

Quality of Life Among Children Suffering From Congenital Heart Disease

Manal Mahmoud Sayeh, Seham Guirgius Ragheb, Waleed Mohamed ELguindy, Rasmia Abd Elstar Ali

Community Health Nursing Department, Faculty of Nursing Ain Shams University.

Abstract

Aim of the study: this study aimed to assess quality of life among children suffering from congenital heart disease. **Research design:** A descriptive design was utilized in this study. **Setting:** The study was conducted at cardio-pulmonary outpatient clinic in pediatric hospital at Ain Shams University. **Sampling:** A purposive sample. 200 children with their mothers. **Tools of data collection:** For data collection two tools were used: The first tool:- A pre-designed questionnaire contains Socio-demographic data of children, socio-demographic data of mothers and fathers, environmental assessment for children living in assessment of mother's knowledge about congenital heart disease, and assessment of mother's practice related to children needs and problems. **The second tool includes** Quality of life inventory scale was constructed to assess level of quality of life for children with congenital heart disease. **Results:** The finding of the present study revealed that; more than half of the studied children were females. The present study showed approximately half of the studied mothers start given weaning foods to their infant at the age of two. **Conclusion:** The Study concluded that there was a highly statistical significant relation between mother's age ,educational level and their total knowledge there was a highly statistical significant relation between mothers educational level and their total practice While, there was a highly statistical significant relation ($P < 0.001$) between total knowledge and total QOL **Recommendations:** Periodic training programs for the congenitally heart children and their mothers about their disease, management and control to improve their knowledge and consequently their quality of life. Effort should be made to reduce the CHD complications among children through adopting a national strategies and plan of CHD.

Key words: Quality of life, congenital heart disease, Mother's Knowledge, Community health Nursing roles.

Introduction

Congenital heart defects are heart problems that developed before birth. They can occur in the heart's chambers, valves or blood vessels. A baby may be born with only one defect or with several defects. Of the dozens of heart defects, some are mild and may need little or no medical treatment even through adulthood (*Mayo Clinic, 2015*).

Congenital heart disease (CHD) is a problem with the heart's structure and function that is present at birth. Congenital heart disease CHD can describe a number of different problems affecting the heart. It is the most common type of birth defect. CHD causes more deaths in the first year of life than any other birth defects (*Webb GD et al., 2015*).

CHD is the most common birth defect, occurring in approximately 8 out of every 1,000. The American Heart Association (AHA) estimates that 1 in 150 adults are living with CHD. Most of

these children are diagnosed in early childhood and infancy (AHA, 2013). Recent recommendations for critical CHD screening with pulse oximetry added to universal newborn screening during the first 24 hours of life have been shown to identify the presence of CHD prior to hospital discharge. It is estimated that 25% of infants with CHD will require invasive treatment during the first year of life, while Egyptian children incidence are 5-6/ 1000 live birth. The CHDS are the major causes of death other than prematurity in the first year of life (Go et al., 2014; Centers for Disease Control and Prevention, 2014).

Quality of life: The patient's ability to enjoy normal life activities. Quality of life is an important consideration in medical care. Some medical treatments can seriously impair quality of life without providing appreciable benefit, whereas others greatly enhance quality of life (Garcia et al., 2014).

Nurses caring for children with CHD are uniquely skilled at educating families about the importance of health maintenance needs. Nurses must partner with parents in order to develop an individualized health maintenance and promotion plan that will address the child's physical, developmental, psychosocial, and cognitive needs as well as foster parental well-being and appropriate coping mechanisms (Banar, 2014).

Significance of the study:

Infant and childhood mortality related to CHD decreased by 31% between 1987 and 2005. This survival trend is predicted to increase each year due to advancements in treatment and management of CHD. This significant shift in the epidemiology of CHD requires nurses to take action in preparing children with CHD and their families for their teenage years and young adulthood. Child with CHD has specific physical, intellectual, emotional and developmental needs that must be considered and managed using a multidisciplinary approach (Khairy et al., 2010).

Children with many types of CHD are living beyond the expectations of the healthcare providers who performed their initial repair and beyond the expectations of the healthcare team who cared for them in the very early stages of their disease process. Advances in cardiac surgery,

cardiac catheterization, interventional cardiology, noninvasive imaging, early diagnosis with fetal assessment, and complex critical nursing care have led to 85% to 90% of children with CHD reaching adulthood. Unfortunately, some families do not appreciate the need for long-term follow-up and care, believing instead that their child's repair or stable cardiovascular status deems the visits unnecessary (Gurvitz et al., 2013).

