severe, pre-operative). **Exclusion criteria**: Children who are lost to sight, or deceased, children with other major associated anomalies and children with associated other chronic illness, or cardiac surgical correction that may affect growth and development.

Sample size: The sample size was calculated to be (279) cases, using Open Epi I program(Epidemiological information package) software version 6.1 at 5% level of significance and 5% estimate of error, As total number of children with CHD attending Zagazig pediatric hospital was (720 child /6 months) and total number of children with CHD attending Tripoli children hospital was (360 child /6 months) and percentage of abnormal Denver II assessment for growth and development was 41.9% in children with congenital heart disease [15].

Sample technique: Systematic random sampling was used; accordingly, the K interval was determined after a random selection, then every K^{th} child coming fulfilling the inclusion criteria was included in the study, proportional allocation of sample according to number of attendants was done, the sample size was divided into 2 categories:

93 children From Tripoli, Libya and 186 children from Zagazig, Egypt.

Data collection: All studied children were subjected to the following assessment tools:

A. designed questionnaire to measure

- Socio-demographic characteristics and socioeconomic status, calculated according to [16].
- Medical history, asked about (age, sex, Diagnosis of congenital heart disease, drug history, nutritional history including: type of milk, weaning time, solid food contents and Vit D supplement).
- Clinical examination, concentrating on signs of the congenital heart defects, their complications especially heart failure and pulmonary hypertension, and finally signs of rickets.

B. All patients evaluated by:

- Quality of life in Congenital heart diseases: using pediatric cardiac quality of life inventory version 4.0 [17].
- Quality of life of families: using World health organization group Quality of life instrument (WHOQOL-BREF), generic for quality translated in Arabic and previously validated for use in Arab populations[18].

Data management: The collected data were analyzed by computer using Statistical Package of Social Services version 24 (SPSS) [19], Data were expressed as number and percentage for qualitative variables and mean ± standard deviation (SD) for quantitative one. The significance level was set at $P < 0.05$.

Ethical Considerations:

Institutional Review Board (IRB) of the Faculty of Medicine, Zagazig University approved the study protocol (No.4473). An informed consent was obtained from all participants of this study and they were told about the aim of the study, and were informed that the data would be used for scientific purposes only.

RESULTS

The current study included 279 children (149 male and 130 female), their age was 22.03±18.75 months and it ranged from 6 months to 6 years old, they were diagnosed with congenital heart disease, the study subjects were allocated into 2 groups according to country into Egyptian children with CHD and Libyan children with CHD. Mean of age among the studied Egyptian children with CHD was20.5±18.75 months, with a range from 6 months to 6 years old. While age of the studied Libyan children with CHD was25.09±19.19 months, with a range from 6 months to 6 years with statistically significant difference between both groups regarding age (p=0.011)**(Figure1)**.

Half of the studied sample were of middle social class, there was high statistically significant difference between Egyptian and Libyan CHD patients regarding socioeconomic level where low and middle socioeconomic status found in (41.9% and 37.1%) of Egyptian studied families respectively versus (17.2% and 76.3%) of Libyan studied families respectively**(Figure2)**.

There was no statistically significant difference regarding diagnosis of congenital heart diseases among the studied two groups. Cyanotic congenital cardiac lesions are statistically lower among Egyptian cardiac children than Libyan cardiac children**,** with ASD is the commonest cardiac lesion in Egyptian patients, and while in Libyans VSD is the commonest. Regarding Complications of congenital heart diseases among the studied children, 6.1% had heart failure and 5% had pulmonary hypertension. Regarding clinical presentation of congenital heart diseases among the studied children,74.2% of the studied children are asymptomatic. The most frequent manifestation was cough followed by recurrent chest infection, Cyanosis and dyspnea.

Table (1): showed that 22.9% of the studied children hadRecurrent URT infections less than average (9 times URTI /year) or (4 times OM/year),14.7 % of them didn't sleep well. Egyptian cardiac children didn't play or laugh with others than Libyan cardiac children (7.5% versus zero %) respectively with statistically difference (p=0.007*), also Egyptian cardiac children didn't go out with his family for a walk than Libyan cardiac children (12.9% versus 6.5%) respectively with statistically difference (p=0.029*).Child's QoL score among the

studied Egyptian and Libyan children had no significant difference,79.2% of the studied cardiac children had Bad QoL**,** Bad QoL higher in Libyan children than Egyptian (83.9% vs 76.9%)respectively.

Table (2): demonstrated only 28% of the studied siblings had bad QoL,10.4% of the studied children' brothers sometimes afraid of being infected with the disease of their brother with statistically significant difference between Egyptian and Libyan sibling's (5.9% versus 19.4%) respectively (p=0.001*), there was no statistically significant difference between both groups regarding Siblings' QoL score.

