

GUIDING PROGRAM FOR MOTHERS TO IMPROVE THE QUALITY OF LIFE OF THEIR CHILDREN WITH CONGENITAL HEART DISEASE

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Abstract

Background: Congenital heart defects (CHD) is one of the major congenital irregularities among children, representing as a major worldwide wellbeing issue. **Aim:** this study aimed to examine a guiding program for mothers to improve the quality of life of their children with congenital heart disease. **Design:** A quasi-experimental design was used. **Setting:** The study was carried out at the Cardiology Department and Outpatient Clinic of Mansoura University Children Hospital (MUCH). **Subjects:** A convenient sample of 70 children with congenital heart defects and their accompanying mothers at MUCH, their age ranged from 3 to 12 years, from both sex and confirmed the diagnosis as congenital heart disease, either cyanotic or a cyanotic. **Tools:** Data were collected using, an interview questionnaire to collect socio-demographic data, for both mothers and their children with CHD. Assessment of mothers' knowledge and practice about congenital heart defects, and quality of life scale for studied children (**QOL scale**). **Results:** high statistical significant were found between knowledge score and practice post immediate intervention as well as statistically significant differences between immediately post-program knowledge score and immediately post-program QOL score. **Conclusion:** The study concluded that mothers' knowledge, reported practice, and quality of life of their children with congenital heart disease were improved after the implementation of the guiding program either immediately or 3 months later than before its implementation. **Recommendation:** Organizing training programs for children with CHD in their homes about their public life such as nutrition, sports, and protection from infection.

Keywords: Children, Congenital heart disease, Guiding program, Mothers, Quality of life.

Introduction

Congenital heart defects (CHD) or congenital cardiovascular defects defining as a structural problems that arise from the abnormal formation of the heart or major blood vessels (**Mozaffarian, 2016**). A child may have born with as it were one fault or with various defects (**Mayo clinic, 2015**).

Congenital heart defects are considering deadly, if not effectively

untreatable. Not all congenital heart diseases are critical, some cases of children cure, spontaneously; some with small damage doesn't require any medicine at all; other with moderate or critical symptoms can treated with drugs or corrected by surgery or other procedures (**Webb, Robert, Douglas, Zipes, Libby, 2015**).

Greatest kinds of congenital heart disease have no identified etiology. Some

heart problems happen more often in families, so there may be a hereditary relation to some heart conditions (**Children's Hospital of Philadelphia, 2018**). More than 32,000 babies born each year with a few shapes of heart fault (1 out of each 125 to 150) (**American Heart Association, 2015**), while Egyptian children incidence are 5:6/1000 life birth (**Center for disease control and prevention, 2014**). These children are often diagnosed in the first year of life and childhood (**American Heart Association, 2013**).

Quality of life for children with congenital heart disease means the children's particular physical and psychological well-being, level of confidence, social relationships, environmental agents, and individual opinions. While evaluating quality of life, the child is asked what consider about their own life, and the purpose is to grade the child physical, psychological, and social well-being by discussing the child as a whole with all their characteristics (**Sertcelik, Alkan, Sapmaz, Coskun, Eser., 2018**).

The role of the nurse toward children have congenital heart defects must have special skills to teach their parents the importance of maintaining their needs. Nurses and parents should organize a plan to maintain their physical, psychological, social and mental health, which requires good adaptation by parents (**Bergemann, 2015**).

According to (**Rozenblum, 2015**), nurses ought to center regions of the first resources, while arrange to grow also reinforce the scientific nursing education for congenital heart defects. Give satisfactory dietary and liquid to preserve the growth and developmental needs of the child. Nourish small amounts with

high-calorie foods to support their bodies. It is also essential to go immediately check intake and output daily also check weight daily (**Du, 2015**).

The most common problem is postoperative complications is infection. Children more responsive to infection and their bodies are risky. Consequently, nurses must pay attention when their patients come after to the intensive care unit post operation to prevent the infection (**Bryan, 2015**).

The significance of the study

Health education is essential for parents having children with congenital heart defects (CHD) regarding contributing factors such as illness and care of the child. Emphasis program related to nutritional status, feeding problems. Nurses should give parent and their children with CHD effective a guiding about their illness and lines of management. Encourage maternal participation in the care of their children suffers from CHD (**El-Gendy, 2014**). Furthermore, absences of studies in Africa to evaluate the mother's knowledge and attitudes towards their children with congenital heart disease, as well as their quality of life (**Knowles, Bull, 2014**).

Aim of the study

This study was aimed to examine a guiding program for mothers to improve the quality of life of their children with congenital heart disease.

Research hypothesis

- Mothers' would have better knowledge and reported practices while caring to their children with CHD after implementation of a guiding program.
- Quality of life of children with CHD would be improved after implementation of a guiding program.

