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### Needs and challenges as perceived by mothers and their hospitalized children having congenital anomalies

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#### Abstract

Mothers of children with congenital anomalies (CA) have many unique challenges during the process of treatment and concern to meet the needs of their hospitalized children. **Aim:** the aim of the current study was to assess the needs and challenges as perceived by mothers and their hospitalized children having congenital anomalies.

**Design:** a descriptive exploratory research design was utilized to fit the aim of the current study. Setting: the study was conducted in the pediatric surgical ward in Cairo University Specialized Pediatric Hospital (CUSPH).

**Sample:** A purposive sample of 100 mothers and their children with congenital anomalies participated in the current study.

**Data collection tools:** data was collected using the following tools: A structured interview questionnaire, parent needs scale, children needs questionnaire and children challenges questionnaire.

**Results:** the results revealed that, higher mean score of needs for mothers and their children such as emotional support; communication with medical team, participation in child care, mothers closeness, nutrition, learning and guidance. Higher mean score of challenges for mothers and their children such as health team communication, family acceptance, social stigma, poor mothers bonding, parent stress and financial responsibility. There were statistically significant correlations between mothers' challenges and their ages, place of residence and educational level, such as knowledge about surgical management, poor mothers bonding, parent stress, stigma, financial challenges and family acceptance. There were statistical significant correlations between children needs such as learning, child and mother closeness, support and guidance with their ages.

**Conclusion:** the study findings of the current study presented higher levels of mother's needs and challenges with their children having congenital anomalies.

**Recommendation:** Empowerment programs and supportive care for mothers and their children with congenital anomalies are mandatory.

**Keywords:** Mothers, hospitalized children, congenital anomalies, needs, challenges. hanaa diab khalafallah

#### Introduction

Congenital anomalies (CA) include a wide variety of abnormalities of body structure or function that are present at birth and are of prenatal origin. These are defined as structural changes that have significant medical, social consequences on the child and family <sup>[1]</sup>.

Congenital anomalies represent a health concern in developed and developing countries. Approximately 50% of all CAs cannot be related to a definite cause <sup>[2]</sup>. The World Health Organization (WHO) 2019 declared that about 303,000 newborns and infants die yearly. In Egypt, the frequency of CA was 20/1000 live births in 2019 <sup>[3]</sup>.

The hospitalization of a child is an extremely stressful experience for both the parents and their child. The medical team and nursing staff play a significant role during the child's stay in the hospital to support him physically, psychologically, socially and emotionally <sup>[4]</sup>.

Mothers of children born with CA face serious challenges such as financial pressures. As well as the burden of providing care to a child with complex needs. Children with CA had a direct effect on child care and increased mothers stress levels <sup>[5]</sup>. Parents' ability to initiate the physical and emotional closeness is essential to development of attachment between parent and their children <sup>[6]</sup>.

Parents and their children with CA face many problems as well as multiple surgical interventions, long hospitalization periods and often uncertainty about quality of life <sup>[7]</sup>. The anomalies have an effect on a child's needs, health status, physical, or social functioning <sup>[8]</sup>.

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The expectation of parents with children with CA to have different types of emotional experiences is often similar to the loss of the child. This is often complicated by existing negative social and cultural attitudes toward children with anomalies. Parents experience several psychological, emotional, social, and economic challenges while caring for the child <sup>[9]</sup>.

Pediatric nurses should support mothers to use coping strategies to be more effective. Understanding the utilization patterns of the care given by mothers will promote in planning, design, and delivery of suitable integrated care for children with CA <sup>[10]</sup>.

Pediatric nurse's important to understanding both the needs and challenges for mothers and their children, such as quality of nursing care and child outcomes. Healthcare providers must facilitate the recovery of children and meet their needs of these families and offer adequate instructions to the parents regarding the provision of home management <sup>[11]</sup>.

## 1.2. Significant of the study

According to <sup>[12]</sup> documented that worldwide 48% of cases had musculoskeletal anomalies, 44% maxillofacial anomalies, 26% nervous system anomalies, 22% congenital heart disease, 17% gastrointestinal anomalies, and 12% genitourinary system. Also <sup>[13]</sup> reported that birth defects cause a further 170 000 deaths of children between the ages of 1 years and up to 5 years. CA can contribute to children's disability and poses significant challenges for children, families, care giver and society.