Aim of the study:

This study aimed to assess quality of life among children suffering from congenital heart disease through:-

1. Identifying the mothers' knowledge about congenital heart disease.
2. Assessing mothers' practices toward their child's needs.
3. Identifying levels of child quality of life.

Research questions:-

1. Is there a relation between mothers' socio demographic characteristics and their knowledge about CHDS?
2. Is there a relation between mothers' socio demographic characteristics and their practices related to child's needs?
3. What are the levels of child quality of life?

Subject and methods:

The aim of this study was to assess quality of life among children suffering from congenital heart disease.

*** Research design:-**

A descriptive exploratory design was utilized in this study.

*** Setting:-**

The study was conducted at cardio-pulmonary outpatient clinic in pediatric hospital at Ain Shams University. Where these specialized

clinics many of the medical staff that was working to help these special cases to adapt to these diseases and try to access the quality of life for them.

*** Sampling Techniques :-**

A purposive sample: The total cases attending at outpatient clinics at 2012 were estimated at 2,000 cases, according to the Statistical Office of the Pediatric Hospital in November 2012. So, the study sample will be consisted of ten percent of the total cases which equal 200 children.

The criteria of sample:- The exclusion criteria:- Excluded all children suffering from any physical and mental disabilities.

*** Tools of data collection:-**

For data collection three tools were used:

- **The first tool:-** Child interviewing questionnaire was developed by investigator based on review of literature, and content validated by the supervisor and experts opinion, it was written in simple Arabic language, it included the following (Appendix I):-
 - a) Socio-demographic data of children include age, gender, child rank, [Q₁ – Q₈].
 - b) Socio-demographic data of mothers and fathers include age, educational level, occupation....etc [Q₉ – Q₁₄].
 - o Environmental assessment for children living in [Q₁₅ – Q₂₆]
 - o Crowding index was calculated by using the following equation.

$$CI = \frac{\text{No. of family members.}}{\text{No. of home's rooms}}$$

- c) The child's medical history, it includes [Q₂₇ – Q₃₃].
- d) Mother's knowledge about congenital heart disease, it includes, definition causes, signs and symptoms, treatment [Q₃₄– Q₄₁].

- e) As the children health needs and problems related to CHD by mother's role towards the needs and problem for the children [Q₄₂ – Q₆₂].

*** Scoring system:-**

- A scoring system for each of the knowledge items a correct response was scored "1", an incorrect "zero". For each area of knowledge, was considered satisfactory if the percent score was 50% or more and unsatisfactory if less than 50%.
- A scoring system for each of practice items done correctly was scored "1" and not done "zero". For each area of practice, was considered done correctly if the percent score was 60% or more and not done if less than 60%.

*** The second tool:- (Appendix II):-**

Quality of life inventory scale was constructed to assess level of quality of life for children with congenital heart disease it was adapted from (Varni, 2003) and modified by the investigator.

Quality of life scale consists of four domains; physical, social, psychological, spiritual and general will be every domain contains some of items. Physical domain contains of 28 items, social domains contain of 11 items, a psychological domain contains of 22 items, and spiritual domains contains of 9 items

*** Scoring system:-**

Scoring were ranged from (0-4) with "zero" representing never, with (1) representing almost never, with (2) representing sometimes, with (3) representing often and (4) representing almost always for each item.

For each part, 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 third tool:-**

Child's medical record to assess health status of children which included diagnosis, when the disease started, the time of the treatment initiation and evaluate physical, circulatory, respiratory, urinary tract, nervous, motor system and skin condition for the child also included the results of laboratory investigations.

*** Pilot study:-**

The pilot study was conducted on 10% of children and their mothers to test the feasibility of the tools and the time consumed for filling in the questionnaire and also to test the language clarity of the tools data obtained from the pilot study were analyzed and accordingly the necessary modifications were done. The number of the pilot study was excluded from the study sample. The completion of each sheet took about 45 minutes.

*** Content validity:-**

The study tool was revised by group of experts in community health nursing and pediatric medicine to judge the clarity.

*** Field work:-**

An official letter was submitted to the director of pediatric hospital at Ain Shams University.

