

Quality of Life among School Age Children with Congenital Heart Disease

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Abstract

Background:- Congenital heart disease consider one of the most common pediatric chronic disease that can have an improve on the lives of affected children and their families. **This study aimed to** identify the quality of life among school- age children with congenital heart disease. **Materials and Method:** Convenience sampling of one hundred school-age children with congenital heart disease and their mothers were selected from outpatient clinic and inpatient pediatric cardiac departments at Assiut University El-Orrman Hospital. The children's age ranged from 8 to 12 years & free from any associated disease. **Three tools** were used for gathering data in this study; tool (1): A structured interview questionnaire, it involved characteristic and clinical data of children connected to congenital heart disease. Tool (2) Pediatric Quality of Life Inventory scale used to assess the influence of congenital heart disease on child's quality of life. Tool (3) Socio-economic scale; used to assess the socio-economic status of the children with congenital heart disease. **Results** shown that more than three quarters of school-age children with congenital heart disease had a neutral quality of life and less than quarter of them had high. Only small percent of studied subjects had poor. Children 's parents' reports established such results, where there were significant positive correlations among children reports and their parents reports in the majority of studied items regarding congenital heart disease. **Conclusion** the study decided that, there were significant positive correlations between children reports and those of their mothers in the majority of the studied items of quality of life concerning congenital heart disease. Therefore, **it is recommended** to conduct health education program for school-age children who had congenital heart disease and their parents to the different measures of high quality of life is recommended to aid those children to improvement their quality of life.

Key words: Quality of life, School-age children, Congenital heart disease.

Introduction

Congenital heart diseases (CHD) are the second most important causes of death in early period and childhood, as well as the only reason of heart disease in the pediatric population in developing countries. The occurrence is 10 per thousand, i.e. 10 babies every 1,000 births have congenital heart disease (Dionysia & Apostolos., 2010) & Gale,T 2006).

Congenital heart diseases are defined as the conformation deformities of the heart or the blood vessels, formed through fetal life (3 to 6 weeks of pregnancy), i.e. when the heart or the major blood vessels of the heart cannot develop accurately before birth. The abnormalities containing the arteries, the valves, the coronary and the main vessels of the heart can be either simple or complex (Bajolle, 2009).

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Number of people aged 0-18 years who had CHD was probable to be between 1,905,000 and 2,102,000, and there are variable qualities of life that these children experience based on disease severity. In addition to children who are born with CHD, children who are obese can develop like cardiac problems (Marelli et al., 2012).

The reasons of these diseases in 80-90% of the cases is unknown, in the literature, it is mentioned that genetic and environmental factors are concerned for the incidence of CHD. More in detail, if there is a child in the family with congenital heart disease, the chance of a 2nd child being born with congenital heart disease is 3-4 times more, comparative to families that have healthy children. As to the external factors, the most recurrently associated with congenital heart disease are congenital rubella, the use of different drugs by the mother during the first trimester of gravidity, and maternal diabetes mellitus. Chromosomal abnormalities instantaneous with congenital heart disease is the Down syndrome, the Turner Syndrome, the Marfan syndrome, and trisomy 18 and 13-15 (Misraet al., 2015).

CHD are clinically classified depending on the presence of cyanosis in non-cyanotic, which are categorized by physiological amount of oxygen in arterial blood and normal skin color, and in cyanotic, which are described by decrease oxygen in arterial blood and cyanotic skin color. (Gale E 2018)

Most common non-cyanotic CHD are the interventricular septum communication (30- 50%), the open ductus arteriosus (10%), the atrial septal defect (7-10%), the pulmonary valve stenosis (7%), the aortic coarctation (6%) and the aortic valve stenosis (6%). Most common cyanotic HD are the Fallot's tetralogy (5%) and transposition of great vessels (5%). The respite of the CHD a group of rare and complex illnesses of the

anatomy of the heart, such as common trunk arteriosus, single ventricle, triglochin valve atresia, total abnormal convergence of pulmonary veins (Schumacher, 2013).

