

Effect of Family-Centered Care on Maternal Coping and Care Participation for their Children with Congenital Heart Diseases

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ABSTRACT

Contents: Families of children with congenital heart disease face frequent healthcare encounters due to their child's care trajectory. With an emphasis on assuring caring in healthcare, it is necessary to understand parents' perceptions of healthcare providers' actions when their child undergoes heart surgery.

Aim: This study aimed to evaluate the effect of family-centered care intervention on maternal coping and participation in care for their children with congenital heart diseases.

Methods: A quasi-experimental design was used. The study was carried out at the pediatric inpatient department in Cardiovascular Hospital, affiliated to Ain Shams University Hospitals. A purposive sample of 50 children undergoing heart surgery and their accompanying mothers. The study was used a structured interview questionnaire, the family-centered care scale, the index of mothers' participation, mothers' practice observational checklists, and the coping process scale to collect the study's data.

Results: The study reveals a statistically significant difference in the mothers' total coping pattern after family-centered care intervention compared to before intervention at $p=0.000$. A statistically significant difference was also revealed regarding the total mothers' participation in the care of their children with congenital heart disease at $p=0.000$. There was a strong positive correlation between total mothers' coping patterns, participation, and mothers' total actual practices regarding their children's care suffering from congenital heart diseases after the intervention.

Conclusion: The family-centered care intervention effectively improved mothers' coping patterns and participation in care for their children with congenital heart diseases. Emphasizing the importance of family (usually the mother) participation in care for their children with congenital heart diseases during hospitalization for heart surgery. Designing and carrying out educational programs for pediatric nurses to promote family-centered care in clinical practice.

Keywords: Family-centered care, congenital heart diseases, maternal coping, care participation

1. Introduction

Congenital Heart Diseases (CHD) are the most common types of congenital disabilities and accounts for nearly one-third of all major congenital anomalies (Avolio *et al.*, 2015; Liu *et al.*, 2015; Torres-Cosme *et al.*, 2016). A systematic review revealed that approximately 1.35 million infants are born with CHD each year worldwide (Nematollahi *et al.*, 2016). The estimated prevalence of CHD is 8 to 10 per 1000 live births, with a higher rate of stillbirth, spontaneous abortion, and prematurity (Liu *et al.*, 2015; Natraj Setty *et al.*, 2017).

The improved survival rate of CHD leads the researchers to increase the focus on parent-infant relationships. An infant's CHD diagnosis can be a crisis for the family due to its numerous related stressors, such as the uncertainty of surgical outcomes, loss of parental control, changes in infants' physical appearance, and fear of the technological atmosphere of the Pediatric Intensive Care

Units (PICUs) (Wei *et al.*, 2016).

Mothers of CHD children tend to experience considerable distress during the children's treatment and experience higher anxiety levels than do fathers. Mothers also typically seek more information because they tend to readily participate in children's care and stay at their bedside for a longer time (Uhm & Choi, 2019).

Mothers of children with CHD cope differently depending on the individual and familial factors beyond the severity of the child's condition, the timing of the diagnosis, the presentation leading to the diagnosis, previous experiences with illness, and family's responses to the child (Jackson *et al.*, 2018; Brown *et al.*, 2019).

Family-centered Care (FCC) is a central pillar of modern pediatric care that recognizes the family's role and experience in care delivery (Arabiat *et al.*, 2018). In other words, the FCC is a philosophy and a method for taking care of children and their families in health services in which the designed plan focuses on the entire family rather than just the child (Al-Motlaq & Shields, 2017; Smyth *et al.*, 2017).

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Developing a partnership with the pediatric patients and their families that built on mutual respect, using collaborative communication, providing extensive support for the family unit and, encouraging the pediatric patient and their family to participate in all aspects of care including, shared medical decision making are considered fundamental principles that, essential to the practice of family-centered Care (Clark, 2017).

2. 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 from September 2014 to June 2016, it was revealed that 1053 children were admitted to the hospital for surgical intervention, 11.7% of those children died after surgery.

Mothers of CHD children 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 with CHD children and their involvement regarding the daily practices required to care for their children with CHD. The current study was carried out 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.

