Quality of life among Children with Congenital Heart Diseases

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Abstract

Background: Congenital Heart Diseases (CHDs) are the most common cause of major congenital anomalies which are one of the major causes of morbidity and mortality among children in the world that substantially reduce the quality of life(QOL) of children. **Aim:** the current study aimedto assess quality of life among children with congenital heart diseases. **Research design**: a descriptive research design was used. **Setting**: the study was conducted at inpatient and outpatient department of the Academic Heart affiliated to Ain-Shams University. **Sample**: the study involved 68 children suffering from congenital heart diseases. **Tool**: consists of two tools: **I:** predesigned questionnaire sheet, **II:** Quality of life scale. **Results:** More than one third of studied children were isolated ventricular septal defect. More than one third of studied mothers weren't aware about causes of congenital heart diseases. More than half of studied mothers weren't aware about complications. Less than two thirds of studied children had poor quality of life. **Conclusion**: the present study concluded that there were a statistical significant deferences between their total practice and their total knowledge regarding children with congenital heart diseases. And there were a statistical significant deferences between their total quality of life and their total practice and their total knowledge regarding congenital heart diseases **Recommend to**: continuous health education to mothers regarding congenital heart diseases,complications, management plan and provision a rehabilitation program for children with congenital heart diseases to improve quality of life.

Key words: Children, Congenital Heart Diseases, Quality Of Life.

Introduction:

Congenital heart diseases**(CHDs)**are the most common cause of major congenital anomalies that are representing nearly 25% of all congenital malformations**. The**CHDs are the most common structural and functional abnormalities of the heart for children, having a major impact on morbidity and general mortality **(Tankeu et al.,2017).** Congenital heart diseases are defined as the anatomic malformations of the heart or the blood vessels, formed during intrauterine development i.e. the abnormalities involving the arteries, the valves, the coronary and the major vessels of the heart can be either simple or complex **(Pramila & Chandni. 2017).**

The etiology of CHDsare unknown, but may be result from acombination of genetic predisposition and environmental factors**.The majority of genetic causes of CHDs are sporadic genetic changes or large chromosomal abnormalities**.Positive family history thatimplicated for the incidence of CHDs(**Chivate et al., 2016).** If there is a

child in the family with CHDs, the chance of a second child being born with CHDs is 3-4 times or more (**Zaki et al., 2018**).

According to American heart assiociation Approximately 35.000 newborn infant are born each year with some types of CHDs and approximetaly 1.01 per 1,000 children reported in Egypt by (**Shahbaz et al., 2014**)among school children. Congenital heart diseases (CHDs) prevalence was estimated at 8 to 10 per 1000 live births in the United States (**Bravo-Valenzuela et al.,2018**).

Children with CHDs may be symptomatic with fast breathing, cough, lossof weight, tachycardia and effort intolerance or may be asymptomatic with less critical lesion but have a cardiac murmur detected during routine examination (**Abdel Salam & Mahmoud. 2018**).

About 20% to 30% of children with a CHDs have other physical problems or developmental or cognitive disorders depend on the severity of disease such asmore than 80% of children with a mild CHDs have no developmental disabilities. However, more than half of those with a more critical type of CHDs have some form of disability or impairment(**Albasheri et al.,2017**).

In many cases, the defect not require treatment such as small defect that not cause any long-term effect on the child's health or activities and may not even be identified until adulthood. Some heart defects are serious and require treatment such as tetralogy of fallot. Most heart defects can be either corrected through surgery, medication or catheterization (**Azhar et al., 2016**).

World Health Organization (**WHO. 2017**) defined health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or morbidity", and concentrated on the subjective perception of the impact of disease on the various dimension of life. QoLconcept comprises different dimensions which include individual's physical and emotional health ,psychological and social wellbeing fulfillment of personal expectations and goals ,economic assurance ,and finally capacity to develop daily routines normally (**Amedro et al., 2015**).Health-related quality of life (HRQoL) considered as an impact or influence of a specific disease or medical therapy on a child's daily activities and ability to perform in various life contexts (**Noori et al., 2017**).

Children with CHDs have numerous factors affecting QoL depending on the type and severity of the disease: for example, the delay in physical growth in terms of height and weight, change in the body image, conflict between family, lack of social acceptance, educational level of the parents, poor financial status of the family are negative impact on QoL in both the children's and the family (**Noori et al., 2017**). Constant evaluation of the children can help medical personnel in making decisions regarding medical procedures, in the process of informing the children or his family on possible effects of the chosen procedure, in determining the effectiveness of chosen treatment and the development of cardiac rehabilitation programs (**Murariu et al.,2015**).

