

Effect of Family-Centered Care on Mothers' Information Needs, Anxiety and Depression Level Regarding Care for their Children Undergoing Heart Surgery

*Amira Sobhy El-Said Hussein, **Wafaa El-Sayed Abd El-Gileel Ouda, **Randa Mohamed Adly

*M. Sc. in Pediatric Nursing, Assist. Lecturer of Pediatric Nursing, Faculty of Applied Medical Sciences, October 6 University **Professor of Pediatric Nursing, Faculty of Nursing, Ain Shams University

Abstract

Background: Families of children with congenital heart diseases needed for accurate and reliable information about the cardiac conditions, heart surgery and psychological and emotional support. **Aim** of this study was to evaluate the effect of family-centered care intervention on mothers' information needs, anxiety and depression level regarding care for their children undergoing heart surgery. **Design:** a quasi-experimental design was used. **Setting:** The study was carried out at the pediatric inpatient department in Cardiovascular Hospital, affiliated to Ain Shams University Hospitals. **Subject & methods:** A purposive sample of 50 children who were undergoing heart surgery and their accompanying mothers. **Tools:** Child' assessment sheet, the needs of parents questionnaire, structured interview questionnaire, and anxiety–depression scale. **Results:** There was a highly statistically significant difference before and after FCC intervention regarding mothers' total knowledge about congenital heart disease, pre-post operative care and follow up care. There was a highly statistically significant difference between the level of anxiety and depression before and after FCC intervention. **Conclusion:** The family-centered care intervention was effective in meeting mothers' information needs as well as reduced the level of anxiety and depression regarding care for their children undergoing heart surgery. **Recommendations:** Emphasize on the importance of family (usually the mother) participation in care for their children suffering from congenital heart diseases during hospitalization for heart surgery. Designing and carrying out programs for pediatric nurses to promote the implementation of family-centered care in clinical practice.

Keywords: Family-centered care, Congenital heart diseases, Surgery, Pediatric nursing, Need assessment Anxiety, Depression.

Introduction

Congenital Heart Diseases (CHD) are the most common type of birth anomaly and remain the leading cause of birth defect-associated with children's morbidity and mortality, representing a major global health problem (Elshazali et al., 2018).

Worldwide, the CHD are relatively common with a prevalence ranging from 1.0-6.6 per 1000 live births. The prevalence was 6.6 per 1000 in Americans, 5.0 per 1000 in Chinese, 1.0 per 1000 in Egyptian children (Institute for Health Metrics and Evaluation, 2016). In Sohag University Hospital, Sohag, Upper Egypt, in a

prospective study for one year, found that the incidence of cyanotic CHD was 9.5% (50/524) in all admitted neonates to Neonatal Intensive Care Unit (NICU) (Abou-Taleb et al., 2017).

Consequently, families of children with CHD needed for accurate and reliable information about CHD surgery and the cardiac conditions, psychological and emotional support and opportunities for supportive social interaction (Nakazuru et al., 2017).

Mothers of children with CHD tend to experience considerable distress during the children's treatment, and experience higher levels of anxiety than do fathers. Mothers also

typically seek more information because, they tend to readily participate in children's care and stay at the child's bedside for a longer time (Uhm & Kim, 2019).

Parents' knowledge of the children's condition, treatment and prevention of complications has been shown to promote better health behaviour for children by bettering understanding of the cardiac problem, improving compliance with treatment and avoiding risky behaviors (Asani et al., 2016; Elshazali et al., 2018).

Family-Centred Care (FCC) is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients (Shields, 2015).

The Institute for Patient- and Family-Centered Care defines FCC as encompassing four core concepts: respect and dignity, information sharing, participation in care and decision-making, and collaboration between patients, families, and the healthcare team (Hill et al., 2018; Segers et al., 2018).

Children with congenital heart diseases have complex, critical needs and require specialized care. Parents must be equipped with the information necessary to provide such care. Incorporating FCC into practice improves patient and family satisfaction, reduces stress and anxiety, fosters the parent-child relationship, and ultimately increases the quality, efficacy, efficiency, and safety of care delivered (Milford, 2016).

Significance of the study

Based on data from the Medical Records and Statistical Affairs Department at the Cardiovascular Hospital affiliated to Ain Shams University Hospitals in the period from September 2014 to June 2016, it was revealed that 1053 children admitted to the hospital for surgical intervention, 11.7% of those children died after surgery.

Mothers of children suffering from CHD face challenges when caring for their children, as most of these defects require long-term treatment and care. Therefore, health care providers should assess the deficit needs and coping patterns of families, facilitate the implementation of family-centered care and their involvement regarding the daily practices required to care for their children with CHD. The current study was carried out in order to shed light on the importance of ensuring that all mothers should be knowledgeable and skilled to fulfill their roles regarding care for their children suffering from congenital heart diseases.

Aim of the Study

The aim of this study was to evaluate the effect of family-centered care intervention on mothers' information needs and stressors regarding to care for their children undergoing heart surgery, through:

- 1- Assessment of the information needs, anxiety and, depression level of mothers having children undergoing heart surgery.
- 2- Evaluate the effect of family-centered care intervention on meeting mothers' information needs, anxiety and, depression level regarding care for their children undergoing heart surgery.

Research Hypothesis

There will be a positive effect on meeting mothers' information needs and anxiety and, depression level regarding care for their children undergoing heart surgery after receiving the family-centered care intervention.

