Mothers Caring for Children Suffering From Congenital Heart Diseases

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Abstract

Background: Congenital heart diseases are considering deadly, if not effectively untreatable. ***The study aims* to** assess mothers' care for their children suffering from congenital heart diseases. ***Research design:*** Descriptive analytical design. ***Setting:*** The study was conducted at cardiology outpatient clinic Pediatric hospital affiliated to Ain Shams University hospitals. ***Sample:*** A purposive sample was used for choosing the study subjects; composed of 75 mothers of children with congenital heart diseases. ***Tool of data collection:*** an interviewing questionnaire for assessing the socio-demographic characteristics of the studied children and their mothers, mother's knowledge and reported practices about the care of their children with congenital heart diseases. ***Results:*** Study finding indicated that, 40% of the studied children with congenital heart diseases were females, 40 % of the children aged < 1 year and Concerning child ranking 46.7% of the studied children were the first child in their own family, 40% of the studied mothers received basic education, 73.3% of them were house wives and 66.7% were living in rural areas. 26.6%, 40%, 37.3%, 45.3%, 41.3%, 49.3% and 40.0% of mothers had satisfactory knowledge regarding Anatomy of the heart, Physiology of the heart, Meaning of congenital heart disease, Types of congenital heart disease, Symptoms of congenital heart disease, Importance of surgical intervention in the treatment of congenital heart disease and Ways to prevent congenital heart disease respectively, 62% of them had inadequate total reported practices about the care provided for their children with congenital heart diseases. Also, 64% of the studied mothers obtained their knowledge from doctors. ***Conclusion:*** The result of the study concluded that, there was insignificant negative correlation between the total mothers' knowledge about congenital heart diseases among studied children and their mothers' total reported practices about the care provided for their children with congenital heart diseases. ***Recommendations:*** Periodic counseling program to all mothers with children suffering from congenital heart diseases who attended the outpatient clinics about diseases, treatment, prevention and control measures.

Keywords: Children with Congenital heart diseases, mother's care.

Introduction

Congenital Heart Disease (CHD) is the most common type of birth defects (**Nakanishi et al., 2018**) Despite recent advances in the treatment of these children, CHD remains the first cause of death in children with congenital malformations, The development of diagnostic technology has led to an increase in the number of newborns diagnosed with CHD (**Zimmerman et al., 2020**).

Congenital heart disease 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 **(EL-Gendy et al., 2020**).

The children with congenital heart disease face problems, such as lack of physical ability, early fatigue, exertion dyspnea, infection, developmental delay, dental problems and heart failure symptoms. Managing all of these problems causing stress and anxiety for mothers and imposes heavy financial, physical and mental burden on them. Also they are having many potential stressors including the scheduling of frequent clinic visits, monitoring and limiting their child's activities, and administering medication (**Abdel-Salam et al., 2018**).

Living with chronically ill children can cause challenges because of illness-specific needs such as maintaining care and treatment regimes, maintaining family relationships, and overcoming financial and social constraints. This condition causes major changes in the routine of family life, which may affect the whole family. However, many mothers experience some difficulties in managing the child's illness and their care giving role ***(Dalir et al., 2021)***.

Nurses play a critical role in instructing the children and their mothers about the detection and reporting the serious symptoms, the nurse should provide the children and mothers with accurate information about disease that help the children and mothers to understand the disease in a different manner **(LaRonde et al., 2022)** Children require individualized care plans according to their physical, developmental, educational, and psychosocial needs. Regular health maintenance activities such as developmental support, healthy weight management, dental care, and immunizations must be provided. Nurses have positive role includes: provide counseling and psychosocial support to children and mothers preventing social isolation **(Elsayed et al., 2020).**

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. More than 32, 000 babies born each year with a few shapes of heart fault (1 out of each 125 to 150), while Egyptian children incidence are 5:6/1000 life birth. These children are often diagnosed in the first year of life and childhood **(Nasrulloyevna et al., 2022**).