3. Aim of the study

This study aimed to evaluate the effect of family-centered care intervention on maternal coping and participation in care for their children suffering from congenital heart diseases through:

- Assessing the coping patterns of mothers having children suffering from congenital heart diseases.
- Assessing the mothers' participation/ involvement abilities in caring for their children suffering from congenital heart diseases.
- Evaluate the effect of family-centered care intervention on the coping patterns and the mothers' participation in care for their children suffering from congenital heart diseases.

3.1. Research hypotheses

There will be a positive effect of family-centered care intervention on mothers' coping patterns and their participation in care for their children who have congenital heart disease compared to their pre-intervention level.

4. Subjects & Methods

4.1. Research design

A quasi-experimental research design was used to conduct the research (one group pre/post-test). A quasi-experimental design is an empirical interventional study used to estimate an intervention's causal impact on the target population without random assignment. Quasi-experimental research shares similarities with the traditional experimental design or randomized controlled trial, but it specifically lacks the element of random

assignment to treatment or control (Dinardo, 2008).

4.2. Research setting

The study was conducted in the Cardiovascular Hospital affiliated to Ain Shams University Hospitals. Surgical departments located on the sixth and seventh floors, specialized areas for the pediatric patients undergoing heart surgery.

4.3. Subjects

According to predetermined inclusion criteria, a purposive sample of 50 children and their accompanying mothers (regardless of their characteristics) were involved in the study. 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.

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

4.4. Tools of the study

Five tools were used for data collection. It was all written in the Arabic language after reviewing related literature and involved the following:

4.4.1. Structured Interview Questionnaire

The researcher designed this tool to gather data related to children and their mothers through individual interviewing of children and their accompanying mothers. The child's medical record was checked when necessary. It was divided into two main parts:

Child's characteristics, namely, age, gender, child's diagnosis, and length of hospital stay.

Characteristics of the studied mothers and family (mothers' age, educational level, occupation, family size, and family type).

4.4.2. The Family-Centered Care Scale (FCCS)

This scale was adapted from an original study conducted by Shields & Tanner (2004); Gill et al. (2014). This scale is used to assess mothers' knowledge (perception) regarding the core concept of family-centered care for a parent (pre/post). The FCCS consists of sixteen items divided into four subgroups (core concepts): Respect (three items), information sharing (four items), collaboration (four items), and family support (five items).

Scoring system

The mothers' responses of the FCCS items were scored using a three Likert type rating scale ranging from disagree: 0 points, somewhat agree: 1 point, and agree: 2 points. Negatively worded items (4, 6, 12, 16) were reverse coded

before calculating the scores. The total score varies between 0 and 32. A higher mean score indicates a higher level of agreement on statements (good knowledge for FCC core concept) and vice versa.

4.4.3. The Index of Mothers' Participation (IMP)⁴⁵

This tool was adapted from the Index of Parent Participation/ Hospitalized Child-Actual Activity (IPP/HC-AA) that was developed by *Melnyk (1994)* and used by *Romaniuk (2009)* and *Abdelkader et al. (2016)*. The IMP was used to assess the level of mothers' participation in childcare during hospitalization (pre/post). It consisted of forty items that included four categories: Activities of Daily Living (ADL) (eight items), psychological support (nine items), supportive care during diagnostic procedures and treatment (eight items), and nursing care activities (fifteen items).

Scoring system

The mother's participation in their children's care during hospitalization was checked on activities on a two-point scale (Zero if No and one if Yes). The total score ranged from 0 to 40 (100%), where higher mean scores indicating higher mothers' participation. It was categorized as the following:

The minimum level of mothers' participation ranged from 0 to 17. This score indicated that mothers' participation included provided minimum activities of care for their children. Moderate levels of participation ranged from 18 to 25. This score indicated that mothers' participation included provided moderate activities of care for their children. The maximum level of participation ranged score from 26 to 40. This score indicated that mothers' participation included provided maximum activities of care for their children.