Subjects and Method

1- Subjects

Research design

A quasi-experimental research design was utilized in this study.

2. Settings

This study was conducted in the Cardiology Department and Outpatient Clinic of Mansoura University Children's Hospital (MUCH), Mansoura city.

3. Study sample

A convenience sample (70) children with congenital heart defects / accompanying mothers, who was available during the period of data collection in the previously mentioned setting. Those children were constituted at N>43. The sample size was computed using the Epi-Info software statistical package created by the World Health organization and center for Disease Control and Prevention, Atlanta, Georgia, USA version 2002. Their age ranged from 3 to 12 years, from both sex and confirmed the diagnosis as a congenital heart defect, either cyanotic or a cyanotic.

Tools of data collection: Data were collected using the following tools

Tool 1. A structured questionnaire sheet it was comprised of two parts:

Part (1) Sociodemographic Characteristics of studied children and their mothers: It was designed by the researcher in simple Arabic language after reviewing the related current literature. Including children's age, gender, birth order, history of the child's condition, duration of disease, medical, family and classification of congenital heart disease either cyanotic or a cyanotic. The father and mother's age, level of education, occupation, address, number of a child within the family and family income and previous history for having children with a congenital heart defect

Part (2) Mothers' knowledge about CHD: That was designed by the researcher to assess mothers' knowledge about congenital heart disease, which covered definition, causes and risk factors, signs and symptoms, complications, and methods of treatment, it included 40 knowledge was 40 grades, which categorized according to the median (the cut point) which was 2 as following:

- ✓ Poor knowledge if less than 20grades (< 50% of total score).
- ✓ Average knowledge if from 20 to less than 30grades (50-75 % of total score).
- ✓ Good knowledge if from 30 up to 40grades ($\geq 75\%$ of total score)

Part III: Mothers' reported practices regarding care of their children with congenital heart disease, which covered the following, feeding, daily activity, personal hygiene and general health of the child, which included 23 queries, the score for each item in the scale was ranged from 1-3, through which the mother was taken (3) scores in response to always done, (2) scores for sometimes done and (1) score for rarely done. Pre, post-immediately & post-three-month guiding program, the full score of each mother was divided as the following:

- ✓ Unsatisfactory < 50% or less than 35 grades.
- ✓ Satisfactory $\geq 50\%$ or if equal to or more than 35, which was categorized as
- ✓ Good if from 35 to less than 52 grades
- ✓ Competent if from 52 up to 66 grades

Tool 2. Quality of life scale for children with congenital heart disease-quality of life scale – children (**QOL scale**) Which adapted from **Shokir, (2009)** to assess the quality of life of the studied

children through 64 statements which divided into physical domain (17 statements), emotional domain (17 statements), social domain contain (16 statements) and educational domain (15 statements), the score for each item in the scale ranged from 1-3, through which the mother took (3) scores in response to always, (2) scores for sometimes and (1) score for rarely. Based on the responses of the children, the total score was ranged from good to poor quality of life (poor QOL <97 score or <50% & high QOL ≥ 97 score or $\geq 50\%$)

- ✓ Low QOL = < 50%
- ✓ High QOL = $\geq 50\%$

This tool was used pre and post program.

Guiding program construction:

Prepared by the researcher following review the relevant literature based on mother's need assessment for the care their children with CHD, which covered the content of the instructional guiding program was definition, causes & risk factor, signs and symptoms, complications and methods of treatment for children with congenital heart disease. The reported practices provided by the mothers regarding feeding, daily activity, personal hygiene and general health care for the child, were also included.

Method

The preparatory phase

This phase included a review of the past and current related literature and studies, using available books, periodicals, magazines, and articles to get acquainted with the various aspects of the study research problem and develop the study tool.

The guiding booklet prepared by the researcher. It was specially designed in a simple Arabic language covering different perspectives of preschool and

school-age children with congenital heart disease and their mothers.

Content validity revised by five expertise's in the pediatric nursing field to test applicability, feasibility, and clarity of the study tool for further required modifications. The tool was tested for its clarity provided that the confidence limit is not less than 95%; the study power is 80%. The developer tools were tried for unwavering quality utilizing alpha Cronbach test, the alpha reliability is 0.87.

Ethical considerations

Ethical approval was obtained from the Research Ethics Committee of the Faculty of Nursing at Mansoura University the researcher has obtained the oral consent from each mother for her participation after explaining the purpose of the study. Privacy and confidentiality of the collected data were assured, and a participant was allowed to withdraw from the study at any time freely without any responsibilities.

The study guide construction process

The designed study program for mothers was presented in eight sessions:

The First, second and third sessions: they were concerned with knowledge about congenital heart disease in children which involved the following: definition, causes & risk factor, signs and symptoms, complications and methods of treatment for children with congenital heart disease.