Subject & Methods

I. Technical design:

The technical design for the study includes research design, setting of the study, subject and tools for data collection.

Research design:

A quasi-experimental research design was utilized for conducting the study.

Setting:

The study was conducted in the Cardiovascular Hospital affiliated to Ain Shams University Hospitals: Surgical departments (located at the 6th and 7th floors, specialized area for the pediatric patients undergoing heart surgery).

Sample:

A purposive sample of 50 children and their accompanying mothers (regardless their characteristics) were involved in the study according to a predetermined inclusion criteria. Children from both genders, in the age group from newborn to adolescent, suffering from congenital heart diseases and undergoing heart surgery for the first time with the exclusion of children suffering from any chronic diseases and illiterate mothers.

The sample size was estimated according to data from the Medical Records and Statistical Affairs Department at the Cardiovascular Hospital affiliated to Ain Shams University Hospitals. The total number of children admitted in 2015 year was 489. Based on this data and according to the predetermined inclusion criteria, the researcher selected 10% of the total admission rate of the children.

Tools for data collection:

Four tools were used for data collection, it was all written in an Arabic language after reviewing related literature and involved the following:

Tool (I): Child' Assessment Sheet:

The child' assessment sheet was designed by the researcher to gather data related to children, through individual interviewing of children and their accompanying mothers. The child's medical record was checked when necessary. It includes data about:

Child's characteristics namely, age, gender, birth order, education and residence. child's diagnosis, medical history, duration of illness, clinical manifestations, number of hospital admission and medications.

Tool (II): The Information Needs Questionnaire (pre/post):

This tool was adapted from **Kristjansottir, (1995) and Shields, et al., (2003)** to assess mothers' needs during and after child hospitalization for heart surgery. The questionnaire contained twenty-three statements that were divided into four groups: The need for information (nine statements), the need for trust (three statements), the need for support and guidance (eight statements) and the need to participate in child care (three statements).

❖ Scoring system:

The mothers' responses explore their needs during and after child hospitalization for heart surgery were determined by the 3-point Likert type rating scale ranging from not important need (0), slightly important (1), and very important (2). Total scoring ranged between 0 – 46, obtaining a higher mean score indicated a greater level of importance of a particular need in a particular domain and vice versa.

Tool (III): Structured Interview Questionnaire Sheet (pre/post):

This tool was used for collection of data related to mothers. It was divided **into two main parts:**

Part 1. Characteristics of the studied mothers and family (age, educational level, occupation, family type, number of family members and the source of their information about the diseases of their children).

Part 2. Mothers' knowledge regarding care of their children suffering from congenital heart diseases who are undergoing heart surgery.

This tool consisted of fifty-four questions in form of close-ended questions, related to (1): Congenital heart diseases (including: anatomy and physiology of the heart, classification of heart diseases, types, causes of CHD and heart surgery). (2): Pre-post operative care (including: breathing

exercises, daily physical activity and movement, diet, medication, hygiene care, oral care, wound care, prevention of infection, psychological support and follow up care).

❖ Scoring system:

The scoring system was graded according to the items of this tool, the answers of mothers were evaluated using a model key answer. Each question scored zero when the answer was I don't know or incorrect answer, incomplete answer scored one grade, while complete answer scored two grades. The total score of the mothers' knowledge was 108 grades (100%). The level of mothers' knowledge was classified as poor knowledge (<50%), fair knowledge (50-75 %) and good knowledge (> 75 %).

Tool (IV): Anxiety-Depression Scale for Parents (pre/post)

This tool was developed by **Rakhawy and Shaheen, (1977)** and adopted from the study by **Mohammed, (2009)**. The scale used to assess the level of mothers' anxiety and depression toward their child's illness. It contains 60 items in the form of "Yes" or "No" response, it was divided into two main subscales anxiety–depression, statement from 1-30 to assess depression, and statement from 31-60 to assess anxiety.

❖ Scoring system:

One degree was given for each statement with response "Yes" and zero for response "No". Total scores measuring the level of anxiety–depression, a total of each subscale score was divided into four levels; no depression or anxiety (<15 scores), mild depression or anxiety (15 < 20 scores), moderate depression or anxiety (20 < 25 scores) and severe depression or anxiety (25 ≤ 30 scores).

II. Operational design:

The operational design consisted of the preparatory phase, pilot study, fieldwork and limitation(s) of the study.

The preparatory phase

During this phase, a review of the literature was done for all available national and international related literatures to be oriented with the various aspects of the research problem and to develop the study tools.

Validity and reliability

The tools were ascertained by a jury of five experts in the field pediatric cardiology and nursing. Their opinions elicited regarding the format, layout, consistency, accuracy and relevancy of the tools. Testing reliability of the study tools were done by Cronbach alpha test, the results was 0.88 for the needs of parents questionnaire and was 0.60 for structured interview questionnaire sheet.

Pilot study

A pilot study was carried out involving five mothers and their children to test the applicability and feasibility of the study tools. Mothers included in the pilot study were excluded later from the main study sample since some modifications were done in the form of rephrasing for some statements. The final form of the tools was then obtained and the time needed for completing each tool was determined.