Significance of the study

Childbirth is one of the invaluable human experiences and is associated with parental happiness. However, when a child is born with congenital heart disease, it creates emotional and

mental distress. As a result, it changes the mothers' response to their child birth. Exploring parenthood experiences add to the body of knowledge and reveal new perspectives **(Nayeri et al., 2021).**

Congenital heart disease is the most common major congenital anomaly, representing a major global health problem the incidence is 8-19 per 1000birth. Congenital heart disease account for one third of babies with significant congenital anomalies diagnosed prenatally or in infancy **(El shazali et al., 2018).**

In Egypt, twenty thousand children were born annually with congenital heart defects. It was found that the number of children who have been detained with congenital heart defects during the year 2018 about 3, 000 children including 133 patients aged between 10 to 21 years **(Medical report at University Hospital, 2018**).

The illnesses of children are emotions stress on both mothers and children. Quality of nursing care from the mothers' perspective plays an important role in the development and improvement of health services performance and image. Mothers satisfaction is significant indicator that evaluates the care quality provided by healthcare services (**Nasrulloyevna et al., 2022).**

Aim of the study

The aim of this study is to assess the mothers' care of their children suffering from congenital heart diseases through: -

1- Assessing mothers' knowledge regarding congenital heart disease

2- Assessing mothers' reported practices regarding care of their children suffering from congenital heart disease

Research questions

1- What are the mothers' knowledge regarding congenital heart disease?

2- What are the mothers' reported practices regarding care of their children suffering from congenital heart disease?

3- Is there relation between mothers' knowledge and their reported practices regarding care of their children suffering from congenital heart disease?

Subjects and Methods

Research design: -

Descriptive analytical research design was utilized to fulfill the aim of this study.

1-Technical Design:

A-Research Setting:

This study was carried out at pediatric cardiology outpatient clinic affiliated with Ain Shams University Hospital as it was a pediatrics' university hospital and one of the major hospitals in Egypt that provides health care for all

children from all governorates in Egypt.

Sampling:

Sample size: -

A purposive sample of 75 mothers of children diagnosed with congenital heart disease, children attended the cardiology outpatient clinic. The study sample was chosen according to the following inclusion criteria: all available children aged from birth to 4 years diagnosed with any type of congenital heart disease. Both gender and accompanied with their mothers.

Data collection tool:

One tool was used for data collection to conduct this study after reading the related literature and taking expert's opinion, it was written in Arabic language.

An interviewing questionnaire it includes three parts as follow**.**

Part I (a): The socio-demographic of the studied children: as age, sex and children's ranking among their siblings**.**

Part I (b): Socio-demographic characteristics of mothers **(**age, educational level, occupation, consanguinity between the fathers and the mothers)

Part II: to assess mothers' knowledge

Mother's knowledge about the congenital heart diseases **(**anatomy and physiology of the heart, meaning of congenital heart disease, types of congenital heart disease, causes of congenital heart disease, symptoms of congenital heart disease, diagnosis of congenital heart disease during pregnancy, diagnosis of congenital heart disease after birth, complication of congenital heart disease, treatment of congenital heart disease, importance of surgical intervention in the treatment of congenital heart disease and ways to prevent congenital heart disease).

Scoring System of knowledge:

The scoring system was adopted with rating ranging from 1 to 2. A correct answer was scored (2) and the incorrect answer was (1) where the higher score indicates that the mothers had satisfactory knowledge about congenital heart diseases.

Score % = (the observed score / the maximum score) × 100

Knowledge consists of 18 items and total score ranging 18-36 grades:

- Satisfactory Knowledge ≥50%
- un satisfactory Knowledge<50%

Part III: to assess Mother's reported practices:

Mother's reported practices related to the care of their children with congenital heart diseases (Proper nutrition, physical activities, preventing the child from infectious diseases, mouth and dental care, dealing with disease symptoms, the event of rise in temperature, when there is cyanosis of the body such as the lips, mucosa, and nails, difficulty in breathing and dealing with medication)**.**

Scoring system of practices:

The scoring system was adopted with rating ranging from 1 to 3. Each Mother's reported practice response was either always (3 grade), sometime (2 grade) and never (1 grade), where the higher score indicates that the mothers had adequate level of reported practice about dealing with health problems for their children.