The nurse should provide the child and family with accurate information about disease that help the child and family to understand the disease in a different manner. (**Chen et al.,2017**). Children require individualized care plans according to their physical, developmental, educational, and psychosocial needs. Regular health maintenance activities such as developmental support, healthy weight management, dental

care, and immunizations must be provided. Nurses have positive role includes: provide counseling and psychosocial support to children and families, preventing social isolation **(Boyle et al.,2015).**

Aim of the Study:

The study was aimed at toassess quality of life among children with congenital heart diseases.

Research Questions:

1. Is there a relation between mothers' practice and their knowledge about CHDs?

2. Is there a relation between children QoL and their mothers' knowledge and practice about CHDs?

3. What are the factors affecting QoLamong children with CHDs?

Subjects and Methods:

1) The technical design:

A) Research design:

A descriptive design was used to conduct this study.

B) Setting:

The study was conducted at inpatient and outpatient department of the Academic Heart affiliated to Ain-Shams University.

C) Subject:

A purposive sample consisted of 68 children and their accompanying mothers attending to the previously mentioned setting in 6 months period under the following criteria:

- Child's age from 6 to 12 years.
- Children confirmed diagnosis with CHDs.
- Both gender.
- Children free from any acute and chronic diseases.

D) Tools for data Collection:

Tool I: A predesigned questionnaire:

A predesigned questionnaire was developed by researcher after reviewing related literature and it was written in simple Arabic language to suit children's level of understanding and their mother's. It was composed of the following three parts:

The first part:delt with characteristics of children included: age, gender, and child rank and educational level, delt with characteristics of mother included: age, educational level and occupation and material status andchild's medical record to assess health status of children which included physical, circulatory, respiratory, urinary tract, nervous, motor system and skin condition for the child.

The Second part: delt with mothers' knowledge about CHDs such as; definition, types, causes, signs and symptoms, complications and treatments.

Scoring system:

The mothers' complete correct answer was scored "two" & those incomplete correct answer was scored "one" and unknown was scored "zero". The total mothers' knowledge was categorized into; unsatisfactory →less than 50% and satisfactory →50% & more.

The Third part: delt with mothers' reported practice regarding their role in; healthy nutrition, upper respiratory tract

infection, immunization, infectious disease, fever, difficult of breathing, weight loss, drug administration, daily activities.

Scoring system:

Each practice item complete done correctly was scored "two" &those incomplete done was scored "one" and not done "zero". The total mothers' reported practice was categorized into inadequately →less than 50% and adequately → 50% & more.

Tool II: Quality of Life Scale: It was adapted from **Varni et al, (2003)** it was used to determine the level of QoLfor children with CHDs. This scale was modified and translated into Arabic form by investigator. The quality of life domains: physical, psychological, spiritual, social, parent relations and home life, social support and peers, school environment and financial resources.

Scoring system:

This scale used 5 points likert scale ranged from "zero to 4" for never to always For each domain, the scores of the items summed up and the total divided by the number of the items, giving a mean score for the part, these scores were converted into a percent score, means and standard deviation were computed. The QoL was considered poor →less than 60% and good → 60% & more.

Ethical consideration

Prior study conduction, ethical approval was obtained from the Scientific Research Ethical Committee of Faculty of Nursing Helwan University. The purpose of the study was explained to the children and their accompanying mothers and oral consent

was obtained from them to participate in this study. They were given an opportunity to withdraw from the study without given a reason and they were assured that confidentiality of information was protected.

II. Administrative design:

An official permission study would be obtained from dean of Faculty of Nursing Helwan University to the hospital administrators to conduct the proposed study.

III. Operational design:

The study, to be completed, has passed through different phases as follows: the preparatory phase, then the pilot study phase and lastly the field of work phase.

Preparatory phase:

During this phase the researcher reviewed the current, local and international related literature using books, periodicals journals, magazines and internet. This helped the researcher to be more acquainted with the study.

Pilot study:

A pilot study was conducted over period of two months from the beginning of March 2018 to the ending of April 2018. It was conducted on 10% (7 of studied children and their accompanying mothers) to test the applicability, clarity and the efficiency of the study tools.The result of the data obtained from the pilot study helped in removing of some repeated questions related to study tool and all children involved in the pilot study were excluded from the study sample.