The majority 96% of children with CA continue to experience of chronic conditions and disabilities. Numerous numbers of children require comprehensive nursing care, which poses significant physical, psychological, social, and financial burdens on parents <sup>[14]</sup>.

The challenges posed by CA are huge for all parents and children. Healthcare providers should be decreasing the challenges facing mothers with their children. Government organizations have a role in helping parents improve their children's quality of life through meeting their needs according to their ages <sup>[11]</sup>.

Through empirical observations, literature review and clinical experience in the pediatric surgical ward, it was noticed that mothers and their children with congenital anomalies are exposed to challenges during process of treatment and have needs regarding different types of anomalies. A few studies have ever been done in the determination of needs and challenges for mothers with their children having CA, particularly in Egypt. The current study aimed to assess needs and challenges as perceived by mothers and their hospitalized children having congenital anomalies. Eventually, the results of the current study might generate attention and motivation for further research in the field of pediatric surgery. As well as providing guidance and recommendations that should be reflected in pediatric nursing education and practice.

## 1.3. Operational Definition

**1.3.1. Mother's needs:** Needs in the present study are things that mothers of hospitalized children should obtain from the pediatric nurse, such as physical needs, emotional needs, needs for information, need for participation in the child's care, and the needs for communication with the health team.

**1.3.2. Mothers' challenges:** Any obstacles that appears during the hospitalization period and have negatively affects on the mothers, which includes knowledge about surgical management, poor mothers, bounding, parent stress, social stigma, financial responsibility, family acceptance, home care, health team communication.

**1.3.3. Children needs:** Needs regarding children that should be obtained during hospitalization period such as physical care, nutrition, learning, child and mother closeness, emotional and psychological support, guidance and play.

**1.3.4. Children challenges:** Any obstacles that occur during the children's hospitalization period and effects on the children's health that include position, daily care, bathing, daily activities, medications, tubes and child connections and pain.

## 1.4. Aim of the Study

The aim of the current study was to assess the needs and challenges as perceived by mothers and their hospitalized children having congenital anomalies.

## 1.5. Research question

Q1. What are the needs as perceived by mothers and their hospitalized children having congenital anomalies?

Q2. What are the challenges as perceived by mothers and their hospitalized children having congenital anomalies?

## 2. Subject and Methods

### 2.1. Research design

A descriptive exploratory research design was utilized to fit the aim of the study & is one type of effective research design that is very helpful to the true experimental design <sup>[15]</sup>.

### 2.2. Setting

The study was conducted in the fourth floor in the pediatric surgical ward in the Cairo University Specialized Pediatric Hospital (CUSPH). Surgical ward received children with different congenital anomalies and undergoing to surgery.

### 2.3. Sample

Purposive sample of 100 mothers and their children with congenital anomalies was participated in the current.

### Inclusion criteria

- Children diagnosed with congenital anomalies and undergoing to surgery such as (gastrointestinal, genitourinary anomalies and orthopedic anomalies).
- School age children from 6years to12 years.
- Both genders.
- Mother's commitment of care with child in hospital for at least one week.

### Exclusion criteria

- Children with congenital heart disease and nervous system anomalies because the child admitted to Open Heart Intensive Care Unit (OHICU) and Neuro Surgical Intensive Care Unit (NSICU).

**2.4. Data collection tools:** The required data was collected through the following tools, which were developed by the researchers after extensive review of related literature

**2.4.1. Structured interview questionnaire:** It included personal data for the mother and child: it involved nine (9) questions. Four (4) questions about mothers as: age, level of education, occupation, consanguinity. Also includes five (5) questions about of child such as age, gender, residence, frequent of surgical correction, duration of hospitalization.

**2.4.2. Parent Needs Scale (PNS).** The tool was adapted from <sup>[16]</sup> it consists of 22 elements. To assess the mothers needs and challenges during time of hospitalization with their children. The questionnaire was translated from English language to Arabic language and back translation was done. The items in the questionnaire were divided into five groups of needs which included 6 elements according to their content; physical needs, emotional needs; needs for information; participation in the child's care, and need for communication with the medical team. Eight groups of challenges which included 16 elements, according to their content; Knowledge about surgical management, poor mothers bounding, parent stress, social stigma, financial responsibility, family acceptance, home care, health team communication. Also, mothers responded to the statements on a four- point Likert scale ranging from (0) not important at all, (1) slightly important, (2) moderately important, (3) important, (4) very important. The reliability analysis of the inner consistency of the PNS had a Cronbach range, a 0.91.