Ethical Considerations

Ethics approval granted from the Scientific Research Ethical Committee of Faculty of Nursing, Ain Shams University. Informed consent was obtained from the studied mothers prior to data collection. The mothers were informed about the purpose and the expected outcomes of the study. Also, the mothers were assured that the study was harmless to their children, their participation was voluntary and they have the right to withdraw from the study at any time without giving any reason. Mothers were also assured that anonymity and confidentiality will be guaranteed as well, the collected data will be used for the research purpose only. The ethics, values, culture and, beliefs of the studied mothers were respected.

Field work:

Data collection for this study was carried out over a period of seven months starting from the beginning of July 2017 until the end of February 2018. The researcher was available twice /week. Data was collected during the morning and the afternoon shifts from the previously mentioned setting.

The researcher started to collect data through assessment, planning, implementation and evaluation phases as the following:

Assessment phase:

In this phase, each child and the accompanying mother were interviewed individually. The questionnaire (tool, I, II & III) was filled in by the researcher, the time needed to fill in the questionnaire ranged between 30-45 minutes. The anxiety-depression scale (tool, IV) was filled in by the researcher by asking the mothers to rate their response on the rating scales, the average time needed to fill in the scales was 15-20 minutes.

Planning phase:

The family-centered care intervention was designed by the researcher based on the actual needs assessment of the mothers and their children. After review, the relevant literature regarding mothers' needs and care for their children with CHD undergoing heart surgery. An illustrated booklet was designed by the researcher in an Arabic language to serve as a referral guideline for mothers' needs, knowledge and care for their children with CHD undergoing heart surgery.

Selecting the teaching place at the study setting (teaching classroom, mothers' room and children's bedside at surgical department). Different teaching methods were used such as; lecture, modified small group discussion and role-play. Suitable media was used such as booklet, power point presentation, educational videos, lab top, and CD.

Implementation phase:

In this phase, the FCC intervention was implemented in small groups of mothers

where each group included 3-5 mothers. The total number of sessions was five sessions each session took about 60 minutes.

In the first session, after actual need assessment an introduction was given by the researcher about the FCC intervention in terms of its aim, procedure, time frame and evaluation. The expectations of mothers and their children were discussed.

Content of FCC intervention:

Knowledge regarding to FCC (core concept and benefits of FCC) and congenital heart diseases (anatomy and physiology of the heart, classification of heart diseases, types, causes of CHD and heart surgery). Pre-post operative care (breathing exercises, daily physical activity and movement, diet, medication, hygiene care, oral care, wound care, prevention of infection, psychological support and follow up care). Distress (causes, manifestation and management of stress) how to cope with the stressful situation and satisfy needs.

The researcher answered all mothers' questions during sessions, solved any complaint during hospitalization, encourage mothers to express their feelings and mention the sources of their stress and anxiety. Also, given a chance for all mothers to talk for gathering and sharing the experiences.

Use communication techniques by active listening and respect relationships to reduce the anxiety of parents and encourage trust between the researcher, parents (mothers), and their children. Additionally, the researcher contacted with mothers via telephone calls at a specific predetermined time to follow the child's condition and resolve any issues.

Evaluation phase:

In this phase, the researcher evaluated the effect of FCC intervention using the same study tools. This phase was implemented before the child's discharged from the hospital. After discharged, the researcher follow up the studied mothers through phone conversations.

During phone calls, the researcher was provided counseling, advice, reinforce mothers' ability and re-emphasize on the importance of the family-centered care intervention.

III. Administrative design:

An official permission to carry out the study was obtained through an issued letter from the Dean of the Faculty of Nursing, Ain Shams University to the medical and nursing directors of the previously mentioned setting. The letter included the title, aim and the expected outcomes of the study to obtain their approval to conduct the study.

IV. Statistical design:

The collected data were organized, revised, scored, tabulated and analyzed. Statistical analysis was done through computer using the Statistical Package for Social Sciences (SPSS) version 20. The statistical analysis included; number, percentage, means, standard deviation, Chi-square test (X^2), student's "t" test, and Pearson's correlation tests (r) that used for comparisons between qualitative variables. Statistical significant was considered at p -value <0.05 .

Results

Figure (1): illustrated that, more than two thirds (68%) of the studied children were diagnosed with CHD immediately after birth and nearly one quarter (24%) of them diagnosed during the first year of life.

Figure (2): illustrated that, more than one third (36%) of the children's diagnosis was Tetralogy of Fallot (TOF) followed by Ventricular Septal Defect (VSD) (22%) and complex CHD (16%).

Table (1): illustrated that, less than two thirds (64%) of the studied children were previously hospitalized, where 62.5% ($n=32$) of them were hospitalized from 1–2 times for follow up, investigations, and deterioration of health condition as reported by 43.7% of them. All children (100%) were hospitalized to perform surgery and stayed at hospital for 7

<15 days as reported by 66% of them.

Figure (3): illustrated that, more than one third (34%) of the studied mothers don't have any information about CHD. The physician was the main sources of information as reported by 44% of the studied mothers.

Table (2): concerning mothers' needs, a highly statistically significant difference was found as regards their need for information and trust before and after FCC intervention ($t=19.26$, & $t=12.74$, at $p < .000$ respectively), also mothers' need for support and guidance there was a statistically significant difference ($t=2.06$, $p < .044$). Meanwhile, no statistical significant differences in relation to their need to participate in child's care ($t=1.67$, $p < .101$). Regards the mothers' total needs, a highly statistically significant difference was found before and after the FCC intervention ($t=8.39$, $p < .000$).