Children with CHD, whose diagnosis were neglected in early childhood, could be establish in schools and may be symptomatic with fast breathing, cough and effort intolerance . Others with less critical lesion may be asymptomatic but have a cardiac murmur discovered during routine examination. A heightened awareness of CHD and its presentation beyond early infancy or childhood may help detect these children within the context of the school health program and bring their attention to a pediatric cardiologist to mitigate the development of fatal complications (Viana et al., 2016).

Treatment of CHD can be either one conservative or surgical. Recent research data demonstration that from 1993 to 2003, the death incidence for children with congenital heart disease has decreased by 31% due to the perfections in the prognosis and management of the disease (Mocumbi et al., 2011).

The school-age children are characterized by slow, steady physical growth and rapid social and cognitive development. They are in the concrete phase of mental development. This stage improves mental operations in which they are able to combine, isolated, and transform information in a logical way. Increased memory ability allows children to hold two or more aspects of a problem in their minds while they are being process (Hockenberry et al ., 2010).&(Tsao, PC et al 2017)

It has been argued that all chronic illnesses can affect HRQOL of the children; each disease presents unique challenges. QoL has been defined by the WHO(1998) as an individual's awareness of their position in life in the

circumstance of the culture and value systems in which they live and in relative to their goals, expectations, standards and concerns.

HRQOL returns the children's awareness of the impact of the disease and its management on their life. Though considerable progresses were made during last decades in applying measurement of quality of life in daily clinical practice, only until in recent times its' valuation has been progressively acknowledged as an necessary health outcome measure in clinical trials and health services research and evaluation. Furthermore, it reflects an selection for knowing children that need support due to the severe difficulties they experience. (Schlarmann et al ., 2013). & Poeta LS et al ., 2013)

The pediatric nurses are in a unique position to assess QOL as human science, nursing is concerned with how human being experience health and illness. Nurses are able to assess the patient's perceptions of QOL and how these perception s influence their actions and reactions to the diseases. They are trained to intervene to maximize the patient's strengths and potential and they could contribute to their quality of life. Recently, more attention has been directed towards the importance of children's life quality to disease process (Hockenberry-et al., 2010).

Significance of the study

The study of QoL in children, especially in relation to parental perceptions, is a relatively recent endeavor, and it has been difficult to develop appropriate definitions and conceptualizations for analysis. As a result, there is a wide array of scales and items that make up quality of life instruments for children. Since quality of life analysis can be used to aid in the detection of physical and/or psychological problems that can

otherwise not be recognized, monitor disease and treatment, and improve delivery of care. An significant factor in assessing the QoL of children's with CHD is their awareness on the effect of the disease and of its management on their lives(Bertoletti et al., 2014).

In the pediatric population, there are few data on the influence of congenital heart disease on children's of QoL. The few published studies have highlighted a significant influence of congenital heart disease on quality of life in affected children. The purposes of this study were to describe QOL in children with congenital heart disease using HRQOL in affected children. In addition, we recognize the predictors which reduced QOL in affected children.

Operational definitions:-

QoL:- Quality of life

HRQoL:- Health related Quality of life

CHD:- Congenital Heart Disease

Aim of the study

This study aimed to identify Quality of Life among School Age Children with Congenital Heart Disease.

Research Questions:-

The study responded the following questions:

1. Do the congenital heart disease has impact on child's quality of life?
2. What is the relationship between CHD and quality of life?
3. What are the predictors which may decline quality of life in children with congenital heart disease?

Materials and Method

Research design:-

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A descriptive research design was used in this study.

Setting:-

The study was carried out in the outpatient clinic and inpatient pediatric cardiac departments at Assuit University El-orman Hospital .

Sample:

A convenience sampling of 100 school –age children with congenital heart disease and their mothers were selected from the previously mentioned settings who fulfill the following criteria:

- 1- The children's age ranged from 8 to 12 years.
- 2- Children were free from any associated disease.