Score % = (the observed score / the maximum score) × 100

Practice consists of 52 items and total score ranging 52-156 grades:
-Adequate ≥60%
-Inadequate<60%

Tools' validity:

The tools were tested and evaluated for their face and Content validity. Face and Content validity were performed by professors in Community Health Nursing Department of Faculty of Nursing and A professor of the cardiology Department in Pediatric Department, Faculty of Medicine, Ain Shams University, Egypt; they reviewed the tools for content accuracy.

The developed tools were modified according to the expert's opinion; this modifications were in the form of omission or addition of some questions or rephrasing of some statements.

Tools reliability:

The internal consistency was measured to identify the extent to which the items of the tools measure the same concepts and correlate with each other by using alpha Cronbach's test for reliability test – retest was done(0.887).

Administration Design:

An official approval was obtained to carry out the study that issued from the faculty of nursing, Ain shams university to the director of pediatric affiliated to Ain Shams University Hospital

Ethical consideration:

Ethical approval was obtained from the scientific ethical committee of Faculty of Nursing, Ain Shams University. In the addition, written consent was obtained from every participant who agreed to share in the study. They were assured that anonymity and confidentiality would be guaranteed and the right to withdraw from the study at any time.

Pilot Study:

The Pilot Study was 10% from total sample to ensure the clarity of questions, applicability of the tools and the time needed to fill the questionnaires.

According to the result obtained the necessary modification was done and excluded from the study sample.

Field Work:

An official letter was submitted to the director of pediatric hospital at Ain Shams University, the actual field work started data collection from the beginning of August 2021 to the end of October 2021. The previously mentioned setting was visited by the researcher one

day/week from 9.00 A.M. to 1.00 P.M. Subject who met the inclusion criteria were identified through reading medical record of the children and asking mothers accompanying with the children. Each mother was individually in the cardiology outpatient clinic. The researcher started by introducing herself to the mothers of children with congenital heart diseases in the previously mentioned setting and explain the aim of the study, assured that data collected will be confidential and would be only used to achieve the purpose of the study.

Statistical design

The collected data were organized, coded, tabulated and analyzed by using appropriate statistical test as "Chi square", T test for comparing between related sample, and R test for number and percentage distribution, by using the Statistical Package for Social Science (SPSS), version 23 to determine if there were statistically significant relations. P- Value = less than 0.05 was considered significant and less than 0.001 was considered as highly significant.

Results

Table (1): Distribution of the studied children suffering from congenital heart diseases according to their demographic data. (n=75)

Items	No.	%
Sex		
Male	45	60.0
Female	30	40.0
Age (years)		
<1 year	30	40.0
1-<2 years	15	20.0
2-<3 years	12	16.0
3-4 years	18	24.0
Mean $\bar{X}$ ±SD	1.76±0.53	
Children ranking between their siblings		
First	35	46.7
Second	20	26.7
Third	10	13.3
Fourth and more	10	13.3

Table (1): - This table shows that 60% of the studied children were males while 40% of them were females, 40 % of the children aged < 1 year and concerning the children ranking 46.7% of the studied children were the first child in their own family.

Table (2): Distribution of studied mothers according to demographic characteristics (N=75)

Items	No.	%
Age (years)		
<20 years	5	6.7
20-<25 years	28	37.3
25-<30 years	36	48.0
30-<40 years	4	5.3
≥40 years	2	2.7
Mean $\bar{X}$ ±SD	27.36±5.27	
Educational Level		
Doesn't read and write	10	13.3
Read and write	15	20.0
Basic education	30	40.0
Secondary education	12	16.0
University degree	8	10.7
Occupation		
Working	20	26.7
House wife	55	73.3
Consanguinity between the father and the mother		
Yes	15	20.0
No	60	80.0
Residence		
Urban	25	33.3
Rural	50	66.7

