Application of Information- Motivation-Behavioral Skills Model on Mothers' Care and Quality of Life of their Children with Congenital Heart Diseases

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Abstract

Background: Families with Congenital Heart Diseases children experience a great level of anxiety and low self-efficacy. Information- Motivation- Behavioral Skills model provide mothers with guidance, empowerment and ideal use of health services that promote wellbeing and high quality of life. **The study aimed to** evaluate the application of Information-Motivation-Behavioral Skills model on mothers' care and quality of life of their children with Congenital Heart Diseases. **Design:** A quasi- experimental research design was utilized. **Subjects:** A purposive sample of 60 mothers with their children suffering from Congenital Heart Diseases who hospitalized or attended for follow up at Inpatient Pediatric Cardiac Unit and Outpatient Cardiac Clinic of Tanta Main University Hospital. **Tools:** Four tools were used; mothers' knowledge assessment questionnaire, mothers' motivational questionnaire, mothers' reported care sheet and children's quality of life scale. **Results:** There were a statistically significant difference in mothers' knowledge, social support and mothers' reported care scores as well as the quality of life of children from pre-test to posttests of the model application with positive correlation in between immediately after the model and one month later ($p < 0.05$).**The study concluded that** the Information- Motivation-Behavioral Skills model improves mothers' care and quality of life of their children with Congenital Heart Disease. **The study recommended that** the implementation of the Information- Motivation-Behavioral Skills model should be carried out for parents having Congenital Heart disease child to improve their lives.

Keywords: Congenital Heart Diseases, Information-Motivation-Behavioral Skills model, Mothers' care, Quality of Life

Introduction

Congenital Heart Diseases (CHD) are one of the major congenital malformations among children, affecting approximately 1.2 % to 17% per 1,000 live births worldwide, resulting in approximately 1.5 million cases annually. The incidence in Egypt is 5-6/1000 live birth and most cases are often diagnosed in the first year of life and childhood. It is a primary cause of infants' mortality, especially in low and middle income countries within the Arab World. Congenital Heart Diseases are structural and functional anomalies that result from the heart or major blood vessels' aberrant development during intrauterine life. Mortality rates have significantly decreased for children with CHD. It is estimated that almost 85- 90% of children with CHD manage to survive into adulthood (**Hasan et al., 2023; Bitar etal., 2024; Nasrulloyevna., Olmasovna., & Asliyevna, 2022).**

The etiology of CHD remains unknown, but may arise from both genetic and environmental factors during fetal and early life. The majority of genetic causes are large chromosomal abnormalities. In

addition to a positive family history which increases the likelihood of a second child being born with

Congenital Heart Defects to 3-4%. Environmental causes include low socioeconomic status, obesity, diabetes mellitus, rubella, poor nutrition and exposure to pollutants such as pesticides, lithium, smoking, and alcohol (**Zaki., Hussien., & Emery, 2018; Boyd., McMullen., Beqaj., & Kalfa, 2022).**

Congenital heart abnormalities are classified as mild, moderate or severe. Atrial Septal Defect and Ventricular Septal Defect which together represent about one third of CHD cases, are the most common subtypes of the disease. However, the prenatal screening reduces the incidence of single ventricle physiology and other complicated CHD types over the last 30 years **(Bonnet, 2021; Parvar., Ghaderpanah., & Naghshzan, 2023)**.

Congenital Heart Disease children suffer from various health problems such as delayed growth and development, chronic dyspnea, heart murmur, continuous fatigue, infection, oral complications and heart failure. Moreover, they usually have a bad self-image, social stigma, behavioral problems and lowered school performance. Congenital Heart Disease is a significant cause of disability that requires early surgical repair following birth to improve the disease process but, it always causes a serious psychological and financial burden. The child's chronic illness and frequent hospitalizations impose extra responsibilities including provision of psychological, physical and social care during different stages of life. Thus, most parents experience depression and fear from ambiguous future for their child's treatment, interventions and the disease outcomes **(Yi, 2022; Dalir., Manzari., Kareshki., & Heydari, 2021)**.

Chronic conditions such as CHD affect negatively all dimensions of Quality of Life (QoL) of the family members. Mothers' self-efficacy is the perception of their abilities to perform their responsibilities in different situations. The disease challenges increase mothers' frustration and lowered self-efficacy **(Thomet et al., 2018)**.

Children's Quality of Life refers to physical and emotional well-being, confidence level, interpersonal relations, environmental agents and attitudes. Congenital Heart Diseases impair all dimensions of quality of life leading to more familial suffering so, effective social support and motivational programs are crucial for parents have child with CHD to address their fears, assist in coping with serious stressors facing them and enhance self-efficacy (**Zhang etal., 2023; Dardas etal., 2024).**

Effective and continuous nursing recently based on IMBS which develop into a centered clinical nursing management approach. The model include three main constructs; Information, Motivation and Behavioral Skills which consider the fundamental determinants for healthy behaviors. In this model, mothers' information and motivation can activate positive behavioral skills to enhance mothers' awareness regarding their children's care, treatment, follow up compliance and consequently improve the disease outcomes **(Li & Zhu, 2022; Bakır ., Çavuşoğlu., & Mengen, 2021)**.

Information is a basic constructs of the IMBS model. It includes giving accurate knowledge regarding CHD and accessible management options. This information helps mothers to make

correct decisions and take appropriate actions regarding their children's condition **(Xu & Wang, 2023; Du etal ., 2024)**.

Motivation construct of the IMBS model aims to increase mothers' support, self - confidence, empowerment, establishing objectives, and determining the importance of healthy behaviors.