Tools For Data Collection:

Three tools were used in this study to collect the needed data:

Tool I: Characteristics and clinical data of congenital heart disease school-age children questionnaire:

It included demographic data of children such as age , sex, and clinical data such as : history, signs, symptoms, severity of disease, complications and treatment as well as, children's mother data such as age, educational level, occupation ,residence and social class.

Tool II:-Pediatric Quality of Life Inventory scale (Peds QL): This scale was used to assess the HRQOL of school-age children (8- 12) years who have CHD and it consisted of two parts:

Part one:- The Pediatric Quality of Life Inventory 3.0 (Peds Q L) Cardiac Module was used to evaluate health related quality of life through six domains: Heart Problems and Treatment, Treatment II, Perceived Physical Appearance, Treatment Anxiety,

Cognitive Problems, and Communication. It consisted of 27 items that clarifies their cardiac condition in relation to the following categories: heart problems (7 items), currently used heart medicine (5 items), perceived physical appearance (3 items), anxiety related to treatment (4 items), cognitive problems (5 items) and communication problems (3 items).The initial PedsQoL survey has been modified to include many different subcategories and, of interest to this study, is the PedsQoL 3.0 cardiac module. The survey questions are measured on a 5-point Likert scale from 0 (never) to 4 (almost always). The module is scored by transforming the raw values to make responses of 0 equal 100, 1 equal 75, 2 equal 50, 3 equal 25 and 4 equal 0. After summing the 23 values, the average was taken in order to determine the patient's overall quality of life. The highest value, 100, indicates the highest quality of life (Uzark et al., 2008; Varni et al.,1999).

Part two:- Parent's report of cardiac module of pediatric quality of life scale: (DoN M.,2013)It consisted of 27 items that clarifies the cardiac condition of their children in relation to the same categories included in part one.

Response Choices:-

Never-almost never-sometimes-often-almost always

Raw Scores

0	1	2	3	4
0- 100 Scale Scores				
100	75	50	25	0

Score system of school-age children's quality of life distribution is:

Poor quality of life: <50%

Neutral quality of life:50'% - < 75%

High quality of life: 75% and more.

Tool (III): Socio-economic scale; it was developed by Abd El-Twaab (1998) and used to assess the socio-economic

status of the children with CHD. It involved four domains; level of parent's education (8 items), family income (6 items), parents' occupation, life styles (3 items). Each item of four domains has one score. The total score was shared into three classes as high degree from 85-100%, moderate from 60-84% and low less than 60%. Income of family item has been adjusted by the researcher according to the ratio of inflation and rise to be conforming with recent income by comparing variance of the value of the golden pound at 1998 to that, at 2018 and multiplying the amount of rise to the scale.

Method

An official permission to conduct the study was attained from the responsible administrative personnel (the directors of Assiut University El-orman Hospital and the heads of the Pediatric cardiology Out-Patient clinic and cardiology department after explaining the purpose of the study. Explanation for the aim and methodology of the study was done to study participants by the researchers.

Pilot Study

Pilot study was carried out on 10 % (10) of school age children to test clearness and applicability of the study tools and to estimate the time required to collect data. According to the results of the pilot study, the wanted modifications were done. A jury acceptance of the final form was secured before actual study work from both pediatric nursing and medical fields to test its contents **validity** and its result was 93%. **The reliability** was assessed by measuring its internal consistency using Cronbach's alpha coefficient method which was (0.88) for children and (0.91) for their mother .

Field of the study

Data collection was done by the researchers during two months period from the beginning of January until the end of February 2018. It was finished through the routine work of the hospital. The researchers interviewed each participated child and his parent individually to obtain the necessary information. The Pediatric department and cardiology Out-Patient clinics were working all days in the week. The tangible work started by meeting the children, the researchers initially introduced self to them and gave them a complete back ground about the study. The researchers gave older children (who can read and write) or the mothers' of young children the sheet which was pre-designed in Arabic language and stay with them in special room to clarified any question vague to them or to read the sheet if the child or his mothers' unable to read it. The sheet required about 20-30 minutes for filling it; about 2-3 cases were collected per day.