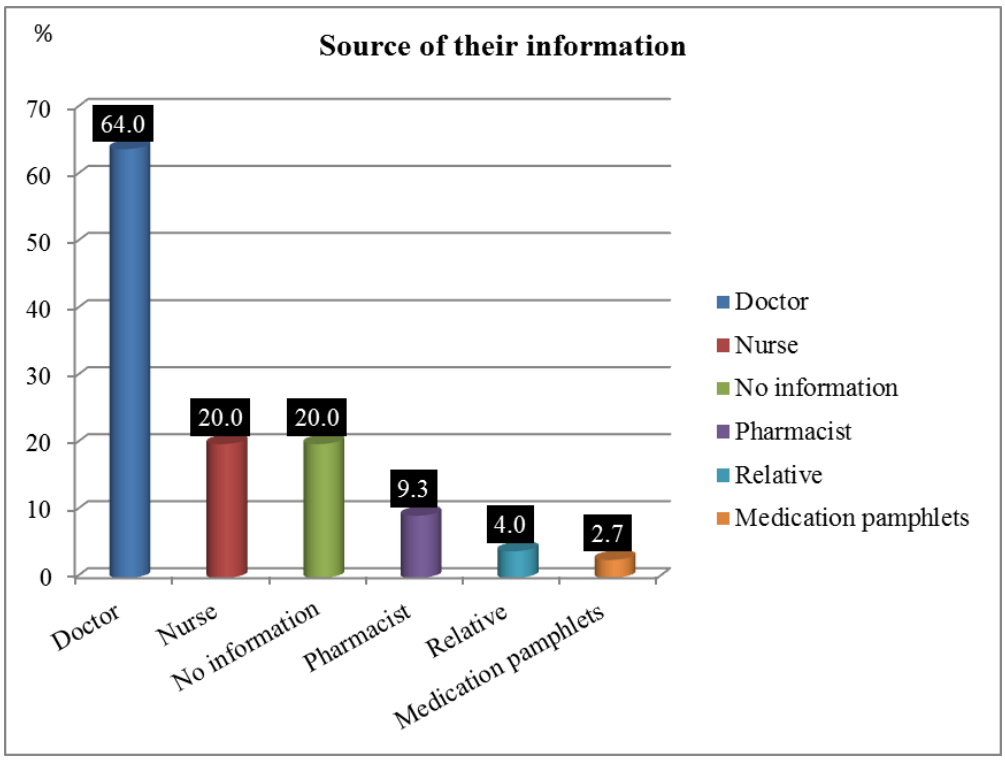
Table (2): This table reports that 48.0% of the mothers age was ranged from 25-< 30 years, 40% of the studied mothers received basic education while 73.3% of them were house wives and 66.7% were living in rural areas.

Table (3): Distribution of the studied mothers according to their satisfactory level of knowledge about congenital heart disease of (n=75).

Congenital Heart Disease	No.	%
Anatomy of the heart	20	26.6
Physiology of the heart	30	40.0
Meaning of congenital heart disease	28	37.3
Types of congenital heart disease	34	45.3
Causes of congenital heart disease	39	52
Symptoms of congenital heart disease	31	41.3
Diagnosis of congenital heart disease during pregnancy	37	49.3
Diagnosis of congenital heart disease after birth	42	56.0
Complication of congenital heart disease	19	25.3
Treatment of congenital heart disease	28	37.3
Importance of surgical intervention in the treatment of congenital heart disease	37	49.3
Ways to prevent congenital heart disease	30	40.0

Table (3): Reveals that mother's had satisfactory knowledge about congenital heart disease, (26.6%, 40.0%, 37.3%, 45.3%, 52%, 41.3%, 49.3%, 49.3% and 40.0%) knowledge as regarding anatomy of the heart, physiology of the heart, meaning of congenital heart disease, types of congenital heart disease, causes of congenital heart disease, symptoms of congenital heart disease, diagnosis of congenital heart disease during pregnancy, importance of surgical intervention in the treatment of congenital heart disease and ways to prevent congenital heart disease respectively.

Fig. (1): Distribution of the studied mothers according to the source of their information



*Total items are not mutually exclusive**.**

Fig.(1) views that, 64% of mothers had their knowledge from doctors, while, 20% had their knowledge from nurses. Moreover, 9.3% had their knowledge from pharmacists. On the other hand, 4% had their knowledge from relatives and 2.7% of mothers had their knowledge from Medication pamphlets.