Fourth, fifth and sixth sessions: they were focused on providing guidance for physical needs that are related to care of child patients with congenital heart disease, such as feeding, daily activities of the child, and daily hygiene as importance of dental care and general health for those children.

Seventh and eighth sessions included guidance to relieve psychological stresses and revision of the foregoing and respond to parents' questions. The program was consisting of two parts knowledge & practice.

Exploratory phase:

It includes pilot study and field work

a)-Pilot study: The pilot study was carried out before beginning data collection to test the applicability, clarity, and efficiency of the study tools, as well as to assess the suitability of the environment for data collection; it displayed on ten percent of a whole the sample size of the studied moms and their children. Based on the results of the study, some adjustments and clarification were carried out to be easily understood. Mothers and their children in a pilot study excluded from the study.

b)-Fieldwork: The study was conducted at conducted in the Cardiology Department and Outpatient Clinic of Mansoura University Children's Hospital (MUCH), in which the researcher introduced herself to the study subjects, simple explanation of the study aims and method of data collection was done to gain their approval to share in the study.

Data collection of this study was carried for a six month period, from the beginning of January 2015 to the end of June 2015.

Every mother was interviewed individually by the researcher to collect the necessary data, interview was conducted them for 30 to 45 minutes (Saturday, Monday, and Wednesday) from 9 am to 2 pm. The researcher filled the questionnaire sheet by herself.

Interview was classified into four phases (assessment phase, planning, implementation phase and evaluation phase)

A-Assessment phase: it was done for children with congenital heart defects

and their moms prior to implementation of the study guiding program (pretest).

The objective of this phase was to assess mother's knowledge (base line assessment) about cardiac defects and what should be performed by the child, such as definition, causes& risk factor, signs and symptoms, complications and methods of treatment for children with congenital heart disease. The practical skills provided by the mothers regarding feeding, daily activity, personal hygiene and general health were also assessed in this phase.

B-Planning phase: the researcher designed the guiding program based on an actual need assessment of the studied mothers through reviewing the related literature. Guiding program was covering the theoretical and practical skills. The content of the program was designed by the researcher and written in simple Arabic language and supported by photos and to help mothers in understanding the content.

C-Implementation phase: The objective of sessions aimed at improving mother's knowledge and practices for their children with congenital heart disease. Mothers were divided into small groups; (7-8 for each group). A program was given in eight sessions (about 30-45 minutes for each). Different teaching strategies were utilized within a frame of addresses; gather talk, the exhibit was done by analyst and re-demonstrations by mothers have done. Several teaching aids were used, such as colored banners, PowerPoint, video, and booklet. A booklet provided to each mother to help her in providing home care.

D-Evaluation phase: The pre-assessment (mothers' knowledge, reported practices and QOL of children) tools (pretest) were repeated immediately after giving the guidance program (post-test), and repeated post three-months (posttest) to measure the effect of a guiding program.

Statistical Analysis

The data collected was coded, and inserted into an input file applying the Excel program for Windows. Frequency analysis and standard review used to identify errors. Following full insertion, the data obtained converted into the version of the Statistical Social Science Package (SPSS) version 18 over which the analysis was conducted by applying frequency tables with the percentage. Data were revised, coded and analyzed. Qualitative data were presented as number and percent. Paired T-test was used to compare the scale level before and after guiding program, the most commonly utilized measurable information investigation strategy for theory testing since it is direct and simple to utilize.

Results

Table (1): Presents distribution of the studied mothers according to their sociodemographic characteristics. This table revealed that, the mean age of the studied mother's was 35.23 ± 8.45 years, all of them were married, 48.57% had a technical diploma and 77.14% were housewives. Concerning family income, it was observed that, 61.4% of them had enough income; while 38.6% of them had not enough income. Moreover, 45.7% of the families were composed of husband, wife, and 3 children and 82.9% were lived in rural area.

Table (2): Revealed the distribution of the studied children according to their current medical history. It was found that 47.1%, 34.3% had ventricular septal defect and an atrial septal defect respectively, 58.6%, 55.7%, 52.9%, 32.9% had difficulty breathing, poor feeding, difficulty in feeding and sleep and delayed growth & development respectively, 52.2% were on medical treatment.

Table (3): This table showed the distribution of the studied mothers according to their total knowledge score about congenital heart disease pre, immediate post & three months after program implementation. 94.3% of the studied mothers had poor knowledge score preprogram, declined to 5.7% of studied mothers had poor knowledge score immediate post and after 3 months program implementation respectively, with highly statistically significant differences at ≤ 0.001 .

Table (4): This table illustrated distribution of the studied mothers according to their total reported practices score about CHD pre, immediate post and 3 months after program implementation. It was revealed that, 92.9% of the studied sample had satisfactory reported practice score preprogram while became all of them competent 100% score post immediate & after three months program respectively, with highly statistically significant differences at ≤ 0.001 .