Ethical considerations

Written informed consent was provided by a mother of each students participating in the study and they are secured that data will be confidential and used only for the research purpose.

Statistical design

The data were test for normality by Anderson-Darling test and for homogeneity variances prior to further statistical analysis. Categorical variables were designated by **number and percent**, where continuous variables described by mean and standard deviation. **Chi-square test** and fisher exact test used to compare between categorical variables where compare between continuous variables by **t-test and Anova**. **A two-tailed p < 0.05** was considered statistically significant. All analyses were accomplished with the **IBM SPSS 20.0** software.

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Results:-

Table (1):Characteristics of School age children and their mothers (N=100) .

Children's characteristic	No=100	%
age in years		
8-<10	53	53.0
10- ≤12	47	47.0
Mean ±SD(range)	9.4±2.8(6-13)	
Sex		
Male	63	63.0
Female	37	37.0
Mother's characteristic		
Age(years)		
25-	20	20.0
30-	34	34.0
35+	46	46.0
Mean ±SD(range)	34.9±6.7(25-50)	
educational level		
Illiterate	62	62.0
Read and write	15	15.0
Primary, preparatory and secondary school	20	20.0
University	3	3.0
Occupation		
Housewife	86	86.0
Working	14	14.0
Residence		
Urban	41	41.0
Rural	59	59.0
social class		
Low	40	40.0
Middle	55	55.0
High	5	5.0

Table(1):Regarding socio-demographic characteristics of studied children, more than half of children (53%) was aged 8-< 10years, while 47% of them their ages ranged from 10-≤ 12years to, about two thirds of the children(63%) were males and (37%) of them were females.

The age of most mothers (46%) lies in the 35 years and more category. More than two thirds of mothers (62%) were illiterate, 20% of them were secondary school. The majority of mother's (86%) were housewives and 14% of them were working. More than half of the studied children came from rural area and have moderate socio economic level (59% and 55%) respectively. (**Table 1**).

Table (2): Characteristics of congenital heart disease among studied children (N= 100)

Item	No. (n=100)	%
positive family history		
Yes	64	64.0
No	36	36.0
signs and symptoms of cyanotic heart disease include		
Breathing difficulties	55	24.0
Chest pains	40	55.0
Cyanosis or bluish lips	16	16.0
Hypoxia	30	30.0
Sweating	24	7.0
Fainting	7	7.0
signs and symptoms of a cyanotic heart disease include		
Cyanosis	18	18.0
Frequent respiratory infections	30	36.0
Congested cough	14	14.0
Diaphoresis	35	35.0
Tachycardia	60	14.0
Tachypnea	35	17.0
Fatigue	27	27.0
severity of the disease		
Mild	8	8.0
Moderate	28	28.0
Severe	64	64.0
presence of associated complications		
Yes	48	48.0
No	52	52.0
treatment interval		
Every day	59	59.0
Every two week	12	12.0
Every three weeks	15	15.0
Every one month	14	14.0
regularity of treatment		
Always regular	89	89.0
Sometimes regular	6	6.0
Irregular	5	5.0

*More than one signs & symptom

Table (2): Shows characteristic of congenital heart disease among the studied children. It was found that congenital heart disease was found to be more in children with positive family history (64%). indicated parents' expectations about various signs and symptoms of cyanotic heart disease. Breathing difficulties and Chest pain were the most common symptoms (55% and 40%) respectively, while signs and symptoms of a cyanotic heart disease were the most common signs & symptoms tachycardia and congested cough (60% and 36%)respectively. about two thirds of cases (64%) were suffering from severe degree of congenital heart disease. Those with mild and moderate degree CHD were (8% and 28 %) respectively. About half of cases (48%) were suffering from different types of complications. More than half

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of cases (59%) were receiving their treatment every day, about 15% every three week and 14% every one month. Regarding regularity of treatment, fast majority of the cases (89%) were always receiving their treatment regularly, 6% were sometimes on regular treatment and 5% received the treatment irregularly.

