

Mothers' Care for their Infants with Congenital Heart Anomalies

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ABSTRACT

Background mothers' care during infancy period is important to prevent complications especially with congenital heart anomalies infants. **The aim** of the study to evaluate mothers' care for their infants' with congenital heart anomalies. **Research design** descriptive research design was used. **Setting** the study was conducted at Cardiac Out Patient at Abo Erish Hospital at Cairo University Hospitals. **The sample** convenience sample of 100 infants with congenital heart anomalies and their mothers'. **Tools** two tools were used to collect the research data An interviewing questionnaire which consisted of four parts **Part (I)** socio-demographic characteristics of the studied mothers, and Infants'. **Part (II)** family history and Infants' medical history. **Part (III)** mothers' knowledge regarding congenital heart anomalies. **Part (IV)** mothers' practices regarding infant's nutrition, hygiene, protection from infection, immunization. **Physical Assessment tool** to measure the infant's physical growth. **Result** 54% of the studied mothers their age ranged between 25-35, the studied mothers had poor knowledge regarding congenital heart anomalies, and only 3% had good knowledge. 71% of the studied mothers general total practices were satisfactory. **Conclusion** the present study revealed that majority of the studied mothers had poor knowledge regarding congenital heart anomalies, and there was statistically significant relation between mother's knowledge and practices regarding their infants care $P < 0.001$. **Recommendations** Health education program regarding congenital heart anomalies and importance of mother's care for their infants to prevent further complication according to guide line.

Key words: Congenital heart anomalies, Infancy period Nursing role, Mothers' care.

List of abbreviations

AS	Aortic Stenosis
ASD	Atrial Septal Defect
CHD	Congenital Heart Defect
COA	Coarctation Of the Aorta
COAs	Congenital Heart Anomalies
DORV	Double Outlet Right Ventricle
HLHS	Hypoplastic Left Heart Syndrome
MCH	Maternal and Child Health
MI	Mitral Stenosis
PA	Pulmonary Atresia

PDA	Patent Ductus Arteriosus
PS	Pulmonary Stenosis
TA	Tricuspid Atresia
TAPVC	Total Anomalous Pulmonary Venous Connection
TGA	Transposition of the Great Vessels
TOF	Tetralogy Of Fallot
VSD	Ventricular Septal Defect

INTRODUCTION

Globally, Congenital Heart Anomaly (CHA) or congenital heart defect (CHD) is a complex problem which can affect the patient, the family, the society and the country. CHAs describe a wide range of conditions resulting from abnormalities of the heart structure and/or function that is present from birth. The severities of conditions are classified as complex, moderate, and simple (Ahmed, 2014).

The cause of congenital heart anomalies is usually unknown but in individual case evidence points to a multifactorial etiology, with the insult probably occurring in the first 8 weeks of gestation. It has been associated with several teratogenic factors includes maternal medications as folic acid antagonists, anti-convulsants, estrogens, maternal infections as rubella, cytomegaloviruses, maternal diabetes mellitus, increased maternal age, genetic factors, and chromosomal abnormalities e.g., Turner, Noonan, Marfan, DiGeorge, and trisomy syndromes that are associated with specific CHDs (Jane et al., 2014)

Major complication of congenital heart defects include slowed growth and smaller than average infant height and weight, developmental delays or disabilities, heart failure which can cause a variety of symptoms, such as severe difficulty breathing or irregular heartbeats (arrhythmias), pulmonary hypertension, heart murmur, Atrial fibrillation, endocarditis, clubbing (a condition in which the ends of the fingers and toes swell and the nails bulge outward), Polycythemia (abnormal increase in the number of red blood cells) this may increase a person's risk for blood clots that can cause heart attacks or strokes (WebMD, 2014)

Parents must understand the underlying cardiac anomalies, the goals and objectives of the surgical repair. In addition to normal newborn care, parents need to learn about

nutritional support, how to safely administer prescribed medications, potential complications, and when to call their health care provider or seek emergency care. Information about infant development, challenges specific to their infant, and strategies to support normal development are important focuses of teaching to parents. Written reference materials, a web resource list, and a family discharge teaching tool provide tangible resources for the family after discharge (PYE, 2015).

Significance of study

One million babies are born worldwide with congenital heart anomalies every year. 100,000 of them will not live to see their first birthday and more thousands die before they reach adulthood. Nearly 1/100 a baby is born with CHAs. They are the first cause of birth defect related deaths, and leading cause of all infant deaths in the United States. Each year approximately 40,000 babies are born in the United States with congenital heart anomalies. Thousands of them will not reach their first birthday (Children Heart Foundation, 2014).