#### 2.4.2.1. Scoring system

The total scale scores are a summation of the 22 item scores and total scores were 88. For statistical purposes, (scores lower than 44) considered lower mothers needs and challenges, (44 and more) indicating higher mothers needs and challenges.

**2.4.3. Children Needs Questionnaire:** Developed by the researchers after extensive review of literature. It consisted of 15 elements to assess the children's needs during hospitalization. The items in the statements were divided into seven groups according to their content; physical care, nutrition, learning, child and mother closeness, emotional and psychological support guidance, and play. Children responded to the statements on a three- point Likert scale ranging from (0) not important, (1) to some extent, (2) important.

#### 2.4.3.1. Scoring system

The total scale scores are a summation of the 15 item scores and total scores were 30. For statistical purposes, (scores lower than 15) considered lower children developmental needs, (15 and more) indicating higher children developmental needs.

**2.4.5. Children Challenges Questionnaire:** Developed by the researcher after extensive review of literature. It consisted of 20 elements to assess the children's challenges during hospitalization. The items in the statements were divided into seven groups according to their content; position, daily care, bathing, daily activities, medications, tubes and child connections, and pain. Children responded to the statements on a three-point Likert scale ranging from (0) not important, (1) to some extent, (2) important.

#### 2.4.5.1. Scoring system

The total scale scores are a summation of the 20 item scores and total scores were 40. For statistical purposes, (scores lower than 20) considered lower children's challenges, (20 and more) indicating higher children's challenges.

#### 2.5. Validity and Reliability

The content of the data collection tools was submitted to five experts in the fields of pediatric nursing and pediatric surgery to test the content validity. Modifications of the tools were done according to experts' judgment on clarity of sentences, appropriateness of content and sequence of items. Reliability coefficients' alpha between questions was 81% for (tools 1,3, 4).

#### 2.6. Pilot Study

A pilot study was carried out on 10 mothers and their children to test the clarity and feasibility of questions and to estimate the time required for the interview. The mild modifications were done and the sample was excluded from the total sample.

#### 2.7. Data Collection Procedure

An official permission to carry out the study was obtained from the director of the Cairo University Specialized Pediatric Hospital (CUSPH) Permission was also obtained from the head of the surgical ward. Mothers and their children who meet the inclusion criteria were asked to participate in the study. The purpose and essence of the researchers are individually explained to mothers and their children. The researchers interviewed each mother and her child, an inpatient ward, for the purpose of gathering personal data about her as well as her child; it took 15 minutes. Hospitalized children were interviewed in the presence of their mothers or individuals as child's preference. The researchers were assessing needs and challenges for mothers and their children after at least one week from hospitalization (tools 2-3-4) it took 30- 40 minutes to assess each mother and their children. The researchers interviewed mothers to collect data once a week. Data was collected from January (2020) to July (2020).

#### 2.8. Ethical considerations

Written consent was obtained from the mothers and their children after a complete description of the purpose and nature of the study in order to obtain their acceptance as well as to gain their cooperation. The researchers informed mothers and their children that all data gathered during the study were considered confidential. The researchers also informed them about their rights to withdraw from the study at any time without giving any reason.

#### 2.9. Statistical Analysis

The collected data are tabulated and summarized. A statistical package for social studies (SPSS) version 20 was used for the statistical analysis of data. Data were computerized and analyzed using appropriate descriptive and inferential statistical tests. Qualitative data were expressed as frequency. Mean and standard deviation were used for quantitative variables. Correlation among variables was done using Pearson correlation coefficient. The level of significance at  $p < 0.05$  and  $p < 0.001$  was used as the cut of value for statistical significance.

### 3. Results

**Table 1:** Percentage Distribution of Personal Characteristics of Mothers of Children with Congenital Anomalies (n= 100).