Table (3): Correlation between the Mean Scores of School-Age Children Reports and their Mothers' Reports Regarding QoL among Children with CHD.

Variable	quality of life Level							
	Children				Mother			
	poor quality	neutral quality	high quality	P. value	poor quality	neutral quality	high quality	P. value
Heart problems treatment	20±0	23.62±2.11	27.21±0.7	<0.001**	21.33±1.53	24.47±2.31	26±0	<0.001**
Treatment II	1±0	7.92±2.94	13.14±2.8	<0.001**	1±0	7.35±2.55	13±0	<0.001**
Perceived physical appearance	1±0	6.24±1.73	9.21±1.72	<0.001**	1.44±0.51	6.27±1.88	9±0	<0.001**
Treatment anxiety	2.43±1.13	7.66±3.49	12.5±1.99	<0.001**	2.89±1.02	6.9±3.49	10±0	<0.001**
Cognitive problems	1.29±0.76	11.2±3.62	17.71±1.07	<0.001**	1.44±0.51	10.8±4.29	19±0	<0.001**
Communication	3.43±1.13	6.47±2.89	8.79±1.63	<0.001**	1.44±0.51	5.78±2.94	10±0	<0.001**

Anova test , ** Significant difference at p. value<0.01

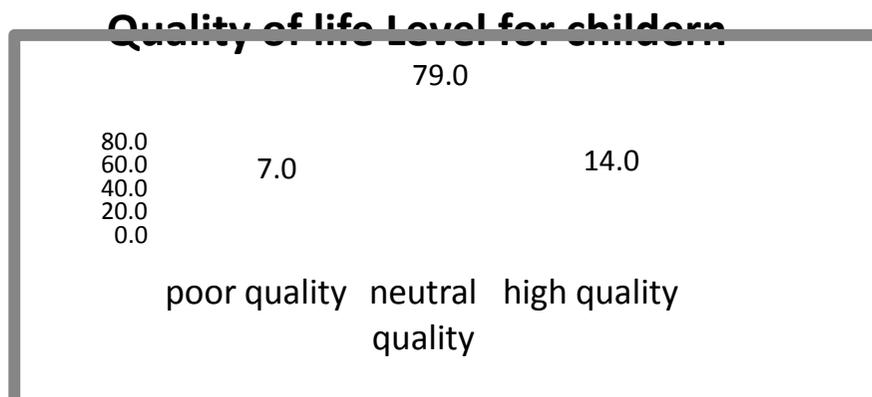
Table (3): Portrays the correlation between the mean scores of school-age children's reports and their mothers' reports regarding quality of life of children with congenital heart disease. There is a positive correlation between children's reports and their mother s' reports in the majority of items and significant differences were illustrated; health problem treatment, Treatment II, Perceived physical appearance, treatment anxiety , Cognitive problems and communication (p <0.001).

Table (4):Percentage distribution of overall QoL for children's and mothers' report

Variables	Children			Mothers'	
	Highest possible score (%)	Achieved points	Level of QQL	Achieved points	Level of Knowledge
Heart problems treatment	28 (100%)	23.87(85.25%)	high quality	23.92(85.43%)	high quality
Treatment II	20(100%)	8.17(40.85%)	poor quality	6.26(31.3%)	poor quality
Perceived physical appearance	12(100%)	6.29(52.42%)	neutral quality	5.43(45.25%)	poor quality
Treatment anxiety	16(100%)	7.97(49.81%)	poor quality	6.21(38.81%)	poor quality
Cognitive problems	20(100%)	11.42(57.1%)	neutral quality	9.2(46%)	poor quality
Communication	12(100%)	6.58(54.83%)	neutral quality	5.04(42%)	poor quality
Total Quality of life	108(100%)	64.3(59.54%)	neutral quality	56.06(51.91%)	neutral quality

Table (4): The correct response rate for all quality of life six domain (health problem treatment, Treatment II, Perceived physical appearance, treatment anxiety, Cognitive problems and communication) in children and their mothers'. This result in an average of (59.54%, 51.91%) respectively points out of 108 points which could be achieved. This demonstrates a neutral quality of life.