4.4.4. Mothers' Practice Observational Checklists

It was adopted from *Potter et al. (2012)* to assess the actual practices of mothers (pre/post) as regards hand washing (14 steps), temperature measurement (9 steps), cold compresses (7 steps), oral medications (10 steps), breathing exercises (8 steps), upper limb exercises (16 steps) and lower limb exercises (16 steps).

Scoring system

Regarding the scoring system for mothers' actual practices, two grades were given to the mothers for each step done correctly and one grade for each step done incorrectly, and zero for not done. Accordingly, the mothers' total actual practices were categorized into either incompetent (< 75 %) and competent (≥ 75 %).

4.4.5. Coping Process Scale

This scale is an Egyptian Standardized Scale developed and tested by *Ibraheim (1994)* and adopted by *Mohammed (2009)*. This scale is used to assess the mothers' coping patterns toward their children suffering from CHD (pre/post). It consists of forty-two items in the form of four points rating scale. Scores on each item in the scale ranged from (1) do not agree, (2) nearly agree, (3) almost agree,

and (4) totally agree. This scale was divided into two main subscales as the following:

Problem-focused coping (18 items=72 scores) included seeking out information and social support (3 items=12 scores), positive reinterpretation (5 items=20 scores), exert of restrain (4 items=16 scores), denial (3 items=12 scores), and active coping (3 items=12 scores). Emotion-focused coping (24 items=96 scores) included helplessness (6 items=24 scores), mental disengagement (5 items=20 scores), wishful thinking (4 items=16 scores), turning to religion (3 items=12 scores), emotional discharge (3 items=12 scores), and acceptance (3 items=12 scores).

Scoring system

The scale's total score ranged from 42-168 scores, which is the sum of the two subscales' items (problem-focused coping and emotion-focused coping). A higher mean score indicated greater utilization of that particular coping pattern and vice versa.

4.5. Procedures

The researcher reviewed all available national and international related literature to be oriented to the various aspects of the research problem and develop the study tools. The validity of the tools was ascertained by a jury of five experts in pediatric cardiology and nursing. Their opinions were elicited regarding the tools' format, layout, consistency, accuracy, and relevancy. The reliability of the study tools was done by Cronbach alpha test (it was 0.56 for the family-centered care scale and 0.87 for the index of mothers' participation).

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 expected outcomes of the study to obtain their approval to conduct the study.

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

Ethical approval granted from the Scientific Research Ethical Committee of Faculty of Nursing, Ain Shams University. Informed written consent was obtained from the mothers before data collection as 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 would 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.

Fieldwork: Data collection for this study was carried out over seven months, starting from 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 researcher filled in the questionnaire. The time needed to fill in the questionnaire was ranged between 30-45 minutes. The researcher filled in the observation checklists during observation of mothers' practices (re-demonstration), and the time needed to fill in the checklists according to each procedure was ranged between 3 to 5 minutes. The researcher filled in the coping process scale by asking the mothers to rate their response on the rating scales; the average time needed to fill in the scale was 15-20 minutes.

Planning phase: The researcher designed the family-centered care intervention based on the mothers' and their children's actual needs assessment after reviewing the relevant literature regarding mothers' needs and care for their children with CHD undergoing heart surgery. The researcher designed an illustrated booklet in the Arabic language to serve as a reference guide for mothers' needs, knowledge, and care for their children with CHD undergoing heart surgery.

Selecting the teaching place in the study setting (teaching classroom, mothers' room, and children's bedside at the surgical department). Different teaching methods were used, such as lectures, modified small group discussion, role play, demonstration, re-demonstration, and suitable media, such as booklet, PowerPoint presentation, educational videos, lab top, and CD. Real objects as thermometer, balloon, and air bubbled used for practical skills.

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 eight sessions for theory (5 hours) and practical (3 hours). Each session took about 60 minutes.

Content of FCC intervention: Knowledge regarding 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). Distress (causes, manifestation, and management of stress), cope with the stressful situation, and satisfy needs.

Practices included hand washing, measurement of temperature, oral medication, breathing exercises, and upper and lower limb exercises. For practical breathing exercises, the researcher gave children, according to their age, balloon or air bubbles and trained them to use them. The researcher guided the mothers to encourage the child to use it before eating and each 4-6 hours in the pre-postoperative period.