Fig. (2): Distribution of the studied mothers according to their total level of self-reported practices towards the care of their children suffering from congenital heart disease

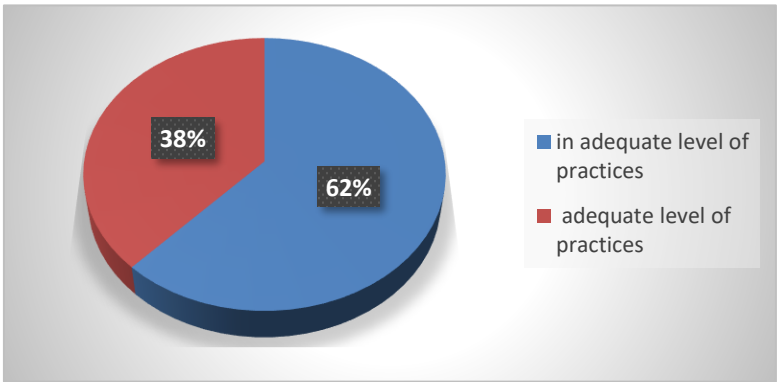


Figure (2): clarifies that 62% of self-reported mothers had inadequate level of practices towards the care of their children suffering from congenital heart disease.

Table (4): Correlation among studied mothers their total knowledge and reported practices about health care of children suffering from congenital heart diseases (N=75).

Items		Total score of knowledge	Total score of practice
Total score of knowledge	**r-value**		-0.044
	p-value		0.756
Total score of practice	**r-value**	-0.044	
	p-value	0.756	

r-Pearson Correlation Coefficient
***Highly statistical significant correlation (p<0.001).*
**A statistical significant correlation (p<0.05)*

Table (4): Proves that there were negative insignificant statistical correlation between total knowledge and mothers‘ reported practices and regarding the care of their children suffering from congenital heart diseases with (p-value >0.05 NS).

Discussion

Congenital Heart diseases are defined as a malformation of the heart or the large blood vessels that develops during the fetal period, and primarily structural alterations that arise due to errors in embryological development of the heart and great vessels. These resulting abnormalities range in severity from miniscule holes between chambers that may subsequently close to complex malformations that will require multiple surgical corrections to allow the affected patient to survive **(Jackson et al., 2019).**

The most nursing intervention in clinical setting (outpatient) is to help the mothers of children with

CHD, such as teaching, caring for and giving direction almost the illness, creating plans for care, being an agent of the health care group and doing as an advisor to mothers (**EL-Gendy et al., 2020).**

As regarding to children sex, the results of the current study illustrated that less than two thirds of the studied children were males. this finding is consistent with that of **EL-Gendyet al (2020),** who found in a study entitled "Quality of life among children with congenital heart diseases" and revealed that more than three quarters of the studied children were male, this finding is supported by that of **Elshazali et al (2018),** who found in a study about "Parent 's knowledge about diagnosis and management of their children with congenital heart diseases in Khartoum, sudan " that more than half of the studied children were male, meanwhile, this result disagrees with that of **Amaewhule et al (2022),** who conducted a study about prevalence of congenital heart diseases among primary school children in the Niger Delta region of Nigeria, West Africa, and revealed that more than half of the studied sample were females.

The current study represent that less than half of the studied children with congenital heart diseases aged less than one year, the concerned child ranking were the first child in their family for the majority of them**,** this finding agrees with that of **Brown&Smith(2018)**who found in a study" The patient journey to home after major cardiac surgery in infancy. Prog Pediatr Cardio" that more than three quarter of the studied sample their age ranged from 2 months to one year.

In the present study less than half of the studied mothers were in the age group from equal or more than 25 to less than 30 years old, the finding agrees with **EL-Gendy et al., (2020)** who study about "Guiding Program For Mothers To Improve The Quality Of Life Of Their Children With Congenital Heart Disease" and **ELsobkey et al., (2018)** "The effect of pre-hospital discharge care program on mothers knowledge and reported practice for children after congenital heart surgery" found more than one third was above twenty years old.