The actual field work started data collection from the beginning of November, 2014, and ended by May 2015, it was done during the morning shifts, two days per week. The investigator met the study sample were identified through reading medical record of the children and asking mothers accompanying with the children, each mother was met individually in the outpatient clinics, the investigator started with introducing herself and explaining the aim of the study for the selected mothers, assured that data collected will be confidential and would be only used to achieve the purpose of the study. The questionnaire was read, explained, and the choices were recorded by the investigator, after agreements of the mothers were allowed to express their feelings. Mother's illiterate need more help to complete the tools. Major of cases wanted to explain every item to respond it and it took a lot of time for every case

to end questionnaire, so I took many months to complete all numbers of cases =200.

Ethical consideration:-

The participant has a right for the study subsets were secured that all. The gathered data would be confidential and should be used for study purpose only.

***Statistical Design:-**

Data collected were analyzed and results were presented in tables using frequency distribution tables. Tests of significance were used to find out associations between study variables. The percentages were used in all tables. The statistical significance of observed differences was assessed using.

Chi-square (X^2) P value is used mean \pm standard deviation ($X \pm SD$) as a test of significance of results, not significance $P>0.05$ significant $P<0.05$ and highly significant $P<0.001$.

Data analysis tests were revised coded, analyzed and tabulated using the number and percentage distribution and carried out using statistical package for social science software program through the computer data SPSS in general (version 7, was presented using descriptive statistics in the form of frequencies percentages for qualitative variables, were compared".

Also Microsoft office excel was used for data handling.

Results:

Table (1):- shows that 58.5% of children were female, 41.0% of them; their age was ranged from day <1 year. Concerning child ranking, 36% of the studied children were the first child in the family, 58.5 % of the studied sample were normal at birth, 36% of them, the birth weight were 3(kg) and more, 50% of them, their age at the beginning of weaning was between one to 2 years and 100% of them were vaccinated according to schedule of vaccination.

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Table (2): States that 72.5% of mothers, their age ranged from 20< 30 years, 59.5% of fathers, their age was ranged from 30<40 years, 95.5% of parent were married, 36.0% of mothers received basic education, 41% from fathers received Secondary education, 82% of mothers were not working, 95.5% of father were working and 32.5% from the studied sample there were relationships between fathers and mothers.

Fig. (1):- Illustrates that 55% of mothers had unsatisfactory level of knowledge.

Table (3):- Illustrates that 86.5% of mothers correctly did their role about exposure of the child to common cold or respiratory infection, all of the mothers 100.0% given the child vaccination, 82% of the mothers correctly did their role in the event of a rise in temperature, 91.0% of the mothers correctly did their role toward the difficulty in feeding and all the mothers 100% had compliance to the treatment.

Fig. (2):- Shows that 90% from mothers' information were known from doctors and nurses.

Table (4): Illustrates that there was a highly statistical significant relation between mothers' age and their total knowledge also table (4) shows that there was a highly statistical significant relation between mothers' educational level and their total knowledge.

Table (5): Reveals that there was a highly statistical significant relation between mothers' educational level and their total practice also table (5) shows that there was a highly statistical significant relation between mothers' work and their total practice. While there was no significant statistical relation between mothers' age and their total practice.

Table (6): Clarifies that was highly statistical significant relation between total knowledge and total practice.

Table (1): Distribution of the children according to their sociodemographic data. (N =200)

Items	N=200	100%
Gender:-		
- Male	83	41.5
- Female	117	58.5
Age:		
- One day -	82	41
- 1year -	45	22.5
- 2years -	19	9.5
- 3 - < 5	54	27
Ranking		
- First	72	36
- Second	46	23
- Third	36	18
- Last	46	23
Uterine months		
- Premature	83	41.5
- Normal	117	58.5
Weight at birth by Kg:-		
- 1-	46	23
- 2-	63	31.5
- 3 and more	72	36
- Unknown	19	9.5
Child's diet in infancy:		
-Breast feeding	118	59
-Artificial feeding	54	27
-Both	28	14

Table (1): (Cont.) Distribution of the children according to their sociodemographic data. (N =200)

Items	N=200	100%
Age at start of weaning:		
- 6 months		
- 1 year -	9	4.5
- 2 years -	18	9
- Do not know	100	50
	73	36.5
Child vaccination according to schedule	200	100

Table (2): Distribution numbers and percentage of the child's parent according to sociodemographic data. (N =200)

Items	N=200	100%
Mother's age		
- <20	18	9
- 20-	145	72.5
- 30-	37	18.5
- >40	0	0
Father's age		
- <20	9	4.5
- 20-	63	31.5
- 30-	119	59.5
- >40	9	4.5
Marital status		
- Married	191	95.5
- Divorced	0	0
- Widower	9	4.5
Education level (mother)		
- Illiterate	37	18.5
- Read and write	46	23
- Basic education	72	36
- Secondary education	27	13.5
- University degree	18	9
Education level(father)		
- Illiterate	45	22.5
- Read and write	18	9
- Basic education	45	22.5
- Secondary education	82	41
- University degree	10	5
Mother s Work		
-Working	36	18
- Not working	164	82
Father s Work		
- Working	191	95.5
- Not working	9	4.5
Relationship between father and mother		
- second degree	65	32.5

Fig. (1): Distribution number and percentage of Mothers according to their total satisfactory and unsatisfactory knowledge.