The researcher answered all mothers' questions during sessions, solved any complaints during hospitalization, encouraged mothers to express their feelings, and mentioned the sources of their stress and anxiety. The

researcher also gave a chance for all mothers to talk for gathering and sharing the experiences.

Use communication techniques by active listening and respect relationships to reduce mothers' anxiety and encourage trust between the researcher, parents (mothers), and their children. Additionally, the researcher contacted 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 family-centered care intervention using the same study tools. This phase was implemented before the child has discharged from the hospital. After discharge, the researcher follows up the studied mothers through phone conversations. During phone calls, the researcher was provided counseling, advice, reinforce mothers' ability, and re-emphasize the importance of the family-centered care intervention.

4.6. Data analysis

The collected data were organized, revised, scored, tabulated, and analyzed. Statistical analysis was done through the computer using the Statistical Package for Social Sciences (SPSS) version 20. The statistical analysis included number, percentage, means, standard deviation, student's "t" test, Wilcoxon signed ranks test (Z), and Pearson's correlation tests (r) used to compare qualitative variables. P-value: Not significant (NS) at >0.05 , significant (S) at <0.05 , and highly significant (HS) at <0.01 .

5. Results

Table 1 illustrates 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%. Stayed at the hospital for 7- <15 days, as reported by 66% of them.

Table 2 indicates that the age of more than half (60%) of the studied mothers was ranged from 20- <30 years (29.42 ± 6.36), and more than one-third (36%) of them were graduated from secondary schools. Regarding occupation, most (82%) of the studied mothers were housewives. As regards the family size, more than three-quarters (78%) of the studied mothers' families had between 3-5 members, and more than half (56%) of them belonged to extended family.

Table 3 indicates highly statistically significant differences between mothers' knowledge about family-centered care's core concept before and after FCC intervention and the total ($t=51.15$, $p=.000$).

Table 4 indicates statistically significant differences before and after FCC intervention about mothers' participation in activities of daily living and psychological support ($t=2.47$, $p<0.017$ and $t=2.64$, $p<0.011$, respectively). This table also shows the highly statistically significant improvement of mothers' participation in supportive care and nursing care activities after FCC intervention ($t=9.66$, $t=23.84$, $p<0.000$, respectively). Also, there were highly statistically significant differences in the

total mothers' participation (reported practices) before and after FCC intervention ($t= 17.82, p < 0.000$).

Figure 1 illustrates the total level of mothers' participation, where more than half (58%) of the studied mothers had a moderate level of participation before the FCC interventions. At the same time, all of them had a maximum level of participation after the FCC intervention.

Table 5 shows highly statistically significant differences ($p < 0.001$) in mothers' actual practices before and after FCC intervention. A higher percentage (82%, 100%, 88%, 60% & 76%) of the studied mothers had incompetent practice level about hand washing, measurement of temperature, breathing exercise, upper and lower limb exercise, respectively, before FCC intervention compared to 100%, 88%, 90%, 80%, and 86% respectively of them who had competent level after FCC intervention.

Figure 2 illustrates that all (100%) of the studied mothers had an incompetent level of total actual practices related to care of their children with CHD before FCC intervention compared to 94% of them who had a competent level of total actual practices after the FCC intervention.

Table 6 shows the studied mothers coping before and after FCC intervention. The total mean score of problem-focused coping is 52.3 ± 8.3 pre-intervention and 60.6 ± 7.4 after the intervention. The total mean score of emotion-focused coping is 65.2 ± 12.7 before intervention increased

to 75.8 ± 11.3 after the intervention, with a highly statistically significant difference between pre and post-intervention regarding all coping patterns and the total.

Table (1): Frequency and percentage distribution of the studied children according to their characteristics (n=50)

Children's characteristics	No	%
Age in years		
< 1	13	26
1 ≤ 3	27	54
3 ≤ 5	5	10
5 ≤ 10	5	10
Mean±SD	2.12±1.92	
Gender		
Boys	21	42
Girls	29	58
Child's diagnosis		
Ventricular septal defect	11	22
Atrial septal defect	4	8
Patent ductus arteriosus	5	10
Tetralogy of Fallot	18	36
Aortic stenosis	1	2
Coarctation of the aorta	3	6
Complex CHD	8	16
Length of current hospital stay (days)		
7 -<15	33	66
15-<30	13	26
30-≤45	4	8

Table 2: Frequency and percentage distribution of the studied mothers according to their characteristics (n=50).