Field work:

The actual field work startedfrom the beginning ofMay 2018to the ending of the

November 2018 through interviewing every child and their accompanying mothers individually at the inpatient and outpatient clinics,of the Academic Heart affiliated to Ain-Shams University.

It was done during the morning shifts, two days per week (Wednesday, Monday), from 9:00am. The completion of each sheet took about 45 minutes.The researcher introduced herself to children with congenital heart disease and their accompanying mothers and the approval of mothers was obtained orally after explaining the purpose of the study and try to establish a trustful relationship.

Results:

IV. Statistical design:

Data were coded, entered, and analyzed by using statistical package of social science(IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp). The quantitative data were presented as mean and standard deviation. The qualitative data were presented as number and percentage. The chi-square ($\chi2$) test was used to find the association between variables of qualitative data. The P value of <0.05 or p<0.001 mean statistical significant difference while the P value of >0.05 non significant.

**Table(1):** Distribution of studied children according to their Characteristics(n=68).

Children's Characteristics	N	%
Age /year		
6 <8	37	54.4
8 <10	8	11.8
10 ≤ 12	23	33.8
Mean±SD	8.06±2.33	
Gender		
Male	40	58.8
Female	28	41.2
Children's diagnosis		
Isolated ventricular septal defect	27	39.7
Atrial septal defect	13	19.1
Tetralogy of fallot	22	32.4
Coarctation of aorta	6	8.8
Education		
Not enrolled in education First	12	17.6
Read and write	4	5.9
the primary	37	54.4
the preparatory	15	22.1
Residence		
Urban	3	4.4
Rural	65	95.6

Table (1): showed that more than half (54.4%&58.8%&54.4%) of studied children aged 6 <8 years, were males and in primary school respectively, while 39.7% of them were diagnosed as ventricular septal defect. The same table clarified that the highest percent (95.6%) of studied children were from rural area.

Table (2): Distribution of studied mothers according to their Characteristics(n=68).

Mother Characteristics	N	%
Age /year		
25 <35	37	54.4
35 <45	22	32.4
<45& more	9	13.2
Mean±SD	32.18±6.74	
Education level		
Illiterate	8	11.8
primary education	9	13.2
preparatory education	26	38.2
secondary education	22	32.4
university education	3	4.4
Occupation		
Working	5	7.4
Housewife	63	92.6
Material status		
Married	61	89.7
Divorce	7	10.3
Consenguinity		
Yes	27	39.7
No	41	60.3

Table (2): showed that more than half (54.4%) of studied mothers aged 25 <35 years old with a mean age 32.18±6.74yearsand the majority (92.6 %& 89.7%) of them were house wives and married respectively. The same table showed that more than one third (38.2%& 39.7%) of studied mothers were in preparatory school and had consenguinity with their husbands respectively.

**Figure (1):** scoring of total knowledge of thestudied mothers.
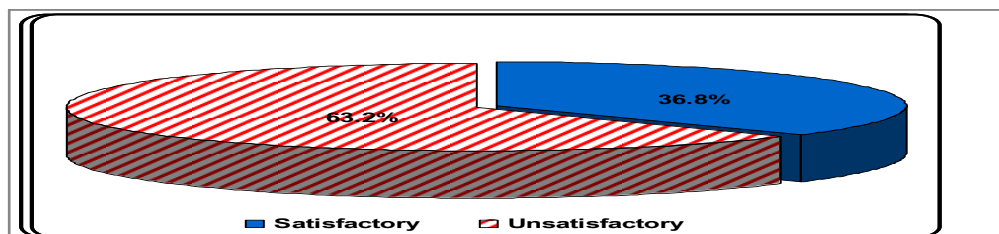
Figure (1): This figure revealed that 63.2% of studied mothers had unsatisfactory knowledge regarding CHDs**.**

Figure (2): scoring of total practices of the studied mothers

Adequately   **Inadequately**
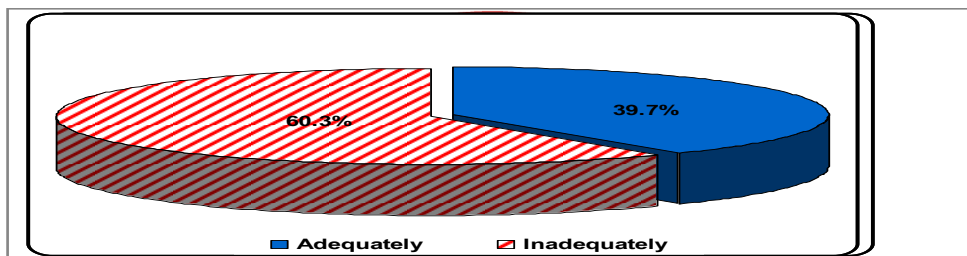
Figure(2): This figure illustrated that 60.3% of studied mothers had inadequate practice regarding the care of their children with CHDs.