Behavioral skills include activities such as problem-solving skills that promote positive attitudes regarding the disease. In addition to improving care skills as mouth hygiene, healthy nutrition, physical activities coordination, infection prevention, treatment adherence, use of social support system and other health services. The components of IMBS model unite together to improve mothers' self-efficacy and adopt healthy practices toward their children so that, they can improve their children's quality of life **(Li & Zhu, 2022; Shkel etal., 2024; Alexander., Hogan., Jordan., DeVellis., & Carpenter, 2024)**.

Significance of the Study

Congenital anomalies are resposible for 303,000 neonatal death every year during the first month of life. Congenital Heart Diseases represent about one-third of all congenital birth defects which is a great serious problem in the pediatric global health **(Pan American Health Organization & World Health Organization, 2023)**. When a diagnosis of CHD is established, parents are faced with a frightening situations lead to psychological problems that negatively affect the family life. Illness ambiguity and poor social support lower mothers' ability to care for their children. Information- Motivation- Behavioral skills model enables mothers to accept and adapt successfully with the illness of their children and promote effective inclusion into community. However, there has been little researches conducted on the effectiveness of IMBS model on primary careproviders for children with CHD (**Madawala., Pimpaporn., & Usanee, 2022**). So that, this research was performed to evaluate the application of Information- Motivation-Behavioral Skills model on mothers' care and quality of life of their children with Congenital Heart Diseases.

The Aim of the study was to

Evaluate the application of Information-Motivation-Behavioral Skills model on mothers' care and quality of life of their children with Congenital Heart Diseases.

Research hypotheses

-Application of Information-Motivation-Behavioral Skills model is expected to improve mothers' knowledge and caring practices of their children with CHD.

- Quality of life of children with Congenital Heart Diseases is expected to be improved after implementing Information-Motivation-Behavioral Skills model.

Subjects and Method

Subjects

Study design: Quasi- Experimental research design was used.

Setting: The study was carried out at Inpatient Pediatric Cardiac Unit and Outpatient Cardiac Clinic of Tanta Main University Hospital which affiliated to Ministry of Higher Education and Scientific Research. Both settings located on the fifth floor and the inpatient unit had five beds.

Subjects: A purposive sample of 60 mothers with their children suffering from Congenital Heart Diseases, who was hospitalized or attended for follow up in the previously stated settings. The flow rate of Congenital Heart Diseases within 3 months was about 70 children. The following formula was used to calculate the sample size:

Sample Size = $[z2 * p(1-p)] / e2 / 1 + [z^2 * p(1-p)] / e^2 * N]$

- *N* = population size
- z = z-score
- *e* = margin of error
- *p* = standard of deviation
- The population size was 70 mothers, confidence level was 99%, standard of deviation was 50% , and margin of error was 5%.

- Z -score was 2.58. The number of the children included in this study were 63, then it was reduced to be 60 childern with their mothers due to withdrawal of three mothers after the immediate phase of the model implementation.

Inclusion Characteristics of Children

- Confirmed diagnosis of Congenital Heart Diseases either cyanotic or a cyanotic.
- Age ranged from 4 and 12 years
- both sexes

Tools of the study; Four tools were used by the researcher to obtain the necessary data, which include the following:

Tool (1): Mothers' Knowledge Assessment Questionnaire about Congenital Heart Diseases

The researchers created this tool for assessing mothers' personal characteristics, childern bio-social characteristics and mothers' knowledge about Congenital Heart Disease, relied on the up- to- dated and recent literatures (**Elshazali et al., 2018 & Bitar etal., 2024)**. It was translated into arabic language and was classified into the following three parts:

Part (I): Personal characteristics of the studied mothers: such as age, level of education, occupation, marital status, residence, income, family size, family history and consanguineous marriage.

Part (II): Bio-Social characteristics of children: as age, sex, onset of diagnosis, treatment and previous hospitalization with its duration.

Part (III) Mothers' knowledge regarding Congenital Heart Diseases: this part composed of: definition, risk factors, classifications, signs and symptoms, diagnosis, treatment and medications. It also covered complications and preventive measures. Each question scored from 0-2 points. Complete correct answer scored 2 points, incomplete correct answer scored 1 point and zero for wrong or I don't know answer.

The mothers level of knowlgde was cateogorized as follows

- Equal or more than 75 % represented high knowledge level
- From 50 - < 75% represented moderate knowledge level
- Less than 50% represented low knowledge level

Tool II: Mothers' Motivational Questionnaire

The investigators developed this tool after reviewing of the related literatures (**Mishel, 1983**; **Zimet., Dahlem., Zimet., & Farley, 1988)**, for assessing mothers' motivation in caring for their children with Congenital Heart Diseases. Mothers' motivation was determined through assessing mothers' perceptions of illness uncertainty and perceived social support.

Part (1): Mothers Perceptions of Illness Uncertainty Scale (Individual Motivation)

It was developed by **Mishel, (1983)** for measuring mothers perceptions regarding the uncertainty of their child's illness and adapted by the researchers. It composed of 31 items covering four domains: ambiguity, lack of clarity, lack of information, and unpredictability with 3-point scale (agree, undecided and

disagree). Responses were summed to calculate a total score.

Scoring system: The mother's perceptions toward uncertainty of illness were measured and categorized into the following total scores**.**

- Less than 50 % indicated low perceived illness uncertainty.
- From 50 - < 75% of the total score indicated moderate perceived illness uncertainty.
- Equal and more than 75 % indicated high perceived illness uncertainty.

Part (2): Multidimensional Scale of Perceived Social Support (Social Motivation)

It was created by **Zimet et al., (1988)** and divided into three subscales (family, friends, significant others). It involved twelve statements rated on a 3-point Likert Scale (agree, undecided and disagree). Each subscale contained number of questions as follows:

-Family subscale contained questions number (3, 4, 8, 11)

-Friends subscale questions No (6,7,9, 12).

- Significant others subscale questions No: (1,2,5, 10). The total items scores were 36 points with higher scores indicated greater social support.