In developing countries, infant mortality rate remains particularly high at 61/1000 live births in Africa (including 31 countries). In Egypt epidemiology of congenital heart anomalies up to date has not been fully determined nor received the attention it warrants infant mortality rate (per 1,000 live births) in Egypt was last measured at 20 in 2015 (World Bank Group, 2016). According to Statistical Department of Pediatric Specialized Hospital at Cairo University infant mortality rate due to congenital heart anomalies was 27.61%. According to a study done at outpatient pediatric clinics of Benha University Hospital revealed that the proportion of CHA among children attended pediatric clinic was 2.14% (Sabry & Osama, 2011).

Aim of the study

The study aimed to evaluate mothers' care for their infants with

Congenital heart anomalies through:

- Assessing mothers' knowledge regarding infant CHAs.
- Assessing mothers' practices regarding caring their infant.
- Develop guideline about CHAs for mothers.

Subjects and Methods

Research design

A descriptive design was utilized in the current study.

Research setting

The study was conducted at Cardiac Outpatient Clinic at Pediatric Hospital in Cairo University Hospitals "Abo Erish Hospital"

Subjects

Convenience sample was used in this study and involved 100 mothers having infants with congenital heart anomalies from the previously mentioned setting with the following criteria less than year, free from other medical health problems, and infant's mothers should be able to read and write.

Tools of data collection

Two tools were used to collect the data

I) An interviewing questionnaire: It was developed by the investigator under supervision after reviewing related literature. It was written in Arabic language and composed of four parts to assess the following (**Appendix 1**)

Part (I): Socio-demographic characteristics of the studied sample which include

A) mother's characteristics such as age, level of education, occupation, residence, and family size, and family history

B) Infant's characteristics such as gestational age, and gender.

Part (II): It concerned with mothers' medical history, and exposure of mothers to contributing factors. Infant's medical history such as first time of discovery, clinical manifestation, type of congenital heart anomalies, place of first diagnosis, and type of prescribed treatment.

Part (III): It concerned with mothers' knowledge regarding congenital heart anomalies as meaning, type, causes, manifestation, and complication.

Scoring system of the studied mother's knowledge

Scoring system of the studied mother's knowledge was calculated for each as correct and complete knowledge was scored two while correct and incomplete was scored one, and wrong or incorrect was scored zero. The total score for all knowledge was classified as the following

- Good knowledge $\geq 75\%$
- Average knowledge $<50-75\%$
- Poor knowledge $<50\%$

Part (IV): It concerned with mother's practices regarding congenital heart anomalies through asking questions regarding infant's nutrition, hygiene, protection from infection, immunization.

Scoring system of the studied mother's practices was calculated as correct practice was scored two while correct and incomplete was scored one and wrong or incorrect was scored zero. The total score for all practice was classified as the following

- Satisfactory practice $\geq 60\%$
- Unsatisfactory practice $<60\%$

Content validity

The tools validity was done by 5 of faculties' staff nursing experts from the Community Health Nursing specialists who reviewed the tool for clarity, relevance, comprehensiveness, understanding, applicability, and easiness for administration. Minor modifications were required.

II) Physical Assessment tool (Appendix 11)

It was developed by the investigator to measure infant's physical growth as weight, length, head and chest circumference, and to evaluate health status of the studied infant's such as pulse, respiration, and blood pressure.

Ethical considerations

Oral consent was taken from each mother to participate in the study. The aim, nature, process, and expected outcomes of the study were explained. The studied mothers were informed that all the gathered data was treated confidentially, information was used only for the research, and they have the right to withdraw without giving any reason.

Preparatory Phase

Review of the past and current related literature covering the various aspects of the research problem was done by using available articles, periodicals, magazines, books, and internet to be acquainted with the research problem, develop the study tools and develop guidelines to be given to the mothers during interview by the investigator.

Pilot study

A pilot study of 10% of the studied mothers which included 10 mothers and their infant to test the content, clarity, and consistency of the tools and to determine

time needed to fill each tool. Modification needed was done included rephrasing of some questions, rearrangement of the questions, and the pilot study was excluded from the main study sample.