Table (5): clarified distribution of the studied children according to their physical domain (many complain of pain) pre, immediately after & post three months. This table indicated that, the mean were 35.9 ± 6.18 , 36.93 ± 5.91 and 35.95 ± 4.99 respectively pre, immediately post & after three months, with no statistical significant differences pre, immediately post and 3 months after implementation of the program. Regarding to psychological domain, it was observed from this table that, the mean 32.14 ± 5.55 , 32.34 ± 6.41 and 32.4 ± 6.85 respectively pre, immediately post & after three months. Concerning to social domain and educational domain this table showed that, a highly statistically significance at 0.001 between pre & immediate post, also between immediate post & post 3 months.

Table (6): Demonstrated distribution of the studied children according to their

overall pattern quality of life pre, immediately post and after three month implementation of the study program, It was observed that 87.1%, 90% and 97.1% respectively were high QOL preprogram, immediately post and after three month, with highly statistically significant differences ($P \leq 0.001$) P1 (between pre and post immediate)also P3 (post immediate and post 3 month).

Table (7): Presented the an association between total knowledge score about CHD and total reported practices pre, immediately post and after 3months implementation, in which there was a highly statistically significant with

weak positive relation between total reported practices and total knowledge score pre, immediately post and after 3months implementation ($r=0.201$, $p=0.05$, $r=0.417$, $p=0.001$, $r=0.400$, $p=0.001$) respectively.

Table (8): Illustrated the an association between total reported practices score about CHD and total QOL pre, immediately post and after 3months implementation, in which there was a statistically significant with weak positive relation between total QOL and total reported practices pre, immediately post and after 3months implementation ($r=0.411$, $p=0.05$, $r=0.124$, $p=0.31$, $r=0.171$, $p=0.078$) respectively.

Table (1) Number and percentage distribution of the studied mothers according to their sociodemographic characteristics (n=70).

Items	No.	%
Age /years		
- <20	2	2.9
- 20<30	19	27.10
- 30<40	35	50
- More than 40	14	20
Mean \pm SD	35.23 \pm 8.45	
Min – max	17-55	
Marital status		
- Married	70	100
Education level		
- Cannot read and write	9	12.86
- Read and write	19	27.14
- Technical diploma	34	48.57
- Higher education	8	11.4
Occupation		
- Employee	16	22.86
- Housewife	54	77.14
Family monthly income		
- Not enough	27	38.6%
- Just enough	43	61.4%
- High income	0	0
Family size /person		
- Three members	8	11.4
- Four members	8	11.4
- Five members	32	45.7
- More than five members	22	31.4
Residence		
- Rural	58	82.9
- Urban	12	17.1

Table 2: Number and percentage distribution of the studied children according to their current medical history (n=70).

Child history of disease:	No.	%
Types of congenital heart defect		
-Ventricular septal defect	33	47.1
-Atrial septal defect	24	34.3
-Great vessels defect	24	34.3
- Patent ductus arteriosus	14	20
-Don't know	19	27.1
Signs and symptoms		
-Difficult breathing (dyspnea)	41	58.6
-Cyanosis of face and extremities	24	34.3
-Difficulty in feeding and sleep	37	52.9
-Poor feeding	39	55.7
-Delayed growth & development	23	32.9
-All of the above	6	8.6
-Others	11	15.7
Decision of treatment		
Medical	37	52.2
Surgical	33	47.8
-Heart catheterization	15	21.4
-Dilation to tight valves	14	20.7
-Open heart surgery	4	5.7

*All items are not mutually exclusive.

Table 3: Number and percentage distribution of the studied mothers according to their total knowledge score about congenital heart disease pre, immediate post & three months after program implementation (n=70).

Grading	Knowledge score						Significance
	Preprogram		Immediate post		After 3 months		
	No.	%	No.	%	No.	%	
Poor <50%.	66	94.3	4	5.7	4	5.7	t1=21.52 p1= $\leq 0.001^{**}$ t2=22.79
Average 50-75%.	3	4.3	21	30	21	30	p2= $\leq 0.001^{**}$ t3=0.218
Good > 75%.	1	1.4	45	64.3	45	64.3	p3=0.828

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Table (4): Number and percentage distribution of the studied mothers according to their total reported practices score about CHD pre, immediate post and 3 months after program implementation (n=70).

Total mothers' reported practices	Pre implementation		Immediately post		Follow up after 3months		Significance
	No.	%	No.	%	No.	%	
Unsatisfactory < 50%	5	7.1	0	0.0	0	0.0	t1=10.2 p1=≤0.001**
Satisfactory ≥ 50%	65	92.9	70	100	70	100	t2=2.5 p2=0.014
Good reported practices < 50-75%	50	76.9	0	0.0	0	0.0	t3=11.762
-Competent reported practices ≥ 75%	15	23.1	70	100	70	100	p3=≤0.001**

Table 5: Percentage distribution of the studied children according to their physical, psychological, social and educational domains of the quality of life pre, immediately post and after three month implementation of the study program (n=70).