Fig (1):- The Level QOL of School-Age Children with congenital heart disease according to the total Percent Score of their children's reports.



Regarding school-age children who had congenital heart disease, **Figure (1)** portrays that more than two thirds of them (79%) had a neutral QOL, while 14% had high QOL and only 7% of them had poor QOL.

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Fig (2) :- The Level Qol of School-Age Children with CHD according to the total Percent Score of their mother's reports

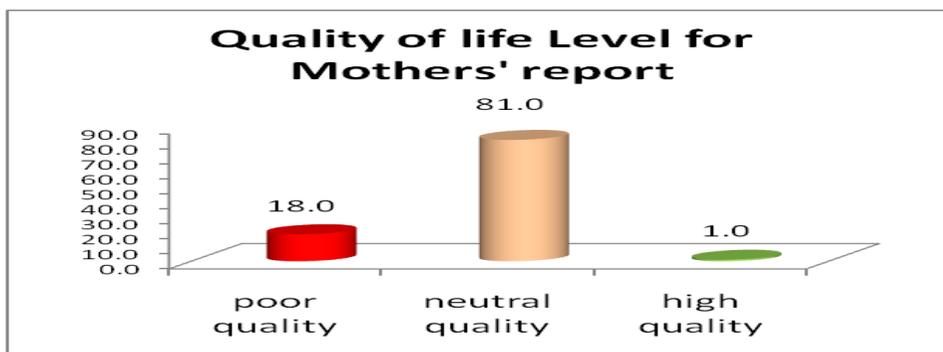


Figure (2):- Concerning children's mothers' reports, the majority of mothers (81.0%) stated that their children had neutral QOL, 18% of them cited that their children had poor QOL and only one percent reported that their children had high QOL

Fig (3): Coloration between Children report and Mothers' report According to total QOL scale.



Figure (3): Illustrates that over seventy percent of children who had congenital heart disease (79%) had a neutral QOL, while 14% of them had high QOL and 7% had poor QOL. Concerning children's mothers' reports, the majority of mothers (81.0%) stated that their children had neutral QOL, 18% of them cited that their children had poor QOL and one percent e of them reported that their children had high QOL.

Discussion

CHD are the most common structural and functional abnormalities of the heart for children, having a major impact on morbidity and general mortality. Evaluation of the impact of these diseases on patients and their families, by knowing their expectations regarding therapy and prognosis, along with their accurate information, can lead to measures that pay to lower level of stress and of pre/ post-interventional

anxiety. The increased level of stress of these families can effect physical and psychological development of childrens with CHD. Since quality of life analysis can be used to aid in the detection of physical and/or psychological problems that can otherwise not be recognized, monitor disease and treatment, and improve delivery of care, it is important for physicians to critically analyze the quality of life of their patients (Solans et al., (2008).

The present study showed that, the higher percentage of CHD was more common in children with rural inhabitation than those with urban inhabitation. From the point of the researchers' view, this difference is related to poor sanitation, lower educational level of parents, and smaller monthly income for rural families as comparative to those for urban families. Similar results were reached by (Sadoh WE, (2010)

CHD is frequently associated with a [family history](#) of the condition (Fritz et al., 2014). In the present study, presence of CHD among studied children was significantly associated with family history of CHD among fathers and/or mothers. This in congruence with a study by Owen et al., (2010). As regard to present of positive family history, this study found that, the children who have positive family history had greater QOL score than those who had positive family history with statistically significant difference. In a trail to explain this finding, it could be interpreted that, those children without positive family history, this problem was considered very stressful for them as all family members, while those with positive family history considered this problem will solve at any time as what happened with other family members as (parent, old brother, uncle.....etc).