Table (3): showed that, the studied mothers had information about the child's condition, place of child after surgery and after discharge from PICU and surgical department (62%, 72% & 60% respectively). On the other hand, more than half of the studied mothers don't have information about the treatment plan, description of the operation, medical procedures and devices that will be connected with the child post heart surgery (60%, 52%, 52% & 56% respectively).

Figure (4): illustrated that 68% of the studied mothers have poor total knowledge before FCC intervention compared with all mothers (100%) who have good total knowledge regarding congenital heart disease, pre-post operative care and follow up care after FCC intervention.

Table (4): showed that 14% and 16% of the studied mothers had severe level of anxiety and depression respectively before FCC intervention compared to 34% and 42% of them had no level of anxiety and depression respectively after FCC intervention ($X^2=45.389$, $X^2=47.019$, $p=0.000$). There was a highly statistically significant difference

between the level of anxiety and depression before and after FCC intervention ($t=7.054$, $t=7.744$, $p=0.000$).

Table (5) clarified that, there was negative correlations ($r = -.937$, $r = -.957$ & $r = -.904$ at $p<0.05$) between mothers' needs

and their total knowledge as well as, level of anxiety and depression respectively regarding care of their children undergoing heart surgery after FCC intervention. However, there is no correlation ($p > 0.05$) between them before FCC intervention.

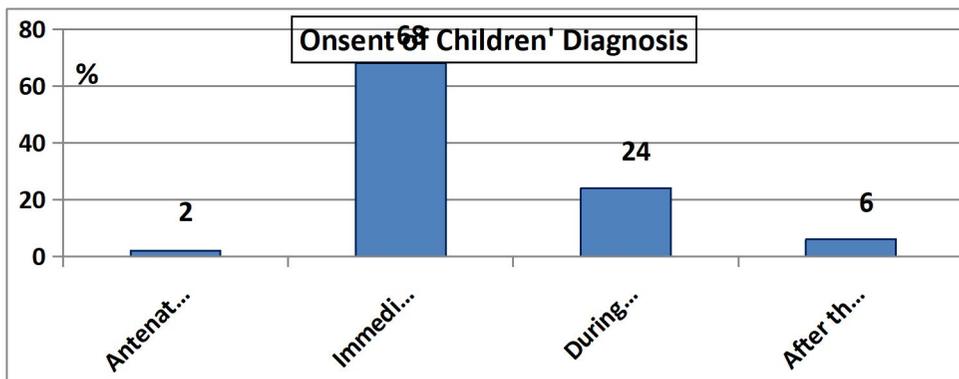
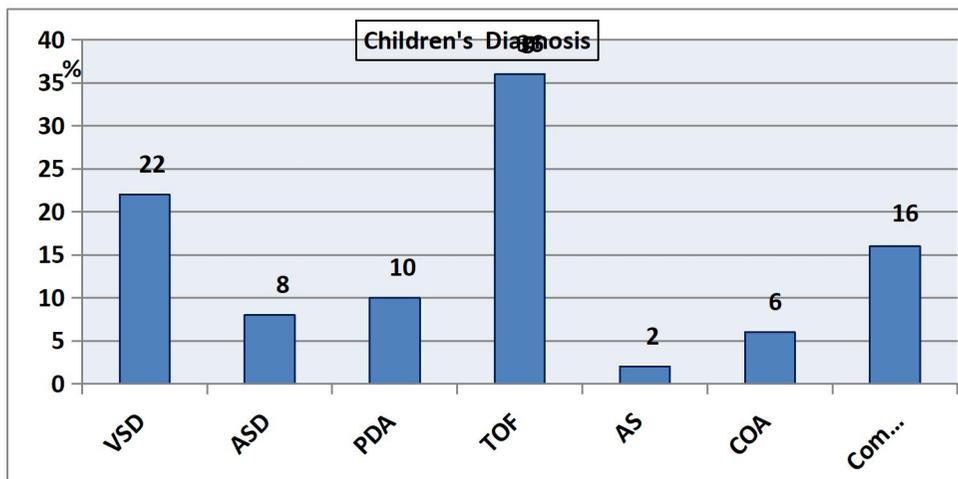


Figure (1): Percentage distribution of the studied children according to their onset of the diagnosis (n=50).



Ventricular Septal Defect (VSD), Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA), Tetralogy of Fallot (TOF), Aortic Stenosis (AS), Coarctation of the Aorta (COA).

Figure (2): Percentage distribution of the studied children according to their diagnoses (n=50).

Table (1): Number and percentage distribution of the studied children according to their previous hospital admission and duration of current hospital stay (n= 50).