Items	Total OOL score about CHD																		
	Pre intervention				Immediately post				Post 3 months intervention										
	always		sometimes		rarely		always		sometimes		rarely		always		sometimes		rarely		
Physical Domain (Many complain of pain)	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
	24	34.2	26	37.2	20	28.6	25	35.7	27	48.6	18	25.7	25	35.7	27	48.6	18	25.7	
	Mean± SD				35.9±6.18				36.93±5.91				35.95±4.99						
Significance		t1=1.566		t2=0.07		t3=1.588		p1=0.122		p2=0.94		p3=0.117							
Psychological domain (Psychological problems)	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
	28	40	24	34.3	18	25.7	29	41.4	25	35.7	16	22.9	29	41.4	26	37.2	15	21.4	
	Mean ± SD				32.14±5.55				32.34±6.41				32.4±6.85						
Significance		t1=0.25		t2=0.366		t3=0.07		p1=0.802		p2=0.715		p3=0.93							
Social domain (Social relation with others)	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
	29	41.4	25	35.7	16	22.9	50	71.4	15	21.4	5	7.1	52	74.2	15	21.4	3	4.2	
	Mean± SD				22.44±7				28.66±7.028				23.257±7.07						
Significance		t1=9.99		t2=1.596		t3=7.35		p1≤0.001**		p2=0.115		p3≤0.001**							
Educational domain (Mental activities and problem solving)	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
	23	32.8	25	35.7	22	31.4	28	40	24	34.3	18	25.7	29	41.4	25	35.7	16	22.9	
	Mean± SD				27.29±5.79				29.9±4.98				28.03±5.37						
Significance		t1=3.749		t2=1.265		t3=1.99		p1≤0.001**		p2=0.21		p3 =0.05*							

Table 6: percentage distribution of the studied children according to their overall pattern of quality of life pre, immediately post and after three month implementation of the study program (n=70).

Score level	Overall pattern QOL about CHD						Significant test
	pre		immediate Post		After 3 months		
	No.	%	No.	%	No.	%	
Low Quality < 50%	9	12.9	7	10	2	2.9	t1=5.38 p1≤0.001**
High Quality ≥ 50%	61	87.1	63	90	68	97.1	t2=1.265
Mean± SD	117.77±17.63		127.28±16.42		119.87±14.71		p2=0.21 t3=4.71 p3≤0.001**

Table 7: Correlation between mothers total knowledge score about CHD and total reported practices pre, immediately post and after 3months implementation.

Variable	Total knowledge score about CHD					
	Pre implementation		Immediate post implementation		Post 3 months implementation	
	r	p	r	p	r	p
Total reported practices	0.201	0.05	0.417	0.001**	0.400	0.001**

If r ≤0.5= weak correlation

If r >0.5= strong correlation

* P value significant if ≤0.05*(**) extremely statistical significance at p <0.001

Table (8): Correlation between mothers total reported practices score about CHD and total quality of life (QOL) pre, immediately post and after 3months implementation.

Variable	Total reported practices score about CHD					
	Pre implementation		Immediate post implementation		Post 3 months implementation	
	r	p	r	p	r	p
Total QOL	0.411	0.05	0.124	0.31	0.171	0.078

Discussion

the most nursing interventions in clinical settings (outpatient and inpatients) is to help the parents of children with CHD, such as teaching, caring for and giving direction almost the illness, creating plans for care, being an agent of the healthcare group and doing as an advisor to parents **Roberts et al. (2016)**.

One of the current study findings revealed that half of the studied mothers were in the age group from 30 to less than 40 years old, (**Table 1**), this study supported by **Elsobky, Amer&Sarhan.,(2018)** who conducted a study about ‘The effect of pre-hospital discharge care program on mothers’ knowledge and reported practice for children after congenital heart surgery, they

found more than one third was above thirty with mean age 30.80 ± 3.27 . From researcher point of view, the finding of the present study might be due to mothers at the middle age of their age with a progressive age increase in life problems.

The finding of current study showed that less than half of the studied mothers had a technical diploma, while more than one quarter of them had a preparatory education (**Table 1**). As in similar study, **Abdel-Salam and Mahmoud (2018)** who conducted a study about "Effect of educational program on the self-efficacy and quality of life of mothers caring for their children with congenital heart disease", less than three quarters of the mothers were intermediate education. This result was in disagreement with **Hussein&Authman (2014b)**, who reported in their study that, half of the studied mothers were illiterate or end their educational achievement at the primary level.