Characteristics	No	%
Age of mothers (years)		
20 < 30	30	60
30 ≤ 40	20	40
Mean±SD	29.42±6.36	
Educational level		
Read and write	16	32
Primary school	3	6
Secondary school	18	36
Highly educated	13	26
Occupation of mothers:		
Housewife	41	82
Working	9	18
Family size		
3-5	39	78
6-10	11	22
Type of family		
Nuclear	22	44
Extended	28	56

Table (3): Comparison of the studied mothers' knowledge before and after FCC intervention (n=50).

Items of the core concept FCC	Before	After	t-test	P-value
	$\bar{X} \pm SD$	$\bar{X} \pm SD$		
Respect	3.82±0.48	5.64±0.63	26.70	0.000
Information sharing	6.72±0.75	7.64±0.87	23.73	0.000
Collaboration	3.84±0.61	7.60±0.83	47.86	0.000
Support	5.52±0.81	8.52±1.43	21.433	0.000
Total	19.90±1.70	29.40±2.51	51.15	0.000

Table (4): Comparison of the studied mothers' participation (reported practice) before and after FCC intervention (n=50).

Mothers' participation	Before	After	t-test	P-value
	$\bar{X} \pm SD$	$\bar{X} \pm SD$		
Activities of daily living (ADL)	7.34±0.65	7.54±0.57	2.475	0.017
Activities of psychological support	7.62±1.0	7.88±1.0	2.648	0.011
Activities of supportive Care	5.16±1.4	7.0±0.85	9.669	0.000
Nursing care activities	6.80±2.2	14.12±0.93	23.84	0.000
Total	26.9±3.6	36.5±2.2	17.82	0.000

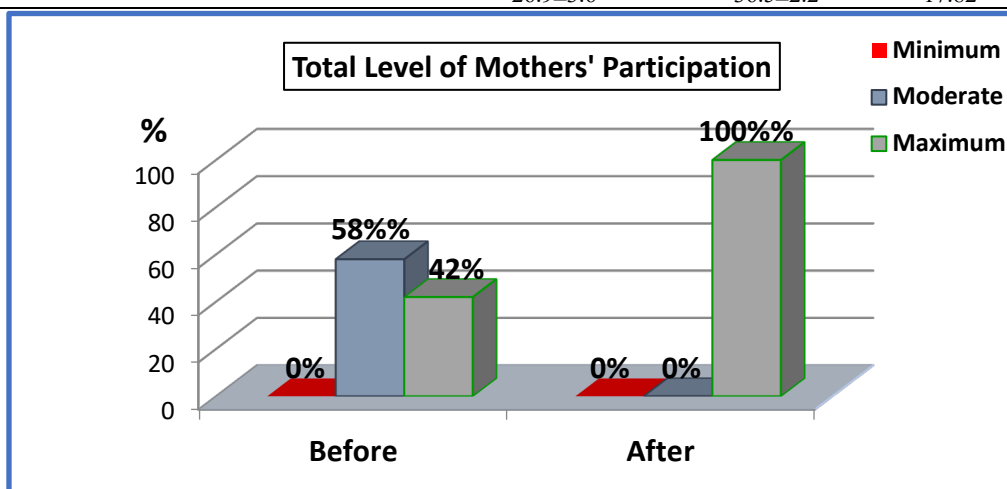


Figure (1): Percentage distribution of the studied mothers according to their total level of participation (reported practices) before and after FCC intervention (n=50)

Table (5): Comparison of the studied mothers' actual practice before and after FCC intervention (n=50).