Physical and psychological health domains mean score were significantly higher among Libyan parents than Egyptian parents. However, there was no statistical significant difference in Social relationships and environmental domains between both groups. Mean of Parent's QoL score among the studied Egyptian children with CHDwas54.53±5.9, While Mean of Parent's QoL score among the studied Libyan children with CHD was58.01± 6.26, (54.8 %) of the studied cardiac children' parents had Bad QoL, Bad Parent's QoL was higher in Egyptians than Libyans (66.1% vs 32.3%) respectively with high statistically significant difference between both groups regarding Parent's QoL **(Table 3)**.

Results showed that bad parents' QoL is higher among Egyptian CHD families than Libyan families (66.1% Vs 32.3%) respectively, while bad child's QOL and bad siblings' QoL is higher among Libyan CHD children than Egyptian CHD children (83.9% Vs 76.9%) and (33.3% Vs 25.3%) respectively**(Figure 3)**.

Results revealed that, among Egyptian families there was significant positive correlation between Parents' QoL and their Siblings' QOL (r=0.152 and p=0.039), And in Libyan families there is highly significant positive correlation between Parents' QoL and their Siblings' QoL(r=0.341 and p=0.001) also there is significant positive correlation between CHD child's QoL and their Parents' QoL (r=0.404 and p=0.000)and their brothers/sisters' QOL (r=0.205 and p=0.049)**(Table 4)**.

Results showed that cyanotic cardiac lesion was statistically higher among CHD children with bad quality of life than CHD children with good quality of life (12.7% Vs zero%), also clinical presentations in the form of low cardiac output, lung congestion and cyanosis were statistically higher among CHD children with bad quality of life than CHD children with good quality of life (P value < 0.05)**(Table 5)**.

Table (1):Child's Quality of life assessment among the studied Egyptian and Libyan children.

The child has/is	Total studied children (N=279)		Egyptian CHD patients (N=186)		Libyan CHD patients (N=93)		#P- value
	No.	%	No.	%	No.	%	
Recurrent URT infections	64	22.9	38	20.4	26	28.0	0.159
many hospital admission	9	3.2	8	4.3	1	1.1	0.301
Last stay in the hospital during the current year	30	10.8	17	9.1	13	14.0	0.302
Delay in vaccination schedule	8	2.9	7	3.8	1	1.1	0.205
Excessive attention from the mother	93	33.3	57	30.6	36	38.7	0.142
Always afraid of the hospital and medical staff	25	9.0	17	9.1	8	8.6	0.723
Don't sleep well	41	14.7	31	16.7	10	10.8	0.113
Don't play or laugh with others	14	5.0	14	7.5	0	0.0	**0.007***
Don't go out with his family for a walk	30	10.8	24	12.9	6	6.5	**0.029***
Child's QOL score Mean ± SD	22.08±1.9		22.11±1.9		22.03± 1.86		##0.427 (NS)
Child's QOL		79.2		76.9	78	83.9	#0.175
Bad QOL	221	20.8	143	23.1	15	16.1	(NS)
Good QOL	58		43				

P < 0.05 is significant, NS: Not significant.

Recurrent URT infections: (> 9 times URTI /year) or (> 4 times OM/year)

Table (2): Siblings' QOL assessment among the studied Egyptian and Libyan children.

Siblings do they	Total studied children (N=279)		Egyptian CHD patients (N=186)		Libyan CHD patients (N=93)		#P- value
	No.	%	No.	%	No.	%	
Always feel jealous	2	0.7	2	1.1	0	0.0	0.468
Sometimes feel neglected	18	6.5	11	5.9	7	7.5	0.605
Level of education a little affected	11	3.9	8	4.3	3	3.2	0.664
Relationship with their parents strained Sometimes	36	12.9	23	12.4	13	14.0	0.705
Sometimes afraid of being infected with the disease of their brother	29	10.4	11	5.9	18	19.4	**0.001* (S)**
Siblings' QOL	78	28.0	47	25.3	31	33.3	#0.157
Bad QOL	201	72.0	139	74.7	62	66.7	(NS)
Good QOL							
Siblings'QOL score Mean ± SD	14.45±1.09		14.51±1.06		14.34±1.15		##0.144 (NS)

P < 0.05 is significant., NS: Not significant.

Table (3): Parents' Quality of life domains according to WHO – 26 BREF questionnaire among the studied familiesof Egyptian and Libyan children with congenital heart diseases.