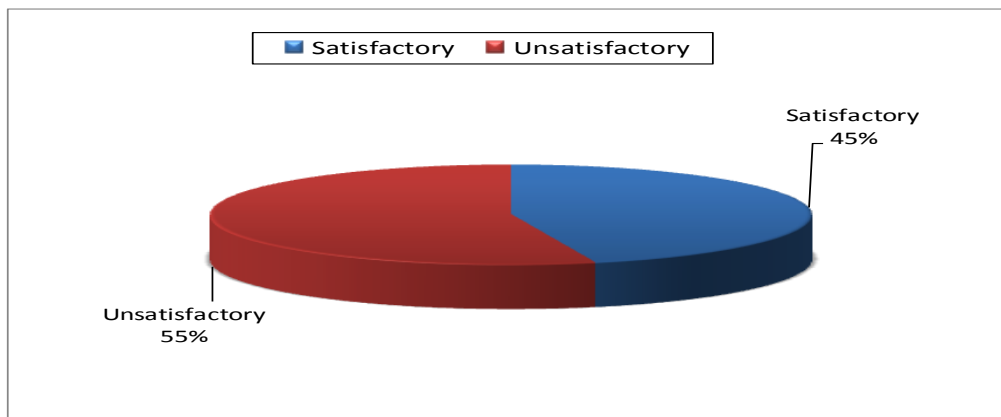


Table (3): Distribution number and percentage of the mothers related to correctly done according to their child care. (N =200)

Items	N=200	100%
Maintain proper nutrition for the child	145	72.5
Role when the child's exposure to common cold or respiratory infection	173	86.5
Vaccinations given	200	100
Protection from infectious diseases	164	82
The role in the event of a rise in temperature	164	82
The role to protect the child from mouth inflammation	81	40.5
The role toward child when there is the blue of the body such as the lips, mucosa.	145	72.5
The role towards having difficulty in feeding	182	91
The role to the weight control	135	67.5
The role toward child when he felt difficulty in breathing	126	63
The role toward child after giving you treatment by injection under the skin or muscle	137	68.5
Compliance to the treatment	200	100
Regularly attend to the clinic for following-up of the child	144	72
The role in the care of your child's teeth and protect them from decaying.	72	36
The role related to child's sports activities	91	45.5
Fluid intake for children is important and helpful to his case	135	67.5
The role in the administration of oral fluids for the child	127	63.5
Child take sufficient sleep	109	54.5

Fig. (2): Distribution of Mothers related to their Source of Information.

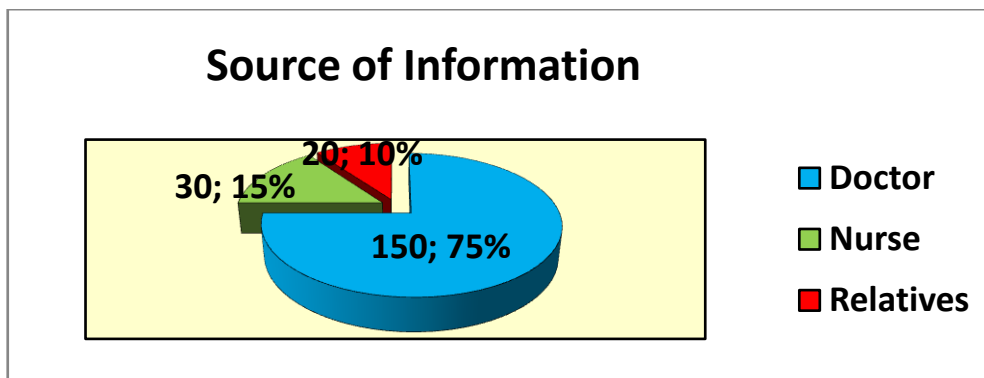


Table (4): Relation between total knowledge and socio-demographic characteristics of the mothers.