Mothers' actual practices	Before				After				Z value	P-value
	Competent		Incompetent		Competent		Incompetent			
	No	%	No	%	No	%	No	%		
Hand washing	9	18	41	82	50	100	0	0	6.403	0.000
Measurement of temperature	0	0	50	100	44	88	6	12	6.633	0.000
Cold compresses	43	86	7	14	50	100	0	0	2.646	0.008
Oral medication	31	62	19	38	42	84	8	16	2.294	0.022
Breathing exercise	6	12	44	88	45	90	5	10	6.091	0.000
Upper limb exercise	20	40	30	60	4	80	10	20	4.082	0.000
Lower limb exercise	12	24	38	76	43	86	7	14	5.096	0.000

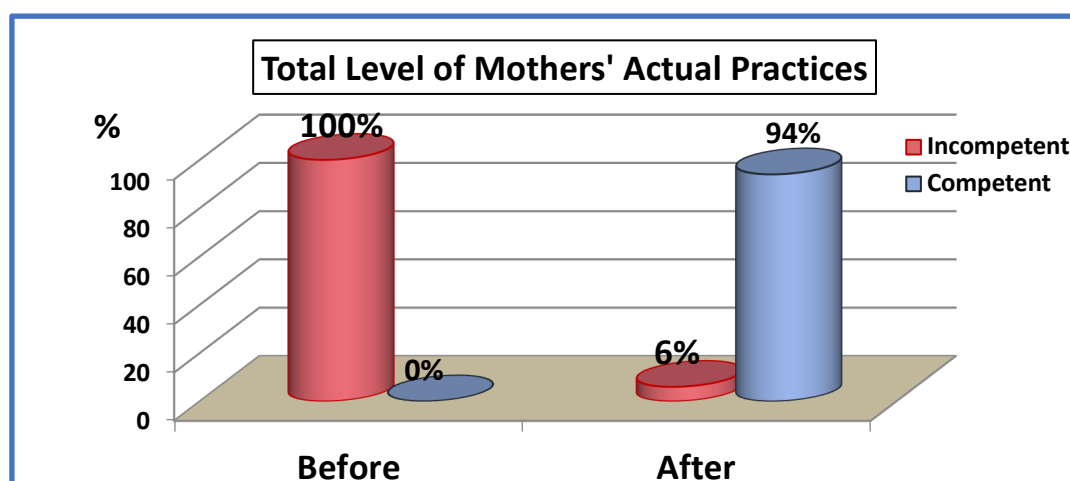


Figure (2): Percentage distribution of the studied mothers according to their total level of actual practices (before and after FCC intervention) (n=50).

Table (6): Comparison of the studied mothers' coping pattern before and after FCC intervention (n=50).

Coping Patterns	Before $\bar{X}\pm SD$	After $\bar{X}\pm SD$	t-test	P-value
Problem-focused coping				
Seeking out information and social support.	7.0±2.19	9.20±2.84	4.851	0.000
Positive reinterpretation	15.76±2.65	18.48±2.23	6.924	0.000
Exert restraint	11.60±3.54	11.68±2.76	0.179	0.858
Denial	8.72±1.60	9.96±1.49	4.372	0.000
Active coping	9.28±1.99	11.28±1.72	6.931	0.000
Total	52.3±8.3	60.6±7.4	5.859	0.000
Emotion-focused coping				
Helplessness	14.28±3.45	16.68±3.61	5.853	0.000
Mental disengagement	14.72±3.41	17.76±3.24	6.971	0.000
Wishful thinking	11.96±2.62	13.80±2.91	5.039	0.000
Turning to religion	7.76±2.51	8.52±2.99	2.423	0.019
Emotional discharge	8.76±1.90	8.92±1.87	0.613	0.542
Acceptance	7.76±2.65	10.12±1.70	6.303	0.000
Total	65.2±12.7	75.8±11.3	7.562	0.000

6. Discussion

Family-Centered care has been widely accepted as an ideal way to care for children in hospitals. According to this philosophy of care, the child's psychological and developmental needs and the family's well-being are best achieved when the healthcare system supports the pivotal role of the family in partnership with healthcare providers to provide care for their children (Staveski & Lincoln, 2014). This study aimed to evaluate the effect of FCC intervention on maternal coping and participation in care for their children with congenital heart diseases.