Field work

The actual field work was carried out for data collection at the beginning of April 2015 to the end of July, 2015. The investigator was available three days/week (Saturday, Monday, and Thursday) from 9am-1pm. The total mothers included in the study 110 mothers 10 of them were excluded in the pilot study. The mother who fulfilled the criteria was invited to participate after providing mothers with a simple and full explanation of the aim and process of the study to obtain her verbal informed consent. The mother who agreed was interviewed using the questionnaire sheet at Abo Erish Hospital. Investigator filled infant's physical assessment sheet by using monitor and measure tab. The time of interviewing each mother ranged between 30–40 minutes.

Administrative design

An official approval was obtained from the Dean of the Faculty of Nursing, Benha University to the Administrator of Abo Erish Hospital, with clear explanation about the nature, importance and expected out-comes of the study. Consent was taken from director of Cardiac Outpatient Clinic to conduct the study.

Statistical design:

The collected data was verified prior to computer entry. Statistical analysis was done by using Statistical Package for Social Science (SPSS) version 20. Data tabulated and analyzed with the suitable statistical methods by using Chi square, for number and percentage. Mean and standard deviation was used for quantitative data and the test of significance was considered.

- P value > 0.05 insignificant
- P value < 0.05 significant
- P value < 0.001 highly significant.

statistically significant differences between satisfactory and unsatisfactory level of practices $p < 0.001$.

Results

Table (1): Showed that 54% of the studied mothers their age ranged between 25-35 with mean and standard deviation 27.7 ± 6.25 and 55% were from rural area. As regards mothers' education 40% of mothers were able to read and write, while 15% were university educated.

Table (2): Showed that 57% of the studied infants were male, while 63% their ages were less than 6 months with mean and standard deviation 4.6 ± 3.5 .

Table (6): Showed that the consanguineous marriage represented 27% of the studied mothers, congenital heart anomalies were in 5% of their sibling, while 95% had not congenital heart anomalies, and regarding the medical history 90% of the studied mothers were healthy. Table (3): Showed that 87% of mothers had poor knowledge regarding manifestation of congenital heart anomalies, while 98% had poor knowledge about complication of congenital heart anomalies. 96% of studied mothers showed poor knowledge regarding side effect of prescribed drug for their infant.

Table (4): Explained that 50% of the studied mothers had satisfactory practices regarding nutrition, and 71% of the studied mothers' general total practices were satisfactory. The table showed also

Table (5): Displayed that mother's whose age ranges between 25-35 53.26% of them had poor knowledge regarding congenital heart anomalies, while 94.5% of house wife had poor knowledge. Regarding mother's education 43.4% of mothers who able to read and write had poor knowledge, and in rural area 57.6% had poor knowledge regarding CHAs. The table also showed no statistically significant difference between mother's knowledge and socio-demographic characteristics. Table (14): Displayed that mother's whose age ranged between 25-35 52.11% of them had satisfactory practices, while 94.36% of house wife had satisfactory practices. Regarding mother's education 45.07% of mothers who able read and write had satisfactory practices, and in rural area 51.72% had unsatisfactory practices. The table showed that there is no statistically significant difference between occupation, educational level, or residence, and mother's practice regarding their infant's

Table (6): Showed that there were statistically significant relation between mother's knowledge and practices $P < 0.001$.

Figure (1) showed that 58% of the studied infants were diagnosed with Ventricular Septal Defect (VSD), while Atrial Septal Defect (ASD) diagnosed in 36% of the studied infants, and only 2% was diagnosed by Tetralogy of Fallot (TOF), and Double Outlet Right Ventricle (DORV).

Table (1) Frequency distribution of studied sample related mothers' socio-demographic characteristics

Mothers' socio-demographic data	Study subject (n=100)	
	No	%
Mothers age/year		
<25	33	33.0
25-35	54	54.0
35<	13	13.0
Mean ±SD	27.7±6.25	
Residence		
urban	45	45.0
rural	55	55.0
Mother education		
Read and write	40	40.0
Primary school	7	7.0
Secondary school	38	38.0
University	15	15.0
Occupation		
House wives	94	94.0
Working	6	6.0
Family number		
<4	28	28.0
4-6	69	69.0
>6	3	3.0

Table (2) Frequency distribution of studied sample related infants' socio-demographic characteristics

Infants' socio-demographic data	Study subject (n=100)	
	No	%
Sex		
Male	57	57.0
Female	43	43.0
Age		
< 6month	63	63.0
≥ 6month	37	37.0
mean± SD	4.6± 3.5	

Table (3) Frequency distribution of studied sample related to mother's past history.