Items	Total knowledge		Chi-squared	P	Sig.
	Unsatisfactory	Satisfactory			
Mother's age			46.8	<0.001	HS
<20	2 11.1%	16 88.9%			
20<30	70 48.3%	75 51.7%			
30<40	37 100%	0 0%			
Education level			36.5	<0.001	HS
Illiterate	28 75.7%	9 24.3%			
Can read and write	25 54.3%	21 45.7%			
Basic education	47 65.3%	25 34.7%			
Secondary education	9 33.3%	18 66.7%			
University education	0 0%	18 100%			
Work of mother			42.4	<0.001	HS
Working	2 5.6%	34 94.4%			
Not working	107 65.2%	57 34.8%			

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Table (5): Relation between total practice of mothers and their socio-demographic characteristics.

Items	Total practice		Chi-squared	P	Sig.
	Not done	Done			
Mother's age			2.33	>0.05	NS
<20	9 50.0%	9 50.0%			
20<30	91 62.8%	54 37.2%			
30<40	19 51.4%	18 48.6%			
Education level					
Illiterate	37 100.0%	0 0%	76.6	<0.001	HS
Can read and write	37 80.4%	9 19.6%			
Basic education	36 50.0%	36 50.0%			
Secondary school education	0 0%	27 100%			
University education	9 50.0%	9 50.0%			
Work of mother					
Working	9 25.0%	27 75.0%	21.69	<0.001	HS
Not working	110 67.1%	54 32.9%			
Total	119 59.5%	81 40.5%			

Table (6): The relation between total knowledge and total practice of the studied sample.

Items	Total practice		Chi-squared	P	Sig.
	Not done	Done			
Total knowledge			24.0	<0.001	HS
Unsatisfactory	82 75.2%	27 24.8%			
Satisfactory	37 40.7%	54 59.3%			
Total	119 59.5%	81 40.5%			

DISCUSSION:

The finding of the present study revealed that; more than half of the studied children were females. This finding agreed with *Salah EL-din (2007)* who studied children with congenital heart defect and care givers in children's cardiology outpatient clinic At Abu-Elrish insurance Hospital and *Mostafa et al. (2008)* who studied children with congenital heart disease and their mothers in heart clinic of the university children's hospital

(El-Shatby) in Alexandria, both of them found females represent more than one half of the studied sample while *Badry (2008)* who studied children in children patient cardiothoracic surgery department-Ain shams university Hospital, with congenital heart disease and their mothers in which it was found that a slight male predominance was more than half of the total number of cases.

The present study showed that approximately less than quarter of the studied children were the second or more in birth order

this finding agreed with *Abd EL-Aziz (2009)* who studied children in cardiac Department at Mansoura children university Hospital , which found that approximately one third of the studied cases were the fourth or more in birth order with no role of birth order in that sample to influence risk of heart disease.

Concerning types of feeding, the study showed that the breast feeding was more common, more than one half of the studied children received a breast feeding in addition *Lambert and Watter (2006)* who studied children with congenital heart diseases in china which studied breast feeding of the infants with cardiac defect and clarified that breast feeding a baby with a heart disease can be harder because the baby gets tired so quickly, but breast milk is the best food for baby the finding of this study agreed with *Abd EL-Aziz (2009)*.

The present study showed approximately half of the studied mothers started giving weaning foods to their infants at the age of two this finding disagreed with *Abd EL-Aziz (2009)*, who showed the majority of the studied mothers started giving weaning foods to their infants before 6 months. There were differences between the two studies as a result of increase the mothers knowledge through the health teaching and media.

Concerning infants vaccination all other mothers complete vaccination of their infants according to schedule this finding agreed with *Abd EL-Aziz (2009)* who showed all of the educated mothers completed the vaccination of their infants and approximately one third of illiterate mothers don't give vaccination to their infant as normal schedule.

The current study found that more than half of mothers had age from 20-30 years. This finding disagreed with *Salah EL-din (2007)* who found that more than half of caregivers were above 40 years old.

The present study showed more than three quarter of the studied mothers were married (table 2), this finding agreed with *Mostafa et al. (2008)* who found more than 90% of the studied sample were married.

Considering mother education less than quarter of the studied mothers (table 2) received basic education *Mostafa et al. (2008)* showed

more than half of the studied mothers were able to read and write and *Abd EL-Aziz (2009)* showed more than half of the studied mothers were illiterate and approximately thirty of them had secondary education.

As regarding to mothers work approximately half of the studied mothers were housewives; this finding agreed with *Mostafa et al. (2008)* who showed more than ninety percent of the studied mothers were housewives.