The present study results illustrate that more than one-third of the children's diagnosis was TOF, followed by VSD and complex CHD. This result matches most of the statistics previous studies indicate that TOF and VSD have been frequently reported to be the most common CHD worldwide. 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 CHDs.

All children were hospitalized to perform surgery, and more than two-thirds of them stayed at the hospital for

7-<15 days. This finding was dependent on the type of surgery, child needs, and progress after surgery. In a similar result, a study carried out by *Azhar and Aljefri (2018)*, regarding the predictors of the extended length of hospital stay following surgical repair of congenital heart diseases", found that more than half of the children who undergo corrective surgery for CHD spend ten days or more in the hospital following surgery, as regard the unadjusted mean length of stay was 15.70 days.

The result of the present study portrays that the means age of the studied mothers was 29.42±6.36 years, and more than one-third of mothers completed a secondary degree of education, and most were housewives. From the researchers' point of view, the mother's work might

positively or negatively affect the child's health status

according to the types of work. These results are consistent with *Abd El Aziz et al. (2016)*, who reported that the mean age of the studied mothers was 30.9±6.66 years, and almost half of them completed a secondary degree of education. Furthermore, the majority were housewives.

Meanwhile, these findings are incongruent with those of *Ebrahim (2017)*, who recently conducted a study entitled "Nursing intervention for school-age children with bronchial asthma in a rural area" and mentioned that more than half of the mothers were in the age group of 35-<40 years, had secondary school degree and were housewives. This finding mostly reflects the normal pattern of parental age.

According to the present study result, more than half of the studied children belonged to an extended family. This family type thought to give extra support for mothers of CHD children. This finding can be explained by *Coyne et al. (2011)*, who mentioned that the FCC incorporates a holistic approach to care, and provision of such care should include not just parents but also extended family members and friends. The researcher believes that extended families offer a good opportunity for family-centered care, especially for children undergoing heart surgery.

The present study illustrates highly statistically significant differences between mothers' knowledge about FCC's core concept (respect, information sharing, collaboration, and support) before and after FCC intervention. In the researcher's point of view, mothers were willing to collaborate in their child's care so, they need respect, clear guidance, information, and support from all medical and nursing staff that focused on the child and their accompanying mother.

This result supported a study by *Gill et al. (2014)* entitled "Parent and staff perceptions of family-centered care in two Australian children's hospitals", and reported that parents had more positive perceptions of their FCC experience than the staff perceptions of providing FCC. Also, found that parents had significantly higher subscale scores for respect, collaboration, and support.

This result also following the qualitative study by Hill *et al.* (2019) entitled "Parent perceptions of the impact of the pediatric intensive care environment on delivery of family-centered care", it found that the FCC core concepts of information sharing, participation, respect, and dignity were present in parent interviews. This finding was inconsistent with a study by Stuart and Melling (2014) entitled "Understanding nurses and parents' perceptions of family-centered care", which found that parent participants were less knowledgeable about the FCC.

Concerning mothers' participation, the present study's findings indicate highly statistically significant differences in the total mothers' participation (reported practices) before and after FCC intervention. From the researcher's point of view, the mother is the only person who can support and deal with their child's physical and psychological disturbances associated with hospitalization.

This result agrees with Romaniuk *et al.* (2014), who conducted a study entitled "Are parents doing what they want to do? Congruency between parents' actual and desired participation in the care of their hospitalized child," and found that parents were a most active participant in providing comfort measures and care related to their child's daily living activities.

These findings were consistent with Abdelkader *et al.* (2016), who carried out a study entitled "Parents' involvement in child's care in an Arab pediatric setting." They found that most parents were responsible for feeding their hospitalized child, changing their clothes, and assisting the child with elimination and sleeping. Besides, most parents could comfort their child when upset and during the painful procedure and assist with medication administration.

Regarding the total level of mothers' participation (reported practices), the result of the present study shows that more than half of the studied mothers had a moderate level of participation before the FCC interventions. At the same time, all of them had a maximum level of participation after the FCC intervention. This finding reflects all mothers' inner desire to assist in childcare during hospitalization to achieve comfort and security for their children.