This conclusion contradicts results obtained from other groups in Mussatto KA et al., (2014). Based on all the limitations that patients can potentially have when they are diagnosed with CHD, it is notable that they showed a significantly higher quality of life than patients without CHD. One possible explanation for this result is that these children have developed a routine with which they live their life, revolving around their disease, which has helped them progress their quality of living. They know exactly when to take their medicine every day, they know what they

can and can't do during exercise, and they have grown accustomed to living with a heart condition. In the communication domain in particular, these children might have a lot of experience in talking with doctors and nurses about their condition, which makes it tranquil to communicate with other people. Further, by constantly being in a doctor's office for treatment and repeated exposure to that environment, the anxiety that surrounds visiting the doctor or hospital may be diminished.

In contrast with Uzark, K., (2008) et al in Nepal among school age children reported that on pediatric QoL yielded conflicting results on whether children with CHD have a lower quality of life comparative to healthy children. Even with this discrepancy, other studies show a lower level of health related quality of life among children with CHD compared to healthy children. One hypothesis for this finding is that the physical limitations, whether real or perceived, in children with CHD interferes with their perceived quality of life. Also, in agreement with this, findings of study done in Turkey by Bertolotti et al., (2014) which shown that health related quality of life in children aged 8-15 years, children with CHD tend to display lower health related quality of life scores in the sections regarding motor function, cognitive function and positive emotional function compared to the healthy control. Specifically, children aged 8-11 years showed dramatically lower scores in health problems treatment, treatment II, perceived physical appearance, treatment anxiety and cognitive problems than healthy peer. (Tahirović, E., et al 2010)

The children's neutral or high QOL that has been shown in this study could be related to certain factors, such as children's coping with their disease and their responses to the chronic illness stress, where they were enabled cope with significant adverse events and still function competently. Therefore, it is

important to analyze the parental perceptions of childhood quality of life as well as the child's perception, because these differences can be significant in methods of a treatment plan and follow through.

The mean scores for the majority of studied school-age children's, and their mothers' reports in the present study were high regarding the health problems treatment and treatment anxiety items (81.1 ± 12.9 , 75.4 ± 15.6 respectively, table 2). These could be related to the children's good response to disease process and its management. **These findings are supported by many authors** in contrast (**latal et al., 2009**). Children with CHD reported a lower quality of life than their parents in aspects such as pain and physical symptoms, motor function, autonomy and positive emotional function. There inclined to be a bigger discrepancy between parent and children replies in the 8-11 year old age group. In my opinion It is hypothesized that the greater a patient's satisfaction is with their physician, the more willing they are to comply with physician treatment and suggestions.

A cyanotic congenital heart diseases were found to be more prevalent in this study representing 96.8% of all cases of CHD seen in the study population. **Jarun et al.,(2010)**found a similar trend among school children, **and Bernier et al., (2010)**, also reported a cyanotic CHD as the commonest CHD among school children. This is probably because most children with cyanotic CHD tend to have more critical lesions with higher morbid state that result in early infant death without intervention. It is also remotely possible that some children with cyanotic CHD might have had early repair of their cardiac defects since attention might have been drawn to them much earlier by health professionals because of cyanosis and surgical intervention sought earlier if they can afford.

Communication is very important because it allows a patient to feel like they are in a safe environment where they can share anything related to their health and not feel threatened, allowing the healing process to begin. Once this process is underway, the chances for a successful outcome and full recovery increase, paving the way for good overall health (**Benbenishty and Hannink, 2015**). Moreover, the better a physician's non-verbal communication skills are, the greater a patient's satisfaction (**Silva AM et al., 2011**). It is hypothesized that the greater a patient's satisfaction is with their physician, the more willing they are to comply with physician treatment and suggestions. **Mussatto KA et al.,2014** investigated whether or not parent and child ratings on the health related quality of life analysis were in agreement. The parents of children in the 8-11 age group reported lower quality of life regarding positive emotional functioning and cognitive function.