QOL domains	The studied CHD children						Test#
	Total (N=279)		Egyptian (N=186)		Libyan (N=93)		
Physical health domain							
Mean ± SD	13.11 ± 1.9		12.91 ± 2.09		13.52 ± 1.5		**0.025* (S)**
Psychological health domain							
Mean ± SD	12.67 ± 1.7		12.37 ± 1.77		13.2 ± 1.5		**0.000* (HS)**
Social relationships							
Mean ± SD	5.09 ± 1.18		5.09 ± 1.14		5.08 ± 1.26		**0.669 (NS)**
Environmental domain							
Mean ± SD	19.39 ± 2.93		18.8 ± 2.72		20.56 ± 2.99		**0.000* (HS)**
Parent's QOL	153	54.8	123	66.1	30	32.3	**#0.000* (HS)**
Bad QOL	126	45.2	63	33.9	63	67.7	
Good QOL							

P < 0.05 is significant. NS: Not significant.

Table (4): correlation matrix of child's QOL, siblings' QOL and Parents' Quality of life among the studied families of Egyptian and Libyan children with congenital heart diseases.

Variables		Correlation coefficient (r)		
		Egyptian CHD Families		
Libyan CHD		**Child's QOL**	**Siblings' QOL**	**Parents' QOL**
Child's QOL	**(r)**	-------	0.054	-0.008
	p-value		0.466	0.915
Siblings' QOL	**(r)**	0.205*	------	0.152*
	p-value	0.049(S)		0.039(S)
Parents' QOL	**(r)**	0.404**	0.341**	------
	p-value	0.000 (HS)	0.001(HS)	

**** Correlation is significant at the 0.05 level (2-tailed).***

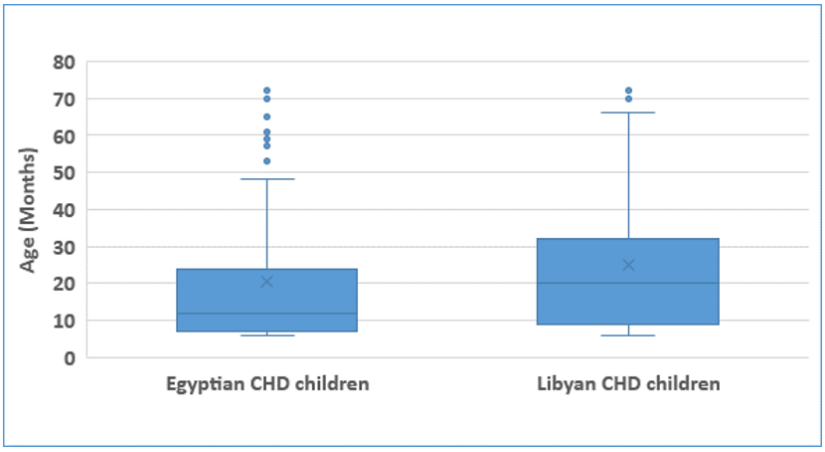

Figure (1): Age of the studied Egyptian and Libyan children with congenital heart diseases (N=279).

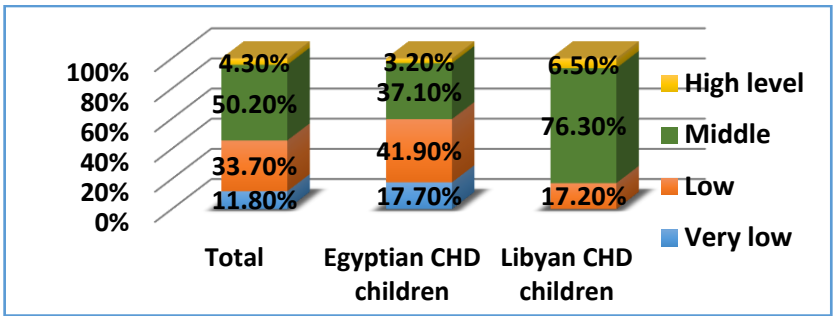

Figure (2): Socioeconomic level of the studied Egyptian and Libyan children' families (N=279).

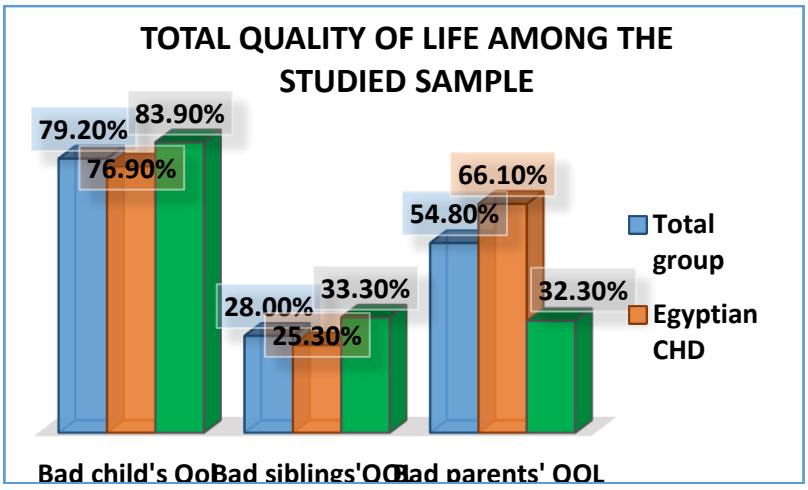

Figure (3):Total quality of life among the studied Egyptian and Libyan CHD children.