Items	No	%
Previous hospital admissions		
- Yes	32	64
- No	18	36
Numbers of previous hospital admissions (n=32)		
- 1-2 time	20	62.5
- ≥ 3 times	12	37.5
Causes of previous hospitalization (n=32)		
- Follow up	3	9.4
- Investigations	7	21.9
- Deterioration of health condition	8	25
- All of the above	14	43.7
Cause of current hospitalization		
- Perform surgery	50	100
Length of current hospital stay (days)		
- 7 < 15	33	66
- 15 < 30	13	26
- 30 \leq 45	4	8
$\bar{X} \pm SD$	16.10 \pm 9.17	

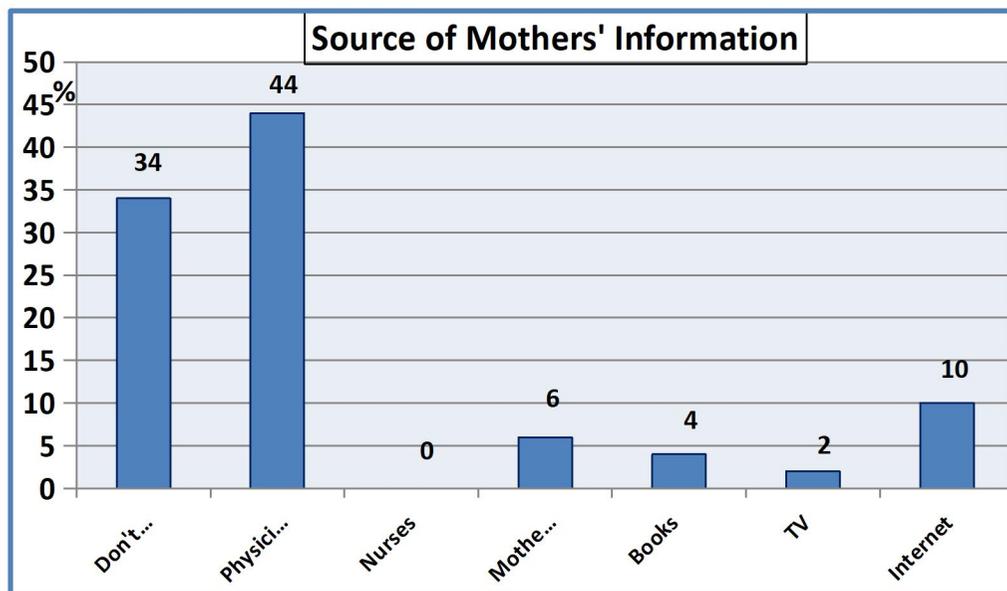


Figure (3): Mothers' source of information about congenital heart diseases (n= 50).

Table (2): Mean scores and standard deviation of the studied mothers regarding to their needs (before and after FCC intervention) (n=50).

Needs of mothers	Before $\bar{X}\pm SD$	After $\bar{X}\pm SD$	t-test	P value
Need for information	15.34 ± 3.19	10.06 ± 1.95	19.263	.000**
Need for trust	5.42 ± .97	3.46 ± .50	12.747	.000**
Need for support and guidance	13.42 ± 3.27	12.48 ± 1.18	2.063	.044*
Need to participate in child's care	5.12 ± 1.23	4.78 ± .67	1.6723	.101
Total	39.30 ± 6.58	30.78 ± 2.34	8.393	.000**

P-value: Not significant NS at >0.05, *significant S at <0.05, ** highly significant HS at <0.01

Table (3): Number and percentage distribution of the studied mothers according to their information about preoperative preparation for heart surgery (n=50).

Information needs about preoperative preparation	Yes		No	
	No	%	No	%
The child's condition	31	62	19	38
The treatment plan	20	40	30	60
Description of the operation	24	48	26	52
Medical procedures	24	48	26	52
The place of child after surgery	36	72	14	28
The devices will be connected with the child post heart surgery	22	44	28	56
The place of child after discharge from PICU and surgical department	30	60	20	40

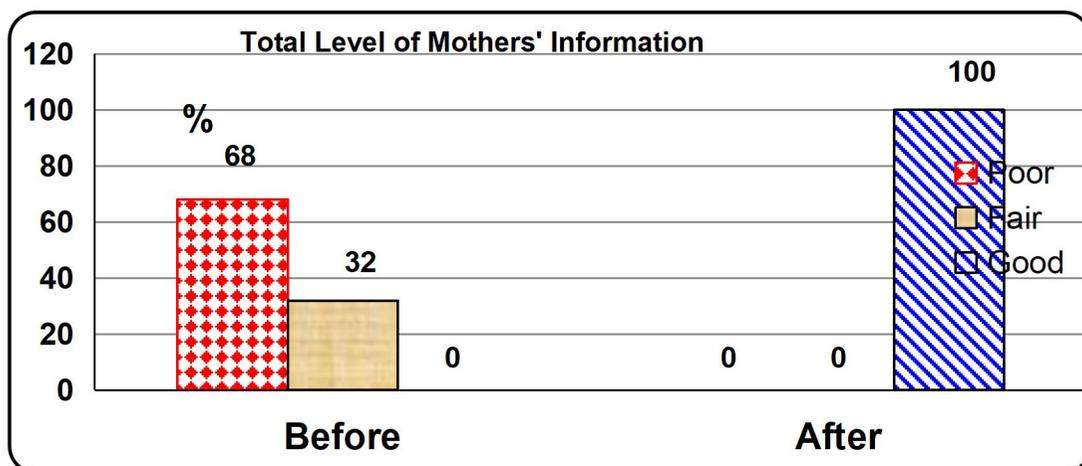
**Figure (4):** Percentage distribution of the studied mothers according to their total level of knowledge about CHD, pre-post operative care and follow up care (before and after FCC intervention) (n=50).

Table (4): Number and percentage distribution of the studied mothers according to their level of anxiety and depression (before and after FCC intervention) (n=50).