Mothers' past history	Study sample (n = 100)	
	no	%
Positive mother history of previous disease		
No		
Genetic heart disease	90	90.0
Acquired heart disease	7	7.0
Diabetes mellitus	2	2.0
	1	1.0
Consanguineous marriage	27	27.0
Presence of CHAs in sibling	5	5.0
Exposure radiation		
X-ray	1	1.0
Intravenous paleography	1	1.0
Sonar	95	95.0
MRI	2	2.0
Nothing	1	1.0
Using drug during pregnancy	2	2.0
Regular antenatal care	72	72.0

Figure (1): Distribution of studied sample regarding types of congenital heart anomalies.

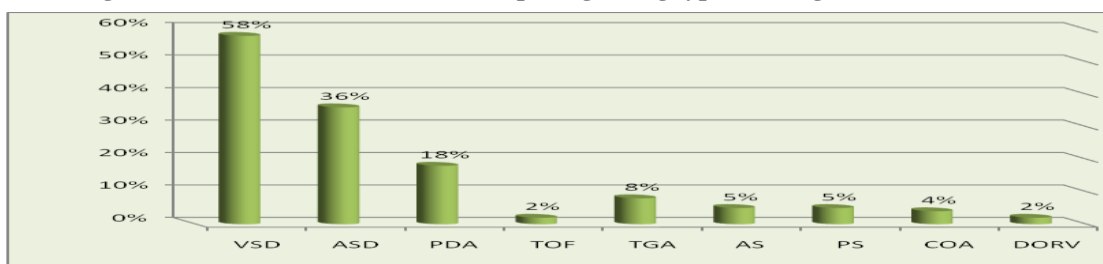


Table (4) Frequency distribution of studied infants mothers' knowledge regarding congenital heart anomalies (n=100)

mothers' knowledge	Mother's knowledge					
	Good		Average		Poor	
	No	%	no	%	no	%
meaning	6	6.0	6	6.0	88	88.0
Type	4	4.0	4	4.0	92	92.0
Causes	2	2.0	1	1.0	97	97.0
Manifestation	7	7.0	6	6.0	87	87.0
Type of precaution	3	3.0	2	2.0	95	95.0
Complication	1	1.0	1	1.0	98	98.0
Side effect of prescribed drug	2	2.0	2	2.0	96	96.0

Table (5) Frequency distribution of studied mothers' according to their practices regarding their infants with CHAs.

Total practices	Satisfactory		Unsatisfactory		Z Test	p-value
	no	%	No	%		
Nutrition	50	50.0	50	50.0	-	-
Infants' hygiene	88	88.0	12	12.0	57.76	<0.001
Protection from infection	84	84.0	16	16.0	46.24	<0.001
total practices	71	71.0	29	29.0	17.64	<0.001

Table (6) Relation between socio-demographic characteristics and mothers' total score of knowledge.

socio-demographic characteristics	mothers knowledge						x2	p-value
	Good		Average		Poor			
	No	%	No	%	No	%		
mother age								
< 25	2	66.6	0	0.0	31	33.6	4.14	>0.05
25-35	1	33.3	4	80	49	53.26		
35+	0	0.0	1	20	12	13.04		
Mother's occupation								
Working							2.68	>0.05
House wife	0	0.0	1	1.08	5	5.43		
	3	100	4	80	87	94.5		
Educational level								
Read and write	0	0.0	0	0.0	40	43.4	10.80	>0.05
Primary school	1	33.3	0	0.0	6	6.52		
Secondary school	2	66.6	3	60	33	35.8		
University	0	0.0	2	40	13	14.1		
Residence								
Urban	2	66.6	4	80	39	42.3	3.29	>0.05
Rural	1	33.3	1	20	53	57.6		

Table (6) Relation between socio-demographic characteristics and mothers' total score of practices.

socio-demographic characteristics	mothers practices				x2	value
	Satisfactory		Unsatisfactory			
	No	%	No	%		
Mother's age						
>25	26.0	36.6	7	24.1	1.69	>0.05
25-35	37.0	52.11	17	58.6		
35<	8.0	11.26	5	17.2		
Mother's occupation						
Working	3.0	4.2	2	6.8	0.70	>0.05
House wife	67.0	94.36	27	93.10		
Educational level						
Read and write					3.23	>0.05
Primary school	32		8			
Secondary school	4	45.07	3	27.5		
University	26	5.63	12	10.3		
	9	36.6	6	41.3		
		12.6		20.6		
Residence						
urban	31	43.66	14	48.27	.177	>0.05
rural	40	56.33	15	51.72		

Table (7) Correlation between total mother's knowledge and total practices regarding CHAs.