The total scores of perceived social support was classified as the following

- Less than 50 % was considered low perceived social support
- From 50% - <75% was considered moderate perceived social support
- Equal or more than 75% was considered high perceived social support

Tool III: Mothers' Reported Care Sheet regarding Congenital Heart Diseases

It was designed by the researchers in the light of relevant literatures review (**EL-Gendy., Hassan., Abd EL-Aziz., & Hafez, 2020; Madawala etal., 2022)** to evaluate mothers' reported care for Congenital Heart Diseases as oral care, infection control, nutrition, physical activity, medication, immunization, follow up and psychological support. Total questions are 38 questions.

Mother's reported care scoring systems

- Done care was scored 1
- Not done was scored 0

Scoring system: It was cateogorized as the following

- Unsatisfactory reported care: < 70% of the total score.
- Satisfactory reported care: ≥ 70 % of the total score.

Tool IV: Children's Quality of Life Scale

It was developed by (**Varni., Burwinkle., Seid., & Skarr, 2003)**, translated into Arabic language and utilized by the researchers to assess quality of life of children with Congenital Heart Diseases. It contained 23 questions across 4 domains : physical, social, emotional, and school well-being. **Physical domain included** (walking, running, sports, lifting heavy objects, taking shower, home activities, pain, and energy level). **Social domain**: (social isolation, friendship, bullying, ability to do things and play). **Emotional domain**: (sense of fear, sadness, anger, sleep problems and worry). **School well-being domain**: (attention, forgetting, school work achievement, school absenteeism due to un-wellness or hospitalization).

Scoring System of Quality of Life

The scale utilized a 5-point Likert scale that ranged from "never" to "always." Each item was given a score within the range of 0 to 100, with 0 representing the lowest score and 100 representing the highest score. The scores for each child were summed and then converted into a percentage score. **The overall scores**

based on all domains of the quality of life

- Equal and more than 75% represents good quality of life
- From 50 % - < 75 represents fair quality of life
- Less than 50% represents poor quality of life

Method

1. The Dean of the Faculty of Nursing at Tanta University and the administrators of inpatient and out patient pediatric department of Tanta University Hospital granted official approval for the conduction of the study.

2. Ethical considerations

a. The study didn't result in any discomfort or suffering for the entire sample group.
b. Data collection process ensuring privacy and confidentiality for all participants.
c. Mothers gave their consent for the study participation,with the freedom to withdraw at any time.
d. Ethical committee approval obtained from Faculty of nursing, **code Number of approval** : **333-11-2023**

3. **Tools development:** Study tools were developed and modified by the researchers based on the review of related literature. There were four tools used for collecting data.
4. **Content validity:** The questionnaire's face validity was established by consulting experts in Pediatric Nursing and Community Health Nursing following the calculation of a content validity index which was 95% for its items.

5-Content Reliability: The study tools were assessed for their reliability by calculating Cronbach's Alpha, which was found to be 0.875.

6. A pilot study: was conducted with10% of mothers accompanying with their children to measure clarity, applicability, feasibility of the tools and the necessary modification was made, the sample of pilot study was excluded from entire study sample.

Phases of the study: there were four phases

1- Phase of Assessment: The researchers utilized existing tools and conducted interviews with mothers and their children in the previousely mentioned setting to gather data about Congenital Heart Diseases pre and post the model **(Tool I, II, III and IV)**

2- Phase of Planning: involved the subsequent steps:

- Setting objectives
- Creating the content of the model including the session's goals.
- The mothers were divided into 10 subgroups and each subgroup was included 6 mothers with their children.
- **Teaching aids**: Power point presentation containing videos and pictures to present the IMBS model content in simple way. booklets were given to every mother.

3) Phase of Application

-The IMBS model was implemented through conducting subsequent sessions for each group focuded on Information, Motivation and Behavioral skills which were covered through six sessions. Each session took 20-40 minutes.

- **The first and the second sessions:** involved information section about meaning, risk factors, classifications, signs and symptoms, methods of diagnosis, treatment, medication prescription, complications and preventive measures.
- **The third & fourth sessions:** covered motivational section. The researcher employed motivational interview techniques to strengthen the mother's positive optimistic outlook. This included offering personalized feedback, asking open-ended questions, providing

affirmations, actively listening, offering psychological support, and setting realistic goals, all these actions helping mothers to comply with medical recommendations for thier children.

- **The fifth & sixth sessions:** contained behavioral skills which focused on teaching how mothers effectively implement oral care, infection prevention measures, healthy nutrition, physical activity, medications administration, vaccinations and regular follow up.
- A variety of teaching techniques used as lectures and group discussions.
- The study was done from the starting of November 2023 to February 2024, covered three months.

4- **Phase of Evaluation**: The effect of the IMBS model on the mothers reported care and children quality of life examined by comparing pre test and post test results. Evaluation phase occurred three times by utilizing the same tools.

5. Statistical analysis

All the collected data was reviewed, organized, coded and entered by utilizing SPSS version 23 software for data processing. Descriptive statistics were utilized to represent the data in various forms, including frequencies, percentages, Mean, and SD. In order to assess the relationship between the different variables in the study, a Pearson correlation coefficient (r) was calculated. Additionally, A t-test was utilized to compare categorical data between two different groups. **(White, 2019)**.

Results

Table (1) displayed mothers' percentage distribution regarding their personal characteristics. It was showed that mothers' ages varied from 18 to 49 years old, with a mean & SD of 32.56±7.5, and half (50%) of them their age ranged from 30-40 years old. About one third (33.3%) of them had preparatory education compared with 10 % who were illiterate. In relation to occupation and marital status, 73.3%, 93.3% and 75% of the studied mothers were housewives, married and came from rural area respectively. As regards to the family income, 56.7% of the mothers didn't have enough income. Slightly less than half of the mothers (48.3%) had reported that their family size composed of five members compared to 10% of them who had only three members. About two thirds (68.3%) and 60% of the studied mothers illustrated that there were no family history of Congenital Heart Diseases and consanguineous marriages between them and their husbands respectively .