Items	Before		After		X ²	P value
	No	%	No	%		
Anxiety						
No anxiety	9	18	17	34	45.389	.000**
Mild anxiety	18	36	20	40		
Moderate anxiety	16	32	13	26		
Severe anxiety	7	14	0	0		
$\bar{X}\pm SD$	19.80 \pm 5.13		16.30 \pm 3.98		t = 7.054	.000**
Depression						
No depression	6	12	21	42	47.019	.000**
Mild depression	21	42	23	46		
Moderate depression	15	30	6	12		
Severe depression	8	16	0	0		
$\bar{X}\pm SD$	18.82 \pm 6.05		16.06 \pm 5.43		t = 7.744	.000**

P-value: Not significant NS at >0.05, *significant S at <0.05, ** highly significant HS at <0.01

Table (5): Correlations between mothers' needs and their total knowledge, level of anxiety and depression regarding care of their children undergoing heart surgery before and after FCC intervention (n=50).

Variables	Mothers' needs			
	Before		After	
	r-value	p-value	r-value	p-value
Mothers' knowledge	-.146	.312	-.937	.000**
Anxiety	-.145	.315	-.017	.909
Depression	-.170	.238	-.015	.919

P-value: Not significant NS at >0.05, *significant S at <0.05, ** highly significant HS at <0.01

Discussion

Family-Centred Care (FCC) is the most essential element of health care providers' promotion of interactions between mothers and their preterm infants. Although the definition of FCC remains elusive, the Institute for Patient and Family-Centered Care (IFPFCC) states four key concepts of FCC: dignity and respect, information sharing, participation and collaboration (IFPFCC 2016).

Information sharing between the nurse and parents and parental participation in their infants' care that is facilitated by the nurse are core components of such partnerships. Parents of children with congenital heart defects need information about what will happen (Sjoberg, et al., 2017).

The aim of this study was to evaluate the effect of family-centered care intervention

on mothers' information needs and stressors regarding to care for their children undergoing heart surgery.

The findings of the present study (figure 1) revealed that, more than two thirds of the studied children were diagnosed as having CHD immediately after birth and nearly one quarter of them diagnosed during the first year of life. This result in the same line with Azhar et al., (2018) in a study entitled "Determinants of successful medical education of caregivers of children with congenital heart diseases", who found that, half of children were diagnosed at birth, nearly one third diagnosed during the 1st year of their life and one fifth of them was diagnosed in childhood. This may reflect an awareness of early detection for children with CHD that will consequently help in the better prognosis of the child's condition.

The result of the present study (figure 2) illustrated that, more than one third of the children's diagnosis was TOF followed by VSD and complex CHD. This result was supported by **Ibrahim et al., (2012)** in a study entitled "Impact of nursing management protocol on selected postoperative outcomes among children with open heart surgery at Cairo University Specialized Pediatric Hospital", who mentioned that, the highest percentage of children was diagnosed as having VSD, ASD and TOF. These results are also consistent with **Abd El Aziz et al., (2016)** in a study entitled "Nutritional education intervention for mothers with children having congenital heart defects" and found that about three-quarters of the studied children had a cyanotic heart defects, whereas one-quarter had cyanotic heart defects. VSD and TOF are the commonest a cyanotic and cyanotic CHDs.

All children were hospitalized to perform surgery and more than two thirds of them stayed at hospital for $7 < 15$ days (table: 1). In the same context **Kempny et al., (2017)** investigated "Outcome of cardiac surgery in patients with congenital heart disease in England between 1997 and 2015", revealed that median post-operative stay was 7.0 days. In a similar result of study carried out by **Azhar and Aljefri, (2018)** "Predictors of extended length of hospital stay following surgical repair of congenital heart diseases", who found that more than half of the children who undergo corrective surgery for CHD spend 10 days or more in the hospital following surgery, as regard unadjusted mean length of stay was 15.70 days.

The results of the present study (figure 3) revealed that, the physician was the main sources of information about CHDs as reported by the studied mothers This result in accordance with **Ibrahim et al., (2014)** who carried out a study entitled "Knowledge, attitude, and practices of pregnant women towards antenatal care in primary healthcare centers in Benghazi, Libya", revealed that more than half of the pregnant women stated that their source of knowledge about antenatal care was from doctors, Also, about one-quarter

of them from relatives and friends, whereas minority from books.

This result also, disagree with **Abou Faddan and Ismail (2018)** who conducted a study entitled "Awareness of married adults about congenital anomalies in a rural village, Assiut", and reported that mass media and relatives were the most common sources of knowledge while the role of medical personnel was limited. In the researcher's point of view, many parents found it hard to digest a lot of information at the time of diagnosis but later they wanted the opportunity to ask questions and get information.

The results of this study (table 2) revealed that a highly statistically significant difference was found as regards mothers' needs for information, trust and support & guidance before and after FCC intervention. Meanwhile, no statistical significant differences in relation to their needs to participate in child's care. This result in agreement with **Sadeghi et al., (2019)** who conducted a study entitled "The impact of family-centered care and meeting the need to learn how much of global anxiety in parents of children with urinary tract infection: a randomized clinical trial", who found that, the FCC was effective at range of meet information needs of hospitalized children parent's and increase their satisfaction.

This finding was supported with **Alsaiani et al., (2019)** study entitled "An investigation of the needs of Saudi parents of preterm infants in the neonatal intensive care unit", who found that the parents viewed needs related to assurance and proximity as most important, followed by information needs. Support and comfort needs were viewed as least important. From the researcher's point of view, parents (mothers) were most often responsible for the child's care after discharge, therefore mothers' need to participate in child's care still most important to ensure that their children receive safe and effective care at home.