The present study revealed that, types of CHD, the present study revealed that slightly less than half of the studied sample had a ventricular septal defect, and more than one quarter had an atrial septal defect and about one-fourth of mothers who don't know the type of congenital heart defect (**Table 2**). This result was coordinated with **Elgendy (2014)**, who found more than half of the studied sample had a ventricular septal defect, and then an atrial septal defect was more than one-third. The finding of the current study demonstrated that nearly two-thirds of the studied sample had dyspnea also more than half of them had poor feeding & difficulty in feeding and sleep and one-third of them had

delayed growth & development with cyanosis of the face and extremities (**Table 2**). This study accordance with **Bruce, Lilja, Sundin (2014)**, who conducted a study about 'Mothers' lived experiences of support when living with young children with CHD' who reported that dyspnea, was the main symptom among children with CHD while impaired growth and development were less common than other symptoms. This results supported by, **Abdel-Salam and Mahmoud (2018)** who mentioned that dyspnea mostly symptoms was reported.

The finding of the current study showed that nearly to half of the children had surgical treatment (**Table 2**). The finding agreed with **Elgendy (2014)** and found that more than half sample had advised surgery such as cardiac catheterization, balloon dilation. The researcher pointed simply get to this line of treatment as an operational procedure performed at children clinic nearly and not need a referral to another place.

In relation to total mothers' knowledge and reported practices for their children with congenital heart disease care improved their knowledge and reported practice score immediate post and after 3 months program, present study noticed the majority of studied mother knowledge were poor knowledge preprogram and became good immediate post and after 3 months program, with competent score regarding total reported practices post immediate & after three months program respectively(**Table 3:4**). The This result supported by **Abdel-Salam and Mahmoud (2018)**, who reported, more than half of studied sample were poor knowledge and reported practice respectively, and improved knowledge and reported practice score immediate post and after 3 months program

respectively. On the contrary, this finding was uncoordinated with **Pramila&Chandni (2017)**, who conducted study about 'Knowledge of mothers regarding home care of children undergone cardiac surgery with a view to develop an information booklet', and reported that, more than half of the mothers had moderately adequate knowledge; more than one third of mothers had inadequate knowledge. Same in line with **Elshazali, et al (2018)**, who conducted study about 'Parent's knowledge about diagnosis and management of their children with congenital heart diseases in Khartoum, Sudan', and stated the knowledge of the parents of children with congenital heart disease regarding their children disease was good, simple measures like providing more information especially written information is beneficial. From the researcher's point of view that all studies that are based on guidance, application and follow-up especially for information and practices result in improvement the general status of the child, which is reflected overall pattern QOL of the child.

The finding of this study cleared that, children with congenital heart disease report significantly about QOL change, the physical, psychological, social and educational domains and reported that the mean improved post-program immediately and post-three-months program respectively (**Table, 5:6**). The finding of the current study can be explained in the light of the belief that guiding is important also **Silva et al. (2011)**, who studied QOL of children with CHD, and mentioned that the children acted much the attention about the QOL concerning the psychological,

social relationship, and environment scales if matched with the normal group. In previously handled studies similarly normal, CHD children presented great either a same QOL as compared with the normal children, while difference with **Apers, Luyckx, Rassart, Goossens, Budts, Moons (2013)**, who conducted a study 'Sense of coherence is a predictor of perceived health in adolescents with congenital heart disease,' who reported the patients had a lower QOL on the subscale, decreased cognitive performance additionally the significant association was found between severity of congenital heart disease and psychological and social domains of caregivers QOL. This finding contradicting with **Atmadja, Evalina, Sofyani and Ali (2017)**, who conducted study 'Quality of life in children with congenital heart disease after cardiac surgery'. There were no significant differences in the social, emotional, and school function parameters. In children aged 2-12 years, there were no significant differences in physical, social, emotional, or school parameters. In a study conducted in Portugal, by **Areias, et al., (2014)** it was reported that QoL perception was better in adolescents and young adults with CHD compared with a healthy community sample, but poorer in cyanotic patients, in patients who underwent surgery, and in patients who had physical limitations.

As regards association between total knowledge score about CHD and total reported practices before and immediately after and post 3 months of the program implementation, the result of the same study proved that, there was a significant positive association total knowledge score about CHD and total reported practices pre, immediately after and post 3 months of the program implementation with statistical significant differences at $P \leq 0.05$, t test

reflect the positive weak correlation (0.201) also found highly statistically significant differences at $P \leq 0.001$ correlation between knowledge score and QOL pre-intervention (**table 7**). These findings are similar with **Landolt (2016)**, who studied the predictors of parental quality of life after child open heart surgery. He has chosen to advance analyze the relationship between this variable and the seriousness of the education program. Hence, appears children with multiple CHD and high social support presented greater perception of QOL in every domain, highlighting already again the value of this variable, social support, on the adaptation to the disease. P value found statistically significant differences (0.035) correlation between knowledge score and practice.