It is important to mention that there were relations between mothers and fathers in this study form the second degree which may act as a genetic predisposition that increases the susceptibility of developing CHD especially when there is exposure to environmental risk factors.

As regarding to the practice of mothers towards the needs of the child suffering from CHD, the present study revealed (Table 6) that more than half of the studied mothers regularly attended to the outpatient clinic for following up of the child; this finding agreed with *Hay et al. (2007)* and *Abd EL-Aziz (2009)* both of them found all the studied children with CHD weather treated medically or surgically had periodic check-up.

The study revealed that all of the studied mothers compliance to the treatment of their child; this finding disagreed with *Bassam (2007)* who studied caregiver and their children in Alexandria, reported that thirty of studied mothers not given medication regularly to their infants.

The present study showed that approximately three quarter of the studied mothers had correctly done to protect child from infection this finding agreed with *Shaaban et al. (2003)*, who studied children with congenital heart in Alexandria on the other hand *Glelhi et al. (2004)* mentioned that infants with CHD are more susceptible to infection and infection affect on heart problems.

The study showed that less than three quarter of the studied mothers had correctly done according to maintain proper nutrition for the child, more than three quarter had correctly done toward having difficulty in feeding, more than quarter had correctly done related to care of child to protect them from decay, less than half of the

studied mothers correctly done related to children sports activities and more than half of the studied mothers had correctly done related to important of fluid intake to their children ,from the researcher point of view these results were related to increase the mothers' awareness and due to health teaching by nursing staff in outpatient clinic.

This study revealed that, one quarter of the studied mothers had taken their information about CHD from doctors and nurses, more than one tenth of mothers received information from relative; this finding agreed with *Salah EL-din (2007)* who shows less than one quarter of caregivers had taken information about heart defect from family and relatives and more than one tenth of caregivers for nurses and doctors.

Table(4) illustrates that was a highly statistical significant relation between mothers' age and their total knowledge, mothers educational level and their knowledge this due to whenever mothers were older whenever the healthy awareness and knowledge increase for them, this agreed with *Abd El kreem (2015)* who showed that there is a highly statistical significant relation between age and total knowledge.

The present study showed that there was a highly statistical significant relation between mothers' educational level and their total practice ($P<0.01$), mothers' work and their total practice while there was no statistical significant relation between mothers' age and their total practice ($P>0.05$) from the researcher point of view that related to whenever mother was older whenever the practice and experience and skills were more than young mother. When the mothers low educational level; they were low practiced and lack of awareness about care of the disease *Mohamed (2011)*, who studied children in outpatient clinic at psychiatric medicine center and the neurological pediatric outpatient clinic affiliated to Ain Shams University, that there were statistical significant relations between mothers' level of education and their level of knowledge and practice towards their children, these relations mean that, mothers' education had direct effect on mothers' knowledge and practice. This can be interpreted that highly educated mothers often have better opportunities to develop skills and knowledge.

Table (6) revealed that there were highly statistically significant relation between total

knowledge and total practice ($P<0.001$) that related to the highly level of healthy awareness of the studied mothers, it was an important role in giving care for the children suffering from CHD.

Conclusion:

The Study concluded that there was a highly statistical significant relation between mothers' age, educational level and their total knowledge. There was a highly statistical significant relation between mothers educational level and their total practice, while there was no significant statistical relation between mothers' age and their total practice, there was a highly statistical significant relation between total knowledge and total practice, there was a highly statistical significant relation ($P<0.001$) between total knowledge and total QOL and there was no statistical significant relation between total practice and total QOL.

Recommendations:

1. Periodic training programs for the congenitally heart children and their mothers about their disease management and control to improve their knowledge
2. Emphasizing the importance of early cases, finding control and management through national screening and surveying programs, targeting congenital heart disease in children.
3. Emphasize the importance of co-operation and co-ordination between policy makers, health services providers as well as social workers and mass media to help to congenitally heart children and their mothers overcome their feeling of stress and adapt positively with the congenital heart diseases.
4. Ensure the importance of community health. Nurses role in teaching, supporting and managing the congenitally heart children and their mothers to comply with management plan that consequently will result in better quality of life.
5. Emphasize the importance of more prospective studies to shed light on the congenitally heart children suffering from

congenital heart disease to help them manage their diseases and its related quality of life.

6. Encourage the importance of regular follow-up and regular investigation of children with congenital heart disease to ensure proper CHD control and early detection of complication.
7. Effort should be made to reduce the CHD complications among children through adopting a national strategies and plans of CHD.

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