As regarding to educational level of mothers, the results of the current study showed that more than one third of the studied mothers received basic education**,** this finding was consistent with that of **Elshazali et al (2018),** who found that less than half of the studied sample were in preparatory school, this finding supported that of **EL-Gendyet al (2020),** who found that more than one third of the studied mothers were in preparatory school. Additionally, this finding is supported with that of **Balat &Sahu (2018**), who carried out a study entitled " Congenital heart disease: factor affecting it and role of RBSK in dealing with situation ".and revealed that less than half of the

studied sample were educated up to primary school. From the researcher's point of view this might be due to early marriage of girls which is a common popular tradition in rural communities.

The present study revealed that less than three quarter of the studied mothers were house wives, this finding agrees with that of **A Hussien et al (2018**), As regarding to residency, the results of the current study showed that less than two third of the studied mothers were living in rural areas**,** this finding agrees with that of **EL-Gendyet al(2020),** who found 82.9% of studied sample live in rural areas, this finding also supported that of **Elsayed et al (2020),** who found that the majority of the studied mothers were from rural areas, additionally, this finding disagrees with that of **Elshazali et al (2018),** who found that more than two thirds of the studied sample were living in urban areas. From the researcher's point of view this might be due to the unavailability of specialized children cardiology hospitals for providing specialized care of children in rural areas.

As regarding to mothers knowledge about congenital heart disease the present study showed that less than two thirds of the studied mothers had satisfactory knowledge about Anatomy of the heart, Physiology of the heart, Meaning of congenital heart disease, Types of congenital heart disease, Symptoms of congenital heart disease, Importance of surgical intervention in the treatment of congenital heart disease and Ways to prevent congenital heart disease **.** This finding disagrees with that of **Elsayed et al(2020) (2020)**, who found less than two thirds of the studied mothers had unsatisfactory knowledge regarding meaning, type, causes, symptoms, diagnosis, complication, treatment and ways to prevent congenital heart diseases. This finding agrees with that of **Ahmed et al (2021)**, who found in a study" Quality of life for adolescent with congenital heart diseases " that more than two thirds of the studied sample had satisfactory knowledge about congenital heart disease from total knowledge.

From the researcher's point of view this might be due to low mothers' educational level that affected their knowledge and the result of the present study could be attributed to the sample criteria and the time that the study was done.

The present study revealed that more than half the of the studied mothers had inadequate total reported practices about congenital heart diseases**,** this result was supported with that of **Abdel-Salam et al (2018) and Mohamed& Mohamed (2019),** who reported that more than half of the studied sample had inadequate total reported practices about congenital heart diseases.

From the researcher's point of view this might be due to low mothers' knowledge about congenital heart diseases that affected their practices regarding the care of their children suffering from congenital heart diseases.

As regarding to correlation between total studied of mother's knowledge and score of reported practice regarding the care of their children suffering from congenital heart diseases, the present study showed that there was negative insignificant statistical correlation between total knowledge and total mothers' reported practices regarding the care of their children suffering from congenital heart diseases**,** this finding is inconsistent with that of **EL-Gendyet al (2020),** who found that there were a significant positive association between total mothers knowledge about congenital heart diseases and mothers' reported practices towards the care of their children with congenital heart diseases with statistical significant differences at P≤ 0.05, r test reflect the positive weak correlation (0.201). This result was inconsistent with that of **Mohamed & mohamed (2019) &Elsayed et al (2020),** both of them noted that there were statistical significant relation between total mothers knowledge and practices regarding the care of their children suffering from congenital heart diseases (p-value = 0.001).

Conclusion:

The current study indicates that, less than half of the studied children with congenital heart disease were females, more than half of them discovered the diseases in age less than one year. More than half of mothers had unsatisfactory knowledge about congenital heart diseases and its care, and more than half of them, had inadequate total practices about the care provided for their children with congenital heart diseases. Also, there were more than half of the studied mothers had their knowledge from doctors. Also, the result of the study proved that there was insignificant negative correlation between the total mothers' knowledge about congenital heart diseases among studied children and reported practices regarding the care of children suffering from congenital heart diseases.

Recommendations:

Based on the findings of this study, the following recommendations were suggested:

- Periodic counseling program should be done to all mothers of children suffering from congenital heart diseases who attended the outpatient clinics about diseases treatment, prevention and control measures.
- Further study should be conducted on a large number of cases at other setting in order to generalize the result.

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