Practices	Mothers, knowledge	
	r	p-value
mothers practices	0.331	.001

Discussion

Congenital Heart Disease (CHD) is a chronic disease, the second cause of death in infancy and childhood in developed countries. Prevalence of this disease has been reported globally 5-8 in 1000 live births. Up to now, more than 35 heart disorders have been identified with Ventricular Septal Defect (VSD) being the most prevalent one (Mitra, 2014).

In most of the communities, mothers tolerate more mental pressure in taking care of the children compared to the fathers. In fact, they spend more time taking care of the children and are more responsible for making

decisions about their treatment. Mothers seem to be trapped in a chain of caring for the children with no rest. Furthermore, taking care of the infant with chronic diseases, such as CHA, has large expenditures for both the family and the society (Hockenberry, 2011).

Regarding maternal age the present study revealed that around half of the studied mothers their age ranged between 25-35 with mean and standard deviation 27.7±6. This finding goes in line with Abd El-Aziz, (2007) who revealed in her research at Mansoura university that nearly half of the studied mothers their age during pregnancy were less than forty year; the mean age found was 29.95±8.5. In addition Claire et al., (2015) who studied the maternal-age-

associated risk of congenital heart disease is modifiable and founded that maternal age is a risk factor for congenital heart disease even in the absence of any chromosomal abnormality in the newborn. **Miller, (2011)** who studied maternal age and prevalence of isolated congenital heart among residents of five central counties in Atlanta and founded that birth prevalence of isolated CHAs might be associated with advanced maternal age, especially 35 years of age or older. Infants born to mothers older than 35 years of age seemed to be at 20% increased risk of CHDs, while infants born to younger mothers tended to be at decreased risk of CHDs. This might be a result of presence of relation between maternal age and the incidence of congenital heart anomalies.

Considering the residence more than the half of the studied mothers was from rural area. This finding goes with **Tchoumi et al., (2011)** who studied occurrence and pattern of congenital heart diseases in a rural and founded that there is a high occurrence of congenital heart anomalies in a rural zone. This might be a result of living in rural areas where access to basic healthcare is already a serious issue. Despite their wealth in natural resources, rural areas in developing countries are usually the poorest regions in terms of financial resources. These regions depend entirely on the availability of public health funding to finance and support their healthcare. Most of the time these funds do not reach them or are simply not provided.

Regarding mothers education two fifth were able to read and write, while more than one third have secondary education and the minority were university educated. This finding goes with **Abd El-Aziz, (2007)** who studied Assessment of care given by the mothers for their infants with congenital heart defects and founded that more than half of the studied mothers were illiterate.

The present study showed more than half of studied infants were male with a male

to female ratio of 1.3:1, this finding agreed with " **Ankit et al., (2015)** who studied assessment of risk factors for congenital heart anomalies and founded male to female ratio was 1.5:1. In addition **Daljit et al., (2012)** who studied Gender equality in India for children with congenital heart and founded prevalence of the male to female ratio of congenital heart disease in India was 1:1

Regarding medical mother's history present study revealed that only minority of the studied mothers had diabetes mellitus (DM). This finding in line with **Gaber, (2014)** who studied one year survey for neonatal congenital heart disease in governmental hospital in north Cairo and founded that only one of studied mothers had diabetes mellitus. This finding disagreed with **Demirpençe et al., (2014)** who studied complications and congenital cardiac diseases in infants of mothers with pregestational and gestational diabetes and founded that near quarter incidence of congenital heart disease was in infants of diabetic mothers. This finding might be related to insulin effect in controlling metabolic disorder, and might be there is no relation between diabetes mellitus and congenital heart anomalies. Further studies might be required to prove the relation between diabetes mellitus and congenital heart anomalies.

The present study indicated that more than quarter had history of positive consanguinity. This finding in line with **Faheem et al., (2011)** who studied risk factors predisposing to congenital heart defects and founded that around third of the studied parents had history of positive consanguinity. In contrast to our study **Gaber, (2014)** who studied one year survey for neonatal congenital heart defects and founded percentage of positive consanguinity was around tenth. This finding might reveal that there is significant relationship between consanguinity and cardiac malformations

mean consanguinity might be a risk factor of congenital heart anomalies.