Table (2): illustrated the distribution of the children according to their biosocial characteristics. It was found that the age of children varied from 6-12years, with a mean & SD of 8.58± 1.98 years old. Slightly more than half (53.3% & 55%) of the studied childern whose age ranged from 6-8 years old and were male respectiveley. Nearly two fifths (43.3%) of children were diagnosed before ending the first month of birth, while 13.3% were diagnosed after the first year of life. About half of of the studied children (51.7%) received pharmacological treatment compared with 48.3 % who had surgical operation. Regarding children who had cardiac operation, 48.3 % of them had heart catheterization and 13.8% had open heart surgery. The majority of children (93.3%) reported that they had previous hospitalization and 80.4% of them stayed more than 5 days in the hospital

Figure (1) showed that, 43.3% & 26.7% of the children were diagnosed with Ventricular Septal Defect and Atrial Septal Defect respectively, while 1.7% of children had pulmonary stenosis.

Table (3): displayed mothers' distribution according to their total knowledge scores about Congenital Heart Diseases. Prior to model application, Most (88.3%) mothers possessed low knowledge level. However, 86.7% of them had high level of knowledge immediately after model application compared to 80% of them one month after IMBS model. The total knowledge mean scores was 7.73±1.53 pre model and improved to be 15.20±1.59 and 14.62±1.48 immediately after and one month later respectively. The total knowledge scores showed a statistically significant improvement from the pretest to one month after model implementation ($p< 0.05$).

Table (4) presented the percentage distribution of mothers' total illness uncertainty scores. It was found that, 68.3% of the mothers had high perceived illness uncertainty while, 31.7% of them had moderate level before model application. After the implementation of the model, 21.7%, 71.7% & 6.6 % had low, moderate and high level of illness uncertainty respectively. After one month of IMBS model, 30% and 65% of the mothers had low and moderate levels of uncertainty of illness respectively. There was statistically decline in the overall high uncertainty illness scores before model till one month after the model ($p<0.05$).

Table (5): showed that 33.3% of the mothers had low perceived social support and 66.7% of them had moderate level pre model. After the implementation of the model, 73.3% & 26.7% had high and moderate level of social support respectively. After one month of model application, 71.7% of the mothers had high level of social support compared to 28.3% of them who had moderate level. The total social support scores showed a statistically significant difference from pre-test to one month of model application ($p< 0.001$).

Table (6) clarified means and standared deviations of mothers' reported care for their children with Congenital Heart Diseases. It was observed that there were statistically improvement in the means of oral care, physical activity, medication care and psychological support within the all study phases ($p< 0.05$). The study results found a significant change in the means of infection prevention measures, nutrition, and vaccination before and immediately after applying the model, with a p-value of less than 0.05.

Table (7) demonstrated that almost all (90%) of mothers had unsatisfactory reported care pre the model implementation. While, 93.3% & 86.7 % had satisfactory reported care immediately and one month after IMBS model respectively. The total mean scores of mothers' reported care has statistically improved through the whole study phases ($p<0.05\%$), it was 20.23±5.03 pre model and increased to be 34.50±3.96 & 32.28±4.41 immediately post the model application and one month later respectively.

Table (8) demonstrated percentage distribution of the children according to their total quality of life scores. Slightly more than half (53.3%) of the children had poor quality of life before model application compared to 75% and 65% of the children who had good quality of life immediately post and one month later. The total quality of life means &SD scores were 50.14± 15.34 prior, the IMBS model, which improved to be 74.70±5.37 and 72.15±6.78 immediately post and one month after the model implementation respectively. The total quality of life scores were statistically

enhanced from pretest to posttests of the model application ($p<0.05$).

Table (9) illustrated that the total mothers' knowledge scores, reported care and children's quality of life scores were positively correlated immediately post model application and one month later ($p = 0.0001$, $p = 0.0001$ and $p = 0.002$) and after one month of the model application ($p = 0.006$**,** $p = 0.011$ and $p = 0.005$) respectively.

Table (10) showed positive connection between mothers' reported care, children's quality of life and social support scores respectively before applying the model ($r=0.298$, $p=0.023$ & $r=0.433$, $p=0.0001$). Mothers' knowledge, reported care and children's quality of life scores were positively afftected by social support scores ($p=0.0001$, $p=0.005$, $p=0.0001$ and $p=0.005$, $p=0.0001$, $p=0.0001$) immediately and one month respectively. on the contrary, the overall mothers' knowledge scores, reported care and children's quality of life scores negatively affected and correlated with illness uncertainty scores from pre to one month respectiveley ($p= 0.010$, $p=0.0001$, $p= 0.0001$, $p=0.0001$, $p=0.014$ & $p=0.028$, $p= 0.022$, $p= 0.043$, $p=0.008$).