As regards mothers' information about preoperative preparation for heart surgery the finding of the current study (table 3), more

than half of the studied mothers reported that they don't have information about the treatment plan, description of the operation, medical procedures and devices that will be connected with their children post heart surgery.

This results was in accordance with main findings of qualitative study by **Sjöberg et al., (2017)** entitled as "Participation in paediatric perioperative care: what it means for parents", who reported that, the parents in the study describe several situations where they lack information causing concern and preventing them from participating and supporting their child. Also, several parents described that the unknown environment, particularly in the waiting room prior to the operation and the operating theatre, influenced them greatly.

Regarding mothers' total knowledge about congenital heart disease, pre-post operative care and follow up care, the result of this study (figure 4) illustrated that, there was a highly statistically significant difference before and after FCC intervention. Similarly, **Soenarto et al., (2018)** entitled "The Effect on education on knowledge level of mothers whose children with congenital heart disease undergoing surgery", who found that half of the mothers had low knowledge of CHD prior to the education session and all mothers increased their knowledge after being given the education.

This study in accordance with **Ahmed and Mahmoud (2019)** who found that, a highly statistically significant difference observed between mothers total knowledge, quality of life and reported practice at pre, post and after three months of educational implementation.

A significant knowledge gain in the mothers might be due to the use of educational materials, including videos and photos and simple descriptions, to be helpful to the mothers more understood.

Considering mothers' stress, the result of the present study (table 4) showed that,

there was a highly statistically significant difference between the level of anxiety and depression before and after FCC intervention. This result is supported by **Uhm and Kim (2019)** who conducted a study entitled "Impact of the mother–nurse partnership programme on mother and infant outcomes in paediatric cardiac intensive care unit", found that the mothers' anxiety level significantly decreased following the mother–nurse partnership programme.

Additionally, this finding was incongruent with **Wei, et al., (2015)** a study entitled "Families of children with congenital heart disease: A literature review" Reported that, most of the studies found that parents were anxious, stressed, and depressed. However, we do not have information on parents' appraisals of their psychological needs and care expectations from the time of their child's diagnosis or during their child's hospitalization for heart surgery.

The results of the current study (table 5) clarified that, there are negative correlations between mothers' needs and their total knowledge regarding care of their children undergoing heart surgery after FCC intervention.

These findings support by **Uhm and Choi (2019)** who conducted a study entitled "Mothers' needs regarding partnerships with nurses during care of infants with congenital heart defects in a paediatric cardiac intensive care unit", concluded that the mothers of infants who underwent cardiac surgery desired different pieces of information according to infants' recovery phase. Similarly, they had different preferred participation activities depending on infants' recovery phase, and could participate actively in caregiving with nurses' help. Also, nurses through meticulous investigation of changing maternal needs and experiences under the present FCC strategies.

In the researcher's point of view, mothers feel that their own needs in the hospital are being met when get to more information on their child's condition and participate in child's care.

Conclusion

Based on the results of the current study, it can be concluded that: The family-centered care intervention was effective in provide and meeting mothers' information needs as well as reduced the level of depression and anxiety regarding care of their children suffering from congenital heart diseases who undergoing heart surgery.

Recommendations

In the light of the results of the present study, the following recommendations are suggested:

-The nursing staff must assess continuously the parent's needs in care of their hospitalized children undergoing heart surgery to satisfy it.

-Designing and carrying out programs for pediatric nurses about how to promote the implementation of family-centered care in clinical practice.

-Emphasize on the importance of availability and distribution of pamphlets, illustrations, videotaped information, Compact Disc (CD) and booklet containing the basic knowledge for mothers (families) about their children regarding care heart surgery.

-Help mothers to cope with stress and anxiety related to care of their children undergoing heart surgery.

-Further researches are required to determine the barriers/ challenges that affect implementation of family-centered care in a pediatric setting.

References

- Abd El Aziz, M.A., Mohammed, B.A., Elsheikh, O.Y. & Mohamed, R.A. (2016). Nutritional education intervention for mothers with children having congenital heart defects. *IOSR Journal of Nursing and Health Science (IOSR-JNHS)*, 2 (3): 153-163.
- Abou Faddan, H., & Ismail, T. (2018). Awareness of married adults about congenital anomalies in a rural village, assiut. *Journal of High Institute of Public Health*, 48(2): 97-106.
- Abou-Taleb, A., Abdelhamid, M.A., & Bahkeet, M.A. (2017). Clinical profile of cyanotic congenital heart disease in neonatal intensive care unit at Sohag University Hospital, Upper Egypt. *Egyptian Journal of Medical Human Genetics*, 18(1): 47-51.
- Ahmed, A. & Mahmoud, F.A (2019). 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.
- Alsaiani, E. M., Magarey, J., & Rasmussen, P. (2019). An investigation of the needs of saudi parents of preterm infants in the neonatal intensive care unit. *Cureus*, 11(1).
- Asani, M.O., Aliyu, I., & Gambo, S. (2016). Parental knowledge and impact on growth in children with congenital heart diseases in Aminu Kano Teaching Hospital. *Nigerian Journal of Paediatrics*, 43(3):162-165.
- Azhar, A.S., & Aljefri, H.M. (2018). Predictors of extended length of hospital stay following surgical repair of congenital heart diseases. *Pediatric cardiology*, 39(8):1688-1699.
- Azhar, A.S., Zaher, Z.F., Abu-Ouf, N.M., Al-Ata, J., & Alsheblie, S.T. (2018). Determinants of successful medical education of caregivers of children with congenital heart diseases. *Journal of the Saudi Heart Association*, 30(1), 28-39.
- Elshazali, O. H., HOHEI, S., & Yousif, E. M. A. (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.
- Hill, C., Knafel, K. A., Docherty, S., & Santacroce, S. J. (2018). Parent perceptions of the impact of the Paediatric Intensive Care environment on delivery of