Regarding CHAs incidence in sibling, the present study revealed that the majority of them had not congenital heart anomalies. This finding agreed with **Richard et al., (2013)** who studied Spontaneous mutations play a key role in incidence of congenital heart disease and founded that many children born with heart anomalies have healthy parents and siblings, suggesting that new mutations that arise spontaneously might contribute to the disease. This finding disagreed with study done in Australia about current knowledge and inheritance of congenital heart defects by **Gillian et al., (2012)** who studied spontaneous mutations play a key role in incidence of congenital heart disease and founded that CHAs recurrence risk as high as 10% when two or more siblings are affected.

The present study revealed that only 2% of mothers take medication which means that there was non- significant statistical affection of maternal medication and incidence of congenital heart anomalies, and this agreed with **Gaber, (2014)** who revealed that there is no significant statistical affection of maternal medication as only three of the studied mothers received medications during pregnancy. According to **Patel, (2012)** who studied analysis of selected maternal exposures and non-syndromicatrio Ventricular Septal Defects in the national birth defects prevention and founded that there was no significant associations observed between AVSDs and antibacterials, antivirals, antifungals, antidepressants, asthma and/or allergy medications, gastrointestinal medications, analgesic and antipyretic medications.

The present study revealed that ventricular Septal defect (VSD) was the most type of CHAs represented more than half among studied infants; this result is in agreement with the result of surveillance study in north Cairo that recorded that VSD

was the most common CHAs (34.78%) (**Gaber, 2014**). In addition **Mitra et al., (2014)** who studied mothers of the infants with CHD in Imam Reza clinic and founded that Ventricular Septal Defect (VSD) was the most prevalent type of CHAs.

Regarding schedule of feeding more than half of the studied mothers give small frequent feeding. This finding agreed with **Marchand et al., (2004)** who studied internal nutrition in pediatric cardiology and found that more than half of care givers give infants small frequent feeding. This might be due to feeding difficulties, so small frequent feedings work better.

Concerning the some precautions followed by mothers during prepare food, mostly of the studied mothers had a satisfactory practices regarding hygiene. This agreed with (**Sharma, 2013**), who revealed that the infant with congenital heart anomalies preventing infection starts with good hygiene, good nutrition, and frequent hand washing. This finding might be a result of increasing of health awareness in the recent years.

Regarding Relation between socio-demographic characteristics and mother's knowledge there was no statistically significant difference between mother's knowledge and socio-demographic characteristics. This finding disagreed with **Bassam, (2007)** who reported that there was a statistically significant relation between maternal educational level and maternal knowledge regarding congenital heart disease. This finding might be due to both of mothers urban or rural didn't receive knowledge regarding congenital heart anomalies

Regarding relation between socio-demographic characteristics and mothers' practices there was no statistically significant difference between occupation, educational level, or residence, and mother's practice regarding their infant's. These findings

disagreed with **Abd El-Aziz, (2007)** who reported that there was a statistically significant relation between maternal educational level, occupation and maternal practice regarding their infants care.

Finally the present study showed that there was statistically significant relation between mother's knowledge and practices $P < 0.001$. This might be as the result that infant with congenital heart anomalies need special care regarding hygiene, feeding calories they need per day for keeping normal growth, healing of cardiac hole, and precaution of administration of CHAs medications for keeping normal blood pressure, slowing pulse rate, and helping the heart pump blood.

Conclusion

Based on the results finding the study concluded that;

Half of the studied mothers their age ranged between 25-35 with standard deviation 27.7 ± 6.25 and more half were from rural area. Ventricular Septal defect (VSD) was the most common type of congenital heart anomalies among studied infants. The majority of studied mothers had poor knowledge regarding congenital heart anomalies. Half of the studied mothers had unsatisfactory practices regarding nutrition, while more than three quarters had satisfactory practices regarding infants' hygiene, and more than two thirds of the studied mothers' general total practices were satisfactory. There was no statistically significant difference between occupation, educational level, or residence, and mother's practice regarding their infant's. More than two thirds of the studied mothers' general total practices were satisfactory. There was statistically significant relation between mother's knowledge and practices regarding their infants care.

Recommendations

- Health education program regarding congenital heart anomalies and importance of mother's care for their infant to prevent further complication according to guideline.
- Further research in studying the predisposing factors of congenital heart anomalies and how to avoid it.

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