Table (1): **Percentage Distribution of the Studied Mothers regarding their Personal Characteristics**

	The studied mothers(n=60)	
Personal Characteristics	**No**	**%**
1-Mother's Age (in years)		
a- < 20	6	10
b- 20- < 30	17	28.3
c- 30-40	30	50
d- >40	7	11.7
Range: 18-49 **Mean ±SD: 32.56±7.5**		
2- Education		
a- Illiterate	6	10
b-Primary	12	20
c-Preparatory	20	33.3
d-Secondary	13	21.7
e-University	9	15
3- Occupation		
a- House wife	44	73.3
b- Worked	16	26.7
4- Marital status		
a- Married	56	93.3
b- Divorced	4	6.7
5-Residence		
a-Urban	15	25
b-Rural	45	75
6-Income		
a-Enough	21	35
b-Enough and save	5	8.3
c-Not enough	34	56.7
7- Family size		
a- 3	6	10
b- 4	11	18.3
c- 5	29	48.3
d- > 5	14	23.4
8- Family History		
a- Yes	19	31.7
b- No	41	68.3
9- Consanguinity		
a- Yes	24	40
b- No	36	60

Table (2): Percentage Distribution of the Studied Children according to their Bio-Social Characteristics

	The studied Children (n=60)	
Bio-Social Characteristics	**No**	**%**
1- Child Age (Years)		
a- 6-8	32	53.3
b- 8-10	15	25
c- 10-12	13	21.7
Range: 6-12		
Mean & SD: 8.58± 1.98		
2- Sex		
a- Male	33	55
b- Female	27	45
3- Age at the first diagnosis		
a- less than one month	26	43.3
b- 1-6 months	15	25.0
c- 6-12 months	11	18.3
d- More than one year	8	13.3
4- Treatment		
a- Pharmacological	31	51.7
b- Surgical	29	48.3
If Surgical option is selected identify type (n=29)		
a- Heart catheterization	14	48.3
b- Dilation to tight valves	11	37.9
c- Open heart surgery	4	13.8
5- Previous hospitalization		
a- Yes	56	93.3
b- No	4	6.7
6- Duration of previous hospitalization (n=56)		
a- Less than 5 days	11	19.6
b- More than 5 days	45	80.4

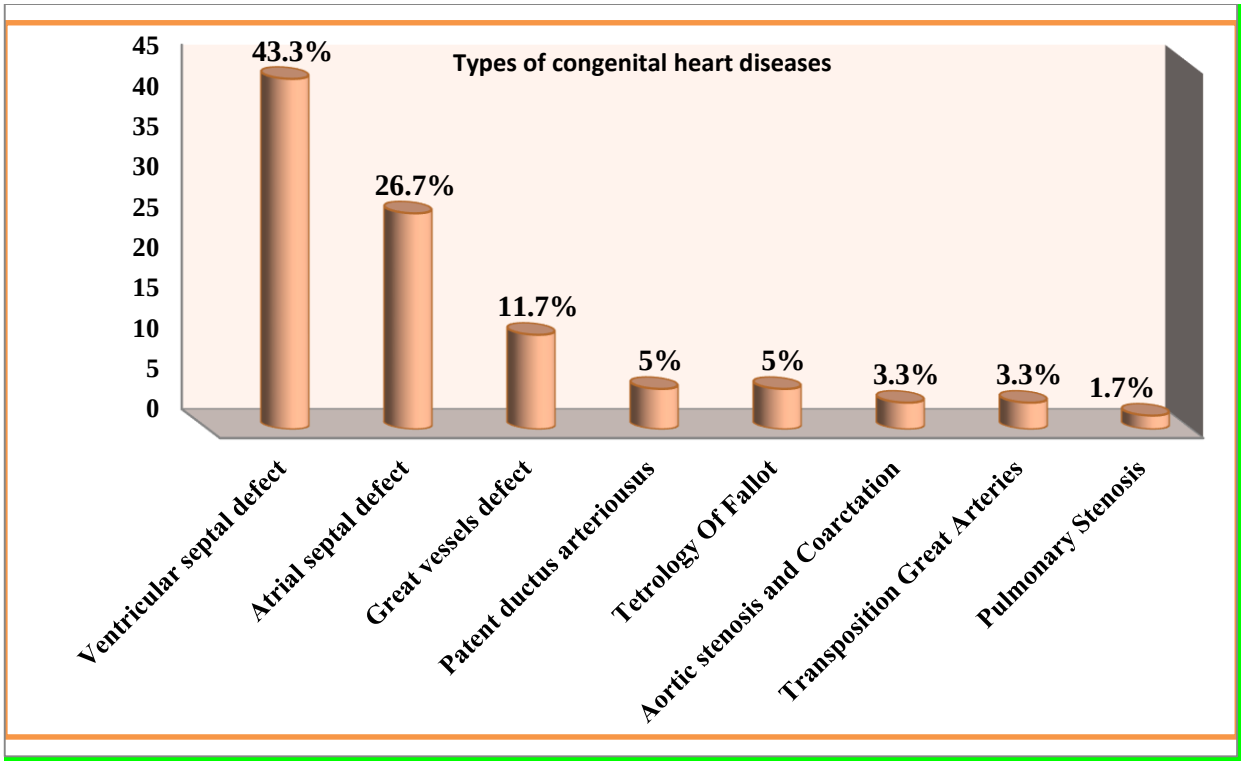

Figure (1): Distribution of the Studied Children regarding Types of Congenital Heart Diseases

Table (3): Percentage Distribution of the Studied Mothers According to Their Total Knowledge Scores about Congenital Heart Diseases

Total Studied Mothers (n=60)								
Mother's total knowledge Scores	**Pre**		**Immediate**		**Post one month**			
	No	**%**	**No**	**%**	**No**	**%**	**T test**	**P-value**
Low	53	88.3	0	0.0	0	0.0	P1=-33.42	< **0.001***
Moderate	7	11.7	8	13.3	12	20	P2= -29.23	< **0.001***
High	0	0.0	52	86.7	48	80	P3= 2.175	0.034*
Range	5-12		11-18		11-17			
Mean & SD	7.73±1.53		15.20±1.59		14.62±1.48			

***Significant at p < 0.01 (2 tailed)** **P1= Pre & Posttest** **P2= Pre &Immediate test**
P3= Immediate & Posttest

Table (4): Percentage Distribution of the Studied Mothers regarding Total Illness Uncertainty Scores