- family-centred care. *Intensive and Critical Care Nursing*; 50:88-94
- Ibrahim, H. K., El Borgy, M. D., & Mohammed, H. O. (2014).** Knowledge, attitude, and practices of pregnant women towards antenatal care in primary healthcare centers in Benghazi, Libya. *The Journal of The Egyptian Public Health Association*, 89(3), 119-126.
- Ibrahim, M. A., Ahmed, E. M., Ezz, M. A., & Mohamed, S. A. R. (2012).** Impact of nursing management protocol on selected postoperative outcomes among children with open heart surgery at Cairo University Specialized Pediatric Hospital. *Journal of American Science*, 8(12).
- IPFCC (2016).** Institute for patient and family-centered care: Core concepts of patient- and family-centered care. Retrieved from <http://www.ipfcc.org/about/pfcc.html>. Accessed November 24, 2018.
- Institute for Health Metrics and evaluation, (2016):**What causes the deaths' in Egypt. Available at: <https://www.healthdata.org>. Accessed November 24, 2018.
- Kempny, A., Dimopoulos, K., Uebing, A., Diller, G. P., Rosendahl, U., Belitsis, G., & Wort, S. J. (2017).** Outcome of cardiac surgery in patients with congenital heart disease in England between 1997 and 2015. *PLoS ONE* 12(6):e0178963.
- Kristjánsdóttir, G. (1995).** Perceived importance of needs expressed by parents of hospitalized two to six year olds. *Scandinavian Journal of Caring Sciences*, 9(2), 95-103.
- Milford, C. A. (2016).** Care of the Family of an Infant With a Congenital Heart Defect During the NICU Hospitalization. *The Journal of Perinatal & Neonatal Nursing*, 30(1), 64–67.
- Mohammed, N. S. (2009).** Impact of supportive care for mothers of children with brain tumor on their coping in Pediatric Surgical Unit at Cairo University Specialized Pediatric Hospital. Unpublished doctorate thesis, Faculty of Nursing, Cairo University.
- Nakazuru, A., Sato, N., & Nakamura, N. (2017).** Stress and coping in Japanese mothers whose infants required congenital heart disease surgery. *International journal of nursing practice*, 23, e12550.
- Rakhawy, Y. and Shaheen, O. (1977).** Preliminary application for the anxiety and depression test, Psychiatric Department, Faculty of Medicine, Cairo University, 140-143.
- Sadeghi, H., Mehrabi, F., Darabiyan, P., Shabani, Y., & Bahrami, M. (2019).** The impact of family-centered care and meeting the need to learn how much of global anxiety in parents of children with urinary tract infection: a randomized clinical trial. *International Journal of Ayurvedic Medicine*, 10(1), 68-74.
- Segers, E., Ockhuijsen, H., Baarendse, P., van Eerden, I., & van den Hoogen, A. (2018).** The impact of family centred care interventions in a neonatal or paediatric intensive care unit on parents' satisfaction and length of stay: A systematic review. *Intensive and Critical Care Nursing*.
- Shields, L. (2015).** What is “family-centred care”? *European Journal for Person Centered Healthcare*, 3(2), 139–144.
- Shields, L., Kristensson-Hallström, I., & O'callaghan, M. (2003).** An examination of the needs of parents of hospitalized children: comparing parents' and staff's perceptions. *Scandinavian Journal of Caring Sciences*, 17(2), 176-184.
- Sjöberg, C., Svedberg, P., Nygren, J. M., & Carlsson, I. M. (2017).** Participation in paediatric perioperative care: ‘what it means for parents’. *Journal of clinical nursing*, 26(23-24), 4246-4254.
- Soenarto, R.F., Prasetyo, Y., Marsaban, A.H., Melati, A.C., & Sukardi, R. (2018).** The Effect on Education on Knowledge Level of Mothers Whose Children with

Congenital Heart Disease Undergoing Surgery. *Advanced Science Letters*, 24(9), 6937-6940.

Staveski, S., & Lincoln, P. (2014). Introduction to Nursing Issues. *Pediatric and Congenital Cardiology, Cardiac Surgery and Intensive Care*, 1307-1308.

Uhm, J. Y., & Kim, H.S. (2019). Impact of the mother–nurse partnership programme on mother and infant outcomes in paediatric cardiac intensive care unit. *Intensive and Critical Care Nursing*, 50, 79-87.

Uhm, J.Y., & Choi, M.Y. (2019). Mothers' needs regarding partnerships with nurses during care of infants with congenital heart defects in a paediatric cardiac intensive care unit. *Intensive and Critical Care Nursing*, 54, 79-87.

Wei, H., Roscigno, C.I., Hanson, C.C., & Swanson, K.M. (2015). Families of children with congenital heart disease: A literature review. *Heart & lung*, 44(6), 494-511.