Figure (3): scoring of total quality of life of studied children.

Good   **Poor**
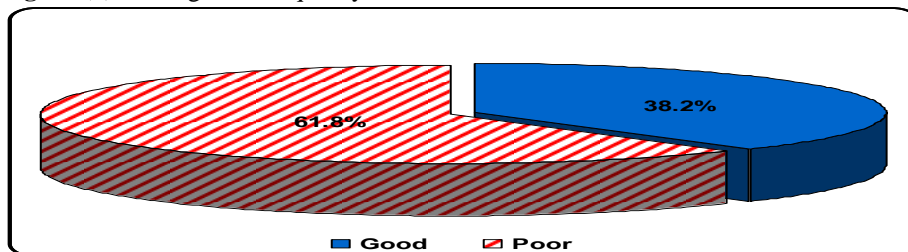
Figure(3): This figure revealed that 61.8% of studied children had QoL.

Table (3): relation between studied children total quality of life and theirtotal knowledge of studied mothers regarding CHDs

Total QOL		Total knowledge			
		Satisfactory (25)		Unsatisfactory(43)	
		N	%	N	%
Good (26)		15	22.1	11	16.2
Poor (42)		10	14.7	32	47.1
Chi-square	X^2			7.930	
	P-value			0.005*	

Table (3): This table demonstrated that there were statistical significant relation between studied children total quality of life and theirtotal knowledge of studied mothers regarding CHDs (p-value = 0.005*).

Table (4):relation between studied children total quality of life and theirtotal practice of studied mothers' regarding the care of CHDs.

Total practice		Total QOL			
		Good (26)		Poor (42)	
		N	%	N	%
Adequate (27)		18	26.5	9	13.2
Inadequate (41)		8	11.8	33	48.5
Chi-square	X^2			15.328	
	P-value			<0.001*	

Table (4): This table demonstrated that there were statistical significant relation between studied children total quality of life and theirtotal practice of studied mothers' regarding the care of CHDs (p-value = 0.005*).

Table (5):relation between studied their total knowledge and theirtotal practice of studied mothers' regarding the care of CHDs.

Total practice		Total knowledge			
		Satisfactory (25)		Unsatisfactory (43)	
		N	%	N	%
Adequate (27)		20	29.4	7	10.3
Inadequate (41)		5	7.4	36	52.9
Chi-square	X^2			26.812	
	P-value			<0.001*	

Table (5): This table demonstrated that there were statistical significant relation between their total knowledge and theirtotal practice of studied mothers' regarding the care of CHDs (p-value = 0.005*).

Discussion:

Regarding to characteristics of children, the finding of the present study revealed that more than half of studied children were aged 6 <8 years. These findings are in agreement with those of **Ladak et al (2018),**who reported that more than half of studied sample were between 5 -9 years. In the same context, these findings are supportedby that of **Ruggiero et al (2018),** Who showed that more than half of them were between 5 -7 years old.

As regards children gender, the result of the current study illustrated that more than half of the studied children were males. These findings were consistent with those of **Abou-Taleb et al (2016),** who reported that more than three quarter of studied sample were males. Meanwhile, this result is disagreement with that of **Ujuanbi (2016),** who revealed that more than half of them werefemales.

Concerning thechildren's diagnosis, findings of the present study demonstrated that more than one third of the studied children were diagnosed as isolated ventricular septal defect. This finding is agreement with finding of**Asani et al (2016),** who found that less than half of studied sample were diagnosed as isolated ventricular septal defect. On the other hand, this findings are incongruent with those of **Ujuanbi (2016),** who reported that the

majority of them were diagnosed as atrial septal defect.

In relation to educational level of children, the current study findings showed that more than one third of studied children were in primary school. This finding was similar to those of **Ladak et al (2018),** who reported that more than of one third of of studied sample were in primary school.

Considering the place of residence, the present study clarified that the highest percent of studied children were from rural area. These findings were supported by that of **Ibrahim&Awad (2018),** who found that more than three quarters of studied sample were from rural area. And also this findingwas came in the same line with finding of **Sabry &Osama (2011),**who illustrated that two third studied samplewere from rural areas. This resultwas disagreement with that of **Elshazali et al (2018),** who revealed thatmore than two thirds of the studied children were from urban areas. From researcher point of view this may be due to unavailability of specialized pediatric heart hospitals for providing specialized care of children.