	The studied mothers (n=60)							
Total Illness Uncertainty scores	**Pre**		**Immediate**		**post one month**		**T test & P value**	
	No	**%**	**No**	**%**	**No**	**%**	**T**	**P**
Low	0	0.0	13	21.7	18	30	P1= 10.45	**<0.001***
Moderate	19	31.7	43	71.7	39	65	P2=10.04	**<0.001***
High	41	68.3	4	6.6	3	5	P3= 2.89	**0.043***
Range	62-93		38-72		33-72			
Mean & SD	79.82±11.3		54.28±8.9		52.45±11.4			

***Significant Difference (p < 0.05)**

Table (5): Percentage Distribution of the Studied Mothers According to their Total Social Support Scores

	The studied mothers (n=60)							
Social support scores	**Pre**		**Immediate**		**post one month**		**Chi-Square**	
	No	**%**	**No**	**%**	**No**	**%**	**X^2**	**P-value**
Low	20	33.3	0	0.0	0	0.0	**75.55**	**<0.001***
Moderate	40	66.7	16	26.7	17	28.3		
High	0	0.0	44	73.3	43	71.7		

***Significant at (p < 0.05)**

Table (6): Means and Standard Deviations of Mothers' Reported Care for their Children with Congenital Heart Disease

Reported care Items	The studied mothers (n=60)				
	Before	Immediately post	One month after	T test	P value
	Mean & SD	Mean & SD	Mean & SD		
1- Oral Health	1-7 3.61±1.4	3-7 6.35± 1.16	3-7 5.98±1.09	P1= 12.69 P2=13.03 P3= 2.06	**< 0.001*** **< 0.001*** **0.044***
2- Infection Prevention Measures	1-9 4.51±1.89	3-9 7.72±1.57	3-9 7.28±1.61	P1=10.56 P2=12.90 P3=1.76	**< 0.001*** **< 0.001*** 0.086
3-Nutrition	0-6 3.38± 1.89	3-6 5.45± 0.95	3-6 5.20± 0.89	P1=9.23 P2= 9.07 P3=1.90	**< 0.001*** **< 0.001*** 0.064
4- Physical activity	1-9 5.06±1.81	4-10 9.38±1.23	4-10 8.65±1.54	P1=13.10 P2=15.06 P3=2.77	**< 0.001*** **< 0.001*** **0.007***
5-Medications	0-3 1.55±0.83	1-3 2.90±0.44	1-3 2.56±0.69	P1=7.66 P2=10.97 P3= 3.66	**< 0.001*** **< 0.001*** **0.001***
6- Vaccination	0-1 0.67±0.48	0-1 0.87±0.34	0-1 0.90±0.30	P1=3.61 P2=2.68 P3= 0.57	**0.001*** **0.009*** 0.57
7-Follow Up	0-1 0.73±0.34	0-1 0.85±0.32	0-1 0.83±0.37	P1=1.28 P2=1.62 P3= 0.46	0.203 0.109 0.811
8-Psychological support	0-1 0.70 ± 0.45	0-1 0.98 ± 0.12	0-1 0.88±0.34	P1=2.62 P2=4.48 P3= 2.43	**0.011*** **0.001*** **0.018***

***Significant at p < 0.01 (2 tailed)** **p1. Pre &one month**

P2. Pre & immediately post **P3. Immediately post and one month**

Table (7): Percentage Distribution of the Studied Mothers According to their Total Reported Care Scores

The Studied Mothers (n=60)								
Total Reported Care Scores	**Pre**		**Immediate**		**post one month**		**T Test & P Value**	
	No	**%**	**No**	**%**	**No**	**%**	**T**	**P**
Unsatisfactory Care	54	90	4	6.7	8	13.3	**P1**=16.93 **P2**=19.48 **P3**= 3.41	**<0.001*** **<0.001*** **0.001***
Satisfactory Care	6	10	56	93.3	52	86.7		
Range	**12-36**		**24-38**		**21-38**			
Mean& SD	**20.23±5.03**		**34.50±3.96**		**32.28±4.41**			

***Significant at p < 0.01 (2 tailed)**
p1. Pre &one month
P2. Pre & immediately post
P3. Immediately post and one month

Table (8): Percentage Distribution of the Studied Children according to their Total Quality of Life Scores

The studied children (n=60)								
Total Quality of Life Scores	**Pre**		**Immediate**		**post one month**		**T Test & P Value**	
	No	**%**	**No**	**%**	**No**	**%**	**T**	**P**
Poor	32	53.3	0	0.0	0	0.0	**P1=12.44** **P2=12.93** **P3= 3.45**	**<0.001*** **<0.001*** **0.002***
Fair	22	36.7	15	25.0	21	35		
Good	6	10	45	75.0	39	65		
Range	27-75		59-85		53-84			
Mean& SD	50.14± 15.34		74.70±5.37		72.15±6.78			

***Significant at p < 0.01 (2 tailed)**

Table (9) :Correlation between Total Mothers' Knowledge, Reported Care and Children's Quality of Life

Time		Total knowledge scores		Total reported Care scores	
		r	P-value	r	P-value
Pre	**Reported Care**	0.116	0.102	-	-
	Quality of life	0.019	0.921	0.105	**0.423**
Immediate	**Reported Care**	0.571	**0.0001***	-	-
	Quality of life	0.618	**0.0001***	0.399	**0.002***
Post one month	**Reported Care**	0.394	**0.006***	-	-
	Quality of life	0.326	**0.011***	0.355	**0.005***

***Correlation is significant at the (p < 0.05 level) (2-tailed).**

Table (10): Correlation between Mothers' Knowledge, Reported Care, Social Support, Illness Uncertainty and Children's Quality of Life