The relation between reported practices score and quality of life (QOL) score in after three months of intervention, the current study illustrated that, statistically significant differences (0.078) (**table, 8**). These findings differ with **Amedro et al. (2015)**, who studied 'The QOL of children with CHD is essentially influenced long practically; as compared with ordinary children's with highly statistically significant differences $P \leq 0.001$.

Limitation of the Study

The outpatient clinics area was too noisy and lacking privacy; therefore it was unsuitable to carry out an interview with the study subjects.

Conclusion

Based on the current study findings, it is concluded that: mothers' knowledge, reported practices, and quality of life of their children with

congenital heart disease were improved after the implementation of the study guiding program than before its implementation.

Recommendations

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

- Organizing training programs for individuals with CHD in their homes or in public life such as nutrition, sports, and protection from infection.
- Community resources must be available for children with congenital heart disease and their mothers who may seek assistance and support to increase their knowledge and practical skills.
- Increase awareness of using mass media, TV and radio, lectures in different community associations or in health centers regarding risk factor, prevention of CHD and home care for a child with CHD.
- Design nutritional health educational programs along with encouraging regular mothers follow up visits, for the children with congenital heart disease.
- Developing school health service programs to serve students with congenital heart defects in their schools.
- The ministry of health should arrange the programs for mothers of children congenital heart disease, to provide them about adequate information and skills regarding care of congenital heart disease. which lead to good management practice

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Conflicts of interest disclosure

Author declares that there is no conflict of interest.

References

1. **Abdel-Salam, A., (2018)** Effect of Educational Program on The self-Efficacy and Quality of Life for Mothers Caring children with Congenital Heart Disease, *IOSR Journal of Nursing and Health Science (IOSR-JNHS)*, 7 (4): 68-78.
2. **American Heart Association.(2013).** Infective endocarditis. Available at http://www.heart.org/heartorg/Conditions/CHD/TheImpactofCHD/InfectiveEndocarditis_UCM_307108_Article.
3. **American Heart Association.(2015).** About CHD. Retrieved at: http://www.heart.org/Conditions/CHD/AboutCHD/UCM_001217_Article.jsp Accessed at: October 21, 2016.
4. **Amedro, P., Dorka, R., Moniotte, S., Guillaumont, S., Fraise, A., Kreitmann, B., Borm, B., Bertet, H., Barrea, C., Ovaert, C., Sluysmans, T., De La- Villeon, G., Vincenti, M., Voisin, M., Auquier, P., Picot, M.(2015).** QOL of Children with CHD: A Multicenter Controlled Cross-Sectional Study. *Pediatr Cardiology Journal*;36:1588–1601. [PubMed]
5. **Apers, S., Luyckx, K., Rassart, J., Goossens, E., Budts, W., Moons, P. (2013).** Sense of coherence is a predictor of perceived health in adolescents with congenital heart disease: a cross-lagged prospective study. *International journal; nurses study* 50(6):776–785. doi: 10.1016/j.ijnurstu. 2012.07.002
6. **Atmadja S, Tobing T, Evalina R, Sofyani S, Ali M. (2017).** Quality of life in children with congenital heart disease after cardiac surgery. PI [Internet]. 5 Jan. 2018 [cited 14 Oct. 2019];57(6):285–0. Available from: <https://paediatricaindonesiana.org/index.php/paediatricaindonesiana/article/view/1026>
7. **Areias, M. Catarina, I. Pinto, Patrícia, F. Teixeira, V. Coelho, R. Freitas, I. Matos, S. Castro, M. Sarmento, S. Viana, V. Quintas, J. (2014).** Long term psychosocial outcomes of congenital heart disease (CHD) in adolescents and young adults *Transl Pediatr. journal*; 2(3): 90–98. doi: 10.3978/j.issn.2224-4336.2013.06.02
8. **Bergemann, A., Hansen, J. H., Rotermann, I., Voges, I., Scheewe, J., Otto-Morris, C., Geiger, F. (2015).** Neuropsychological performance of school-aged children after staged surgical palliation of hypoplastic left heart syndrome. *European journal of cardio-thoracic surgery: official Journal of the European Association for Cardio-thoracic Surgery*, 47(5), 803–811.
9. **Bryan, M. (2015).** Post-operative Care of the Adult with Congenital Heart Disease, *Seminars in Cardiothoracic*