The result of the present study supported with Uhm & Choi (2019), who conducted a study entitled "Mothers' needs regarding partnerships with nurses during care of infants with congenital heart defects in a pediatric cardiac intensive care unit", they found that all mothers generally passively participated at first and gradually developed more positive and enthusiastic participation as infants recovered and became actively participated in child's care with nurses' help.

As mentioned in previous studies, Romaniuk *et al.* (2014) found that most parents at the pediatric setting of Jordan's hospitals reported a moderate participation level in the care of their child. On the other hand, Abdelkader *et al.* (2016) found that only one-fifth of parents had achieved a maximum participation level. This participation level included the activities related to providing the child's health-deviation requisites that need technical skills and

activities for providing the child's universal and developmental requisite.

The researcher could illustrate this improvement by justifying the research hypothesis and reflecting the importance of FCC intervention for children with CHD undergoing heart surgery.

Regarding mothers' actual practices, the present study's result shows highly statistically significant differences in mothers' actual practices after the FCC intervention. This finding indicated that the study intervention had a positive effect on the actual practices of mothers. These findings supported by Elsobky *et al.* (2018), who studied "The effect of pre-hospital discharge care program on mothers' knowledge and reported practice for children after congenital heart surgery", and found a highly significant difference regarding mother's practice of medication, activity, diet, wound care, dental hygiene, immunization and follow up after discharge training.

This study result is similar to Ahmed & Mahmoud (2019), who conducted a study entitled "Effect of educational program on the self-efficacy and quality of life for mothers caring children with congenital heart disease", they found a highly statistically significant difference in mothers' reported practice regarding care of their children with congenital heart disease (like nutrition, child activity, prevent from infection and dental care) at the post and after three months of educational implementation as compared to pre educational implementation.

Concerning total actual practices of the studied mothers, the present study's finding shows an improvement in mothers' practices, and they had a competent level in total actual practices after FCC intervention. This finding was matched with Ahmed *et al.* (2016). They performed a study entitled "The use of self-management skills in improving pediatric asthma outcomes" and reported a highly statistically significant improvement in mothers' practices related to their children with asthma after applying for the self-management program.

Considering mothers' coping patterns, the result of the present study shows a statistically significant improvement in total problem-focused coping and emotion-focused coping before and after FCC intervention. The researcher believes that the mothers of children with CHD tend to use problem-focused coping strategies in acute or life-threatening medical situations. In the stabilization of the child's condition, they used emotion-focused coping strategies.

These results were supported by Sutan *et al.* (2017), in a study entitled "Coping strategies among parents of children with acute lymphoblastic leukemia", who found that parents used both problem-focused and emotion-focused. Also, Douplik *et al.* (2017) carried out a study entitled "Parent coping support interventions during acute pediatric hospitalizations: A meta-analysis" and found that experimental interventions designed for caregivers significantly alleviate psychological distress and help parents to cope with the disease.

These results contradicted with Abdel-Rahman *et al.* (2015), who conducted a study entitled "Stressors and

coping strategies among family caregivers having children with lymphoma at children's cancer hospital Egypt 57357", they found that the majority of the family caregivers were using emotionally focused coping more often than problem-focused coping.

The findings of the current study supported the study hypothesis that mothers of children with CHD after receiving FCC intervention positively affected coping patterns and participation in childcare.

7. Conclusion

Based on the results of the current study, it can be concluded that: The family-centered care intervention was effective in improving mothers' coping patterns and their participation in the care of their children suffering from congenital heart diseases.

8. Recommendations

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

- Emphasize the family's importance (usually the mother) participation in care for their children suffering from CHD during hospitalization for heart surgery.
- Designing and carrying out programs for pediatric nurses to promote the implementation of family-centered care in clinical practice.
- Emphasize the importance of availability and distribution of pamphlets, illustrations, videotaped information, Compact Disc (CD), and a booklet containing the basic knowledge for mothers (families) about their children's suffering congenital heart diseases who are undergoing heart surgery.
- Encourage mothers to cope with stress and anxiety related to their children's care suffering from congenital heart diseases.
- Further research is required to determine the barriers/challenges that affect the implementation of family-centered care in pediatric care settings.

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