Time		Total knowledge scores		Total reported Care		Children's Quality of Life	
		R	P-value	r	P	r	P
Pre	**Social support**	0.160	0.223	0.298	**0.023***	0.433	**0.0001***
	Illness uncertainty	-0.332	**0.010***	-0.458	**0.0001***	-0.759	**0.0001***
Immediate	**Social support**	0.527	**0.0001***	0.355	**0.005***	0.874	**0.0001***
	Illness uncertainty	-0.789	**0.0001***	-0.317	**0.014***	-0.282	**0.028***
Post one month	**Social support**	0.365	**0.005***	0.782	**0.0001***	0.597	**0.0001***
	Illness uncertainty	-0.289	**0.022***	-0.262	**0.043***	-0.341	**0.008***

***Correlation is significant at the (p < 0.05 level) (2-tailed).**

Discussion

Living with a child suffering from Congenital Heart Disease causes psychological stress due to additional regulations, changes of the family life and functions. Parents of children with CHD are the principal caregivers require individualized and multidisciplinary approach focused on giving information, encouragement and care skills to adapt to the dynamic challenges, increase their competence and bonding to sick child. This study addressed that, one thirds of mothers had preparatory education. From the researcher's point of view this might be due to low socioeconomic status and girls' early marriage which is a common tradition in rural communities that preventing them from completing their education. **Balat & Sahu (2018)** were in agreement with the present study, who revealed that nearly half of the studied subjects had primary school education. Similarly, **Mahmoud., Ismail., & Hassan. (2020)** who stated that, about two fifth of mothers completed their preparatory school education.

The result showed that, nearly three quarters of mothers were housewives. This could be explained in the light of mothers are the primary caregivers for their children with chronic illnesses as CHD and have to stay at home to provide care and meet their children's needs. **Zaki et al. (2018) & El - Gendy et al. (2020)** were in harmony with this study, who declared that, the majority of the participants were house wives. In relation to residence, it was realized that, three quarters of mothers and their children came from rural areas. This could be result from poor medical care and follow up during pregnancy in rural settings which can lead to premature labor and risks for neonatal congenital anomalies. In addition to absent of pediatric specialized cardiac health facilities in these areas so, they seek health care and services from Tanta university hospital. This finding agreed with **El - Gendy et al. (2020); Mahmoud et al. (2020**) who found that most the studied children lived in rural areas. On the other hand, **Al-Fahham & Ali (2021)** who discovered that most of the studied sample were from urban settings.

Regarding parents' consanguinity and family history, it was noticed that approximately two thirds and more of the studied mothers had no consanguineous marriages with their husbands and negative family history. This finding explained that consanguinity and family history aren't the main contributing factor in the occurrence of CHD due to increase awareness about problems associated with consanguineous marriages. In addition, there are many environmental factors that can affect fetal heart development as blood flow problems with placental insufficiency, maternal anemia, gestational diabetes and hypertension. Moreover, premature labor, certain medications and teratogens like alcohol, smoking or rubella infection and chromosomal abnormality can raise the chance of congenital heart disease. Similarly, **Şanlı., Agaoğlu., & Kandur. (2023)** who detected that more than three quarters and most of the studied participants had no parental consanguinity or family history, respectively. Also, **Alkaya et al. (2023)** displayed that, there was no association between parents' consanguinity and congenital heart anomalies. On the other side, **Ahmad et al. (2023)** who mentioned that, children with parental consanguineous marriage had a greater frequency of Congenital Cardiac Disorders.

The study displayed that, the majority of the studied children had previous hospitalization. This could be due to surgical interventions and follow up. As well as their chronic illness affect functions of body systems and their immunity. Thus, become susceptible to infection especially respiratory problems and hospital readmission. This findings is consistent with **Ghimire., Chou., Aljohani & Moon-Grady. (2023); Djer., Osmardin., Hegar., & Setyanto.**

(2020); **Şahan., Kılıçoğlu., & Tutar. (2018)** who stated that children with CHD had recurrent hospitalization in winter due to respiratory complications with longer hospital stay and excessive use of healthcare services. Also, **Jat et al**. **(2022)** who mentioned that congenital heart disease children had structural defects that lead to hemodynamic disruptions of lung circulation, which increase the incidence of frequent respiratory tract infections. Concerning medical diagnosis, it was found that nearly half and more than one fifth of children had Ventricular and Atrial Septal Defects respectively. On the same way, **Alkaya etal. (2023)** who claimed that Atrio-Ventricular Septal Defects are the most frequent Congenital Heart Defects. This result were contrary to **Sharifi., Ekram., & Wali. (2023)**, who clarified that the most prevalent CHD was Patent Ductus Arteriosus.

Considering mothers' knowledge about CHD, it was found that, most of the studied mothers had poor level of knowledge. This could be due to low educational level as one thirds of them had preparatory education, absent or low health education programs provided to mothers in different health facilities. These findings supported by **Sayeh., Ragheb., Mohamed., & Elguindy. (2023**) who discovered that more than half of the studied mothers had poor knowledge about meaning, symptoms and treatment of CHD.

On the opposite side, **Khouenkoup., Srichantaranit., & Sanasuttipun. (2021)** who reported that mothers' knowledge regarding CHD were at a high level. Also, **Abdelhamid., Mohamed., & Hasan. (2021)** who found that most participants had good knowledge about Congenital Heart Disease.

The study showed that most mothers had high knowledge scores immediately and one month after the model application. This reflected the clear effect and importance of the model's content which established based on mothers' needs and the use of different audiovisual aids. All these elements lead to knowledge improvement. **Abdel-Salam & Mahmoud (2018)** were in the same line with this result, claimed that more than half of mothers had poor knowledge before teaching program while, post program had high knowledge scores. Similarly, **Elsobky., Amer., & Sarhan. (2018)** who declared that mothers' awareness increased as a result of the model application. The results showed that, about sixty- eight percent of mothers reported high perceived illness uncertainty pre Information, Motivation and Behavioral Skills Model, while nearly three quarters of mothers had moderate illness uncertainty post the model. The researcher's opinion pointed to low awareness and absence of guidance programs conducted for mothers about Congenital Heart Diseases increased illness uncertainty before model implementation, whereas mothers' awareness, empowerment and skills associated with care of their children were improved after model implementation which decrease disease ambiguity and unpredictability. These findings were consistent with **Biber et al. (2019)** who stated that parents with CHD child experience stress as a result of ambivalence and lack of understanding towards illness nature and the child care. Also**, Choi., Park., & Choi. (2021)** who pointed that, IMBS model can be useful for children with chronic diseases as it conveys knowledge and motivation required to modify health-related behaviors and adapt with stressors.