Regarding to mothers' characteristics, the finding of the present study clarified that more than half of studied mothers aged 25 <35 years old. These findings were in agreement with those of **Abdel Salam& Mahmoud(2018),** who reported that more than two thirds of mothers age between 26-35 years old. As regarding to education levelof mothers, the result of the current study showed that more than one third of studied mother were in preparatory school. These findings are consistent with those of **Elshazali et al (2018),** who clarified that less than halfof studied sample were in preparatory school and these findings were supported with those of **Balat & Sahu (2018),** who

mentioned that less than halfof studied sample were educated up to primary school. From researcher point of viewthis may be due to early marriage of girls that common popular tradition in rural community.

Concerning the occupation of mothers, the present study revealed that the majority of studied mother were house wives. These findings were constrasting with those of **Zaki et al (2018),**who found that the majority of studied sample were house wives. From researcher point of viewthis may be due to most of the Egyptian mothers preferred to stay at home to provide the care for their husbands and children specially if they had chronic ill child.

Considering the material statusof mothers, the current study findings demonstrated that the most of studied mothers were married. This finding was similar to those of **Habte & Mekasha (2018),** who reported that the majority studied samplewere married. The finding of the present study demonstrated that the majority of studied children had no family history of CHDs. These findings were in agreement with those of **Elshazali et al (2018),** who found that the majority of studied sample had no family history of CHDs. These results were incongruent with those of **Zaki et al., (2018)**who denoted that less than two thirds of studied samplewere had family history.

Regarding to mothers' knowledge about disease. The present study revealed that more than two thirds of them had unsatisfactory knowledge regarding congenital heart diseases from total knowledge**.** These were consistent with that of **Animasahunet al (2015),** who showed that more than two thirds of studied samplehad poor knowledge about congenital heart diseases.

Regarding to mothers' practice towards the care of their children with congenital heart diseases. The present study revealed that less than two thirds of them had inadequate practice towards needs for their children with congenital heart diseases. This finding is consistent with that of **Mohammed & Mohammed (2019),** who showed that less than two thirds of studied sample had had inadequate practice towards the care of their children with CHDs.

Regarding the total quality of life for children with congenital heart diseases, the current study revealed that more than two thirds ofstudied sample had poor quality of life.These findings were in agreement with those of **Ladak et al (2018),** who reported that the majority of studied sample had lower health related quality of life in all domains.

The current study inshowed that there were statistical significant relation between their total quality of life and theirtotal knowledge regarding CHDs (p-value = 0.005*). This result was consistent with that of **Abdel Salam& Mahmoud (2018),** who revealed thatthere were statistical significant relation between theirtotal knowledge and their total quality of life regarding CHDs. This finding disagreed with finding of **Abdel Wanise (2014),** who reported that that there were no statistical significant deference between their total QoL and theirtotal knowledge regarding CHDs (p-value = 0.005*).

The present study in illustrated that there were highly statistical significant relation between their total practice and theirtotal quality of life regarding CHDs (p-value = 0.001*). This finding was agreed with finding of**Abdel salam& Mahmoud (2018),** who demonstrated that there were highly statistical significant relation

between their total practice and theirtotal quality of life regarding CHDs. Meanwhile this finding was disagreed with finding of **Gill et al(2011),** who reported that there were no highly statistical significant relation between their total practice and theirtotal quality of life.

The finding of the present study demonstrated that there were highly statistical significant relation between their total practice and theirtotal knowledge regarding CHDs (p-value = 0.001*). This result was similar with that of **Mohammed& Mohammed (2019),** who denoted that there were highly statistical significant relation between their total practice and theirtotal knowledge regarding CHDs.

Conclusion:

Based upon the results of the current study, it can be concluded that there were statistical significant differences between their total knowledge and their total practice regarding CHDs**.**In addition to, There were statistical significant relation between theirtotal knowledge and their total practice and their total quality of liferegarding children with CHDs**.**

Recommendations:

In the light of the finding of this study, the following recommendations are suggested;

• Continuous health education to mothers regarding congenital heart diseases, complications and management plan.

• Regular monitoring and periodical evaluating QoL for children with congenital heart diseases to detecting and solving any problems.

• The importance of regular follow up for periodic assessment of children with CHDs for early detection of complications and management for them.

• Provision a rehabilitation programs for children with congenital heart diseases to improve HRQoL.

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