DISCUSSION

Congenital heart disease (CHD) covers a wide variety of anatomical and functional cardiac malformations, with an estimated prevalence of 4 to 5 per 1000 live births [20].The study subjects were allocated into 2 groups according to country into Egyptian children with CHD and Libyan children with CHD. There was statistical significant difference between Egyptian and Libyan children in age **(Figure 1)**, as Libyan children were older, may explained by delayed diagnosis , and restriction of the diagnostic facilities and experiences in few big cities in the governmental hospitals in Libya. A study of **Dolk et al.** [20] is in agreement with the present study. But in the studies of **Limperopoulos et al.** [21], **Nasiruzzaman et al.** [22], **Azhar et al.** [23]; half of the studied children were males but the mean age was older than the present study.

Regarding diagnosis of congenital heart diseases; acyanotic congenital cardiac lesions are found in most of the studied children where VSD, ASD and PS are the highest congenital cardiac lesions among of the studied children. ASD is statistically higher among Egyptian CHD children than Libyan CHD children. Cyanotic congenital cardiac lesions are statistically lower among Egyptian cardiac children than Libyan cardiac children. These results are consistent with findings of **George and Frank** [24]**, Chen et al.**[25], as majority of the cases were acyanotic congenital heart disease.VSD was the most prominent congenital heart disease.However, other studies of **Mari et al.**[15], **Limperopoulos et al.** [21], **Nasiruzzaman et al.** [22]**, Ulfah et al.** [26] included more cyanotic congenital cardiac lesions.

Regarding Quality of life assessment among the studied children, one third of them had excessive attention from the mother, 22.9% had Recurrent URT infections and 14.7 % didn't sleep well. There were statistical significant differences between Egyptian and Libyan children in some items as Libyan children played or laughed with others and went out with their family for walks more than Egyptian children, which

may explained by the less personal/social developmental delay regarding Libyans as resulted in our study. Quality of life score among the studied children was 22.08±1.9. Almost three quarters of the studied children had bad QOL. There was no statistical significant difference between Egyptian and Libyan children in QOL score **(Table 1)**. Information from health professionals is usually restricted to the physical aspects of treatment such as food, observation of signs related to pathology and notices of hygiene to prevent infection. These guidelines leave mothers/caregivers restricted to physical symptoms increasing attention and care, imposing a number of limitations, overprotecting the child. Lack of adequate or appropriate information can be related to the large number of mothers that limit the child's activities [15].

Siblings' QOL score was 14.45±1.09 and only 28% of the studied siblings had bad QoL .Libyan siblings were significantly more afraid of being affected with the disease of their brothers than Egyptian siblings, this may be due to over attention of their Libyan mothers to the sick patients, the recurrent respiratory infections of the diseased Libyans was more than in Egyptians, also the higher mean age of Libyans making them more able to recognize and feel the sickness of their brother. **(table2)**.

Regarding Parents' Quality of life according to WHOQOL – 26 BREF questionnaire, mean total score among the studied parents was 55.69±6.27 and 54.8% of them had bad QoL. Egyptian parents had significantly worse QoL than Libyan parents, may because of their lower social class **(table 3).**

In accordance with the present study, a study of **Amedro et al.** [27]concluded that even with a relative underestimation by parents, the QoL of children with CHD is significantly affected, as compared with normal children's[27]. These conclusions support the reliability of parent-reported QoL of the afflicted children. Conversely**,** a study of **Loup et al.** [28] who reported better QoL indicators among grown-up patients with CHD, as compared with the general population[28].There is positive correlation between Parents' QoL and their Siblings' QoL in both Egyptian and Libyan families. However, there was significant positive correlation between CHD child's QoL and their Parents' QoL and their brothers/sisters' QoL in Libyan families only**(Table 4)**.

Conclusion: CHD can affect QoL. Cyanotic CHD is associated with bad QoL. Child bad QoL was positively correlated to parents and siblings QoL. Although there were some differences regarding Egyptian and Libyan communities; the effect of CHD on growth, development and QoL of the patients and their families is nearly the same. So, it is recommended to concentrate on social and psychological aspects in CHD patient through health education and group therapy as it give a clear tragidial view, helpful psychological support to the parents and siblings, and good source of information about disease nature, therapy, and complications.

No conflict of interest

No financial disclosure

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