Regarding total social support scores, it was found that, about one third of the studied mothers had low perceived social support and two thirds of them had moderate scores of social support before model implementation while, about three quarters of them had high social support post the model. This may result from the Information- Motivation- Behavioral Skills model effectiveness which allowed mothers to ask questions, express their fears and

gave psychosocial support as well as notifying mothers about community and social support services to cope with any stressors and challenges. This finding was in acceptance with **Wray et al. (2018)** who announced that it is crucial to conduct social support programs, family-centered empowerment counseling, and regular communications between health care professionals and families with CHD children. Similarly, **Madawala et al. (2022)** who asserted that social support improves one's coping ability, self-esteem and self-control during difficult circumstances.

In relation to mothers' reported care, it was found that less than half of the studied mothers had unsatisfactory oral care for their children with CHD before the model application. While, the majority of them had satisfactory reported care post the IMBS model. This resulted from little knowledge about oral care benefits and associated complications before the model whereas after IMBS model they received instructions about oral care steps. This finding was consistent with **Koerdt et al. (2017)** who clarified that parents of children with CHD didn't perform dental care measures and needed structured programs about oral health. Similarly, **Sarac., Derelioglu., Şengul., Laloglu., & Ceviz. (2023)** who recommended that regular dental care examinations in children with CHD is very essential to prevent the risk of infective endocarditis.

The study demonstrated that almost all of the studied mothers had unsatisfactory reported care before implementing the model . While, the majority of them had satisfactory reported care immediately and one month after IMBS model which indicated the efficacy of structured mothers' training to promote their care. This was in accordance with **Sayeh etal. (2023**) who explained that more than half of mothers had poor care practices toward their children with CHD before educational programs. Additionally, **Abdel-Salam & Mahmoud (2018)** who found that there was improvement in mothers care during the immediate and after three months of educational intervention.

In terms of total scores of children's quality of life, it was observed that more than fifty percent of the studied children had poor quality of life before the model application. This may be due to poor mothers' knowledge and care provided for their children with CHD, low social support and self-efficacy in addition to the burdens associated with chronic illness as recurrent hospitalization, long term treatment, financial costs, emotional and familial problems that disrupt QoL. This explanation was supported by S**ertçelik., Alkan., Sapmaz., Coşkun., & Eser. (2018)**; **Mahmoud et al. (2020)** who revealed that, the total QoL scores were low in Congenital Heart Diseases children.

The study asserted that there was a statistically significant improvement in all quality of life items immediately after the IMBS model and one month later. From the researcher's view point, this could be due to the effect of IMBS Model on improving mothers' knowledge and skills which reflected positively on all dimensions of quality of life. This result matched with **Kamal., Salih., & Ali. (2024)** who mentioned that educational programs and regular monitoring assist parents in understanding healthcare information, making appropriate decisions, promoting health and quality of life for their children.

The study mentioned that there was a positive correlation between mothers' knowledge, reported care and children's quality of life scores post the implementation of the model. This might be due to increasing mothers' information, skills and turned them into practice during the child care consequently maximizing the children's quality of life. This finding was in agreement with **Mahmoud et al. (2020)**, who noted that there was a statistically positive correlation between mothers knowledge and practices regarding the care of their children

with Congenital Cardiac Defects. **Abdelhamid., Mohamed., & Hasan. (2022)** stated that there were positive correlation between knowledge and quality of life of the adolescents with CHD. This result was Contrary to **Sayeh etal. (2023**) who demonstrated a negative correlation between the total mothers' knowledge scores and reported practices.

The study showed that there were positive correlation between mothers' knowledge, reported care, children's quality of life scores and social support scores. This demonstrated that social support is essential factor for enhancing knowledge, practice and reflected positively on children's QOL. This finding was consistent with **LaRonde., Connor., Cerrato., Chiloyan., & Lisanti. (2022); Abdallah., Mourad., & Ata. (2022)** who claimed that caregivers of children with CHD require adequate social support that increase their self-esteem, wellbeing, and their abilities in dealing with difficult situations, therefore improving QOL for all family. Similarly, **Carlsson & Mattsson (2022)** who said that mothers of children with Congenital Heart Diseases use peer support communication through a variety of methods for exchange of emotional and informational support.

It was demonstrated that mothers' knowledge scores, reported care, children's quality of life and illness uncertainty scores were negatively correlated. This clarified that increasing mothers' knowledge and practice towards care of their children result in low illness uncertainty and ambiguity. This result was agreed upon by **Maneekunwong., Srichantaranit., & Thampanichawat. (2021)** who declared that health care professionals should provide information and teaching programs for decreasing caregivers' uncertainty of their children's illness.

Conclusion

The current study concluded that, the Information- Motivation-Behavioral Skills model improves mothers' care of their children with Congenital Heart Diseases resulting in significant improvement in children's quality of life.

Recommendations

1- The Information- Motivation-Behavioral Skills model should be implemented regularly in all health facilities for children with Congenital Heart Diseases and their mothers.
2- Health care services are necessary for optimizing mothers' self- efficacy and fostering recovery of their children with Congenital Heart Diseases.
3- Further studies must be done to enforce application of IMBS model at different pediatric settings.

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