Children with CHD reported a lower quality of life than their parents in aspects such as pain and physical symptoms, motor function, autonomy and positive emotional function it is important to analyze the parental perceptions of childhood quality of life as well as the child's perception impact family life. These patients are responsible for more medications, visits to the doctor, and have to be more cognizant of their limitations. If parents are able to have access to information on making the transition to adulthood easier, it allows for the child to have a greater sense of support and can aid in parental anxiety that might result from raising a child with CHD (**Stuckey, Kayla 2016**).children 8-12 years old had higher quality of life (76.40 ± 15.58) than children 13 years and older (70.06 ± 17.66). Central to the purpose of this study and counter to our hypothesis, children with heart conditions reported significantly higher quality of life (76.07 ± 14.79) than children without heart conditions (68.57 ± 18.72 ; $p < 0.05$).

Similarly, parents of children with heart conditions perceived significantly higher quality of life (72.48 ± 15.61) than parents of children without heart conditions (67.01 ± 16.28 ; $p < 0.05$) (Figure 3). This means that children who are younger report a higher quality of life than older children, children with heart conditions report higher quality of life than those without a heart condition, and parental perceptions of quality of life for children are higher when the child has a heart condition compared to those with no heart condition between children with HD.

Results of the present study revealed that the majority of school age children with congenital heart disease perceived that they had a neutral QOL (79% for those who had congenital heart disease). However, 17.4% and 27.3% of them had high QOL. Similar results were found regarding the mothers' reports, where the majority of them stated that their children had a neutral QOL (78.3% and 94.8% for those who had congenital heart disease respectively) (**Figure 1 and 2**). This finding supported by the results of **Sable et al., (2011)**. Who found that children 8-12 years old had higher quality of life (76.40 ± 15.58) than children 13 years and older (70.06 ± 17.66). Central to the purpose of this your study Similarly, parents of children with heart conditions perceived significantly higher quality of life (72.48 ± 15.61) than parents of children without heart conditions (67.01 ± 16.28 ; $p < 0.05$) (Figure 3). This means that children who are younger report a higher quality of life than older children, children with heart conditions report higher quality of life than those without a heart condition, and parental perceptions of quality of life for children are higher when the child has a heart condition compared to those with no heart condition.

The child's QOL is greater than that of the parental Qol. This could simply be due to the fact that the parent is unaware

of their child's feelings because there is not an open line of communication among parent and child. Additionally, parents may experience higher anxiety or have a general lack of knowledge about CHD that is causing them to underestimate their child's perception of Qol. It is important to understand the root cause of these differences because they can alter how parents interact with their child and can lead children to have more limited lifestyle than they truly need. Further experimentation would need to be performed to determine the type of relationship between parent and child to confirm these hypotheses (**Fig 3**).

Finally, we believe that, the current study represents one of the comprehensive attempts to document the effect of CHD on the child's quality of life. We optimism that, these findings will aid set better treatment goals and be beneficial in identifying individual factors that can impair Qol. We also hope that, they will enable treating clinicians to arrange simultaneously for counseling or support by qualified individuals to reduce the adverse influence on the well-being of these children and their families.

Conclusion

Based on the results of this study, it can be concluded that,:

The majority of the studied school-age children with congenital heart disease had a neutral HRQOL, and less than a quarter of them had high HRQOL. Only a small percentage of the studied subjects (7.0%) had a poor HRQOL. Reports of children 's mothers established such results where there were significant positive correlations between children reports and those of their mothers in the majority of the studied items of QOL regarding congenital heart disease.

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Recommendations:-

Based on the result of the present study, the following recommendations are suggested:-

- Parents required significant support, and that, treatment must include the whole family rather than have just the child only.
- A health education program is required for school-age children who had congenital heart disease and their parents, Further highlight the need for health education on CHD among health workers, parents, teachers and other caregivers so that attention can be drawn to the condition early, for early intervention
- The items of high HRQOL for school-age children who had congenital heart disease should be incorporated into the routine care of hospitals.
- Further research in a bigger group of children is necessary.
- Further underscores the need for school screening medical examination to identify such children for intervention.

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