- and Vascular Anesthesia. Retrieved from [Http://d.scholar.cnki.net/detail/efdetail?tablename=SJRS_U&filename=SJRS15052700019226](http://d.scholar.cnki.net/detail/efdetail?tablename=SJRS_U&filename=SJRS15052700019226)
 Accessed at: October 31, 2016.
10. **Bruce, E., Lilja, C., Sundin, K. (2014).** Mothers' lived experiences of support when living with young children with congenital heart defects. *Special pediatric nurses journal* 19(1):54–67. doi:10.1111/jspn.12049.
 11. **Centers for Disease Control Prevention (2014).** Facts about birth defects. Available at <http://www.cdc.gov/ncbddd/birthdefects/facts.html> (accessed on 16 April 2014).
 12. **Children's Hospital of Philadelphia, 2018.** Congenital Heart Disease Available at <https://www.chop.edu/conditions-diseases/congenital-heart-disease>
 13. **Du, EY. (2015).** Nursing experience in 62 cases of children with congenital heart disease. *Cardiovascular Disease Journal of Integrated Traditional Chinese & Western Medicine*; 22: (10) 2-3.
 14. **El Gendy, N. (2014).** Psychomotor development of children with congenital heart disease, M.D. thesis pediatrics, Tanta University, 51.
 15. **Elshazali, O., Yousif, E., (2018).** Parent's knowledge about diagnosis and management of their children with congenital heart diseases in Khartoum, Sudan, *Journal of Pediatrics & Neonatal Care*; 8(6):262–266.
 16. **Elsobky, F., Amer, S., and Sarhan, A. (2018).** The effect of pre-hospital discharge care program on mothers' knowledge and reported practice for children after congenital heart surgery. *Journal of Nursing Education and Practice*, 8(9):122-30.
 17. **Hussein K & Authman N. (2014a):** QOL For Caregivers` Of Children with CHD in surgical specialty hospital – Cardiac Center Kurdistan Region/Iraq, *Journal of Kufa for Nursing Science*, 3: (2)
 18. **Knowles, R., Day, T., Wade, A., Bull, C., Wren, C.H., Dezateux, C. (2014).** On behalf of the UK Collaborative Study of CHD (UKCSCHD) *Arch Dis Child*; 1 – 7.
 19. **Landolt, M.A., Ystrom, E., Stene-Larsen, K., Holmstrøm, H., Vollrath, M.E. (2016).** Exploring causal pathways of child behavior and maternal mental health in families with a child with CHD: A longitudinal study. *Psychological medical Journal*; 44:3421–3433.
 20. **Mayo Clinic Staff. (2015).** [http://www.mayoclinic.org/diseases-conditions/aorticstenosis/basics/treatment/c/on20026329;4\(1\):99](http://www.mayoclinic.org/diseases-conditions/aorticstenosis/basics/treatment/c/on20026329;4(1):99)
 21. **Mozaffarian D, Benjamin E, Go A, Arnett D, Blaha M, Cushman M, Das S, de Ferranti S, Després J, Fullerton H, Howard V. (2016).** Heart Disease and Stroke Statistics American Heart Association Statistics update: a report from the American Heart Association. *Circulation.*; 133 (4) :338-60
 22. **Pramila, P. & Chandni, M., (2017).** Knowledge of mothers regarding home care of children undergone cardiac surgery with a view to develop an information booklet. , *An Official Journal of NMC, Birgunj, Nepal*; 2 (1)7, 38-43.

23. **Robert, K., Richard, B., Hal, J. & Bonita, S. (2016).** Congenital heart disease. Nelson Textbook of Pediatrics, Philadelphia, Saunders Co. 1499 -1502.
24. **Rozenblum, R. (2015).** Clinicians' Perspectives on Patient Satisfaction in Adult CHD Clinics a Dimension of Health Care Quality Whose Time Has Come. CHD. Retrieved from http://d.scholar.cnki.net/detail/refdetail?tablename=SJWDTEMP_U&filename=SJWD15042100000229 Accessed at: October 10, 2016.
25. **Sertcelik, T., Alkan, F., Sapmaz, Ş., Coskun, Ş., Eser, E. (2018).** Life quality of children with congenital heart diseases. *Turkish Pediatric Archives of pediatric journal*;53(2):78:86.doi:10.5152/TurkPediatriArs.2018.6428.e Collection 2018 Jun.
26. **Shokir, Z. (2009).** A measure of the diagnosis criteria for QOL (for ordinary and non-ordinary), Cairo, the Anglo-Egyptian.
27. **Silva, A., Cla'udia Vaz, Maria E. G. Areias, Daniela Vieira, Cida lia Proença, Victor Viana, Cla'udia Moura, Jose' C. Areias. (2011):** Cardiology in the Young; QOL of patients with CHD. *Cardiology in the Young, Cambridge University Press Journal*, 21 (06), 670-676.
28. **Webb, G.D., Robert, O., Douglas, N. B., Zipes, M., Libby, P. (2015).** Braunwald's heart disease: A Textbook of cardiovascular medicine, 9th ed., Philadelphia: Saunders. 1411-1464.