Items	No	%
<b>Mother's age/years</b>		
> 20	22	22
20>30	43	43
30 > 40	26	26
40 and more	9	9
Mean $\pm$ SD	27.41 $\pm$ 7.76	
<b>Level of education</b>		
Didn't read or write	12	12
Primary school education	10	10
Secondary school education	42	42
University education	36	36
<b>Mother's Job</b>		
Housewife	73	73
Working mother	27	27
<b>Consanguinity</b>		
Yes	54	54
No	46	46

Table (1) clarified that more than two fifth of mothers in the study, their age ranged from 20 to less than 30 years. The mean age was 27.41 $\pm$ 7.76years. Regarding mothers' level of education, it was found that 42% of mothers had secondary

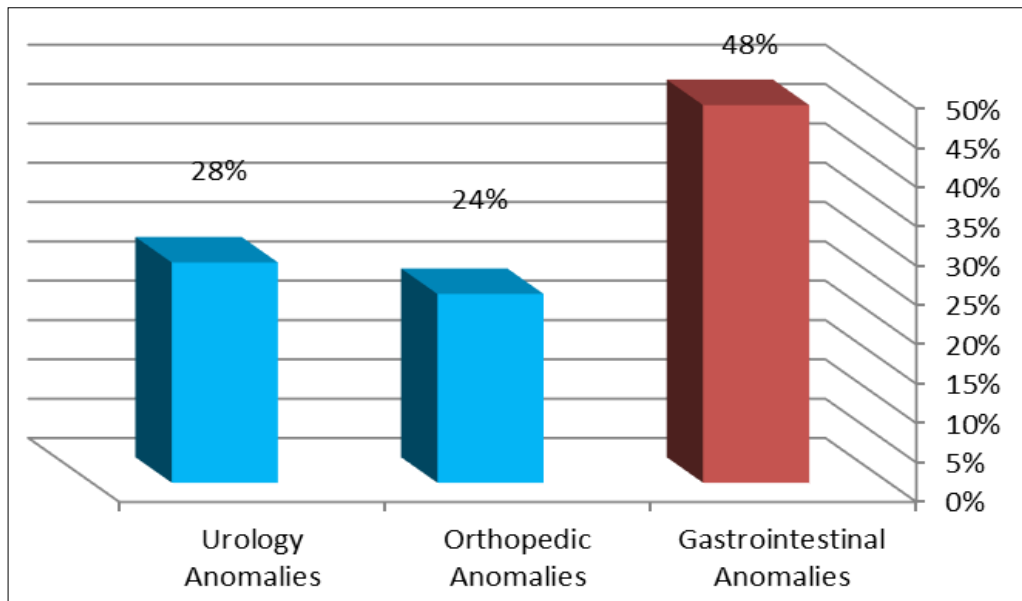
school education and 36% of them obtained university education. In relation to their occupation, it was found that 73% of mothers in the study were housewives and more than half (54%) had consanguineous marriages.

**Table 2:** Percentage Distribution of Personal Characteristics of Children with Congenital Anomalies (n= 100).

Items	No	%
<b>Child age:</b>		
6> 8years	56	56
8 > 10 years	24	24
10 : 12years	20	20
Mean $\pm$ SD	7.33 $\pm$ 3.57	
<b>Gender</b>		
Male	57	57
Female	43	43
<b>Place of residence</b>		
Urban	48	48
Rural	52	52
<b>Number of previous surgeries correction</b>		
Once	41	41
Twice	32	32
Third	27	27
<b>Hospital stay</b>		
1 week	45	45
2 weeks	33	33
3 weeks	22	22

Table (2) revealed that more than half (56%) of children their age was ranged from 6years to less than 8year, and 24% of them their age ranged from 8 years to less than 10 years. The mean age of children was 7.33 $\pm$  3.57years. More than half (57%) of the studied children were males. It was found that, 52% of children live in rural areas. The same

table reflected that 41% of children in the study had one previous surgery correction and 32% of them performed twice the surgical correction and 22% of children had three times of surgical correction. More than two fifth of studied children stay one week in hospital and 33% of them stay two weeks in hospital.



**Fig 1:** Percentage Distribution of Children Diagnosis (n= 100).

Figure (1) the current study found that less than half 48% of children in the current study had gastrointestinal CA. More than one quarter (28%) of children complained of urology CA and 24% of children had orthopedic CA.

**Table 3:** Percentage Distribution of Needs as Perceived by the mothers and Their Hospitalized Children having Congenital Anomalies (n=100).

Mothers needs	Yes		No		Mean $\pm$ SD
	No	%	No	%	
Physical comfort	91	91	9	9	1.09 $\pm$ .287
Information about CA	86	86	14	14	1.14 $\pm$ .348
Emotional support	70	70	30	30	1.31 $\pm$ .464
Participation in child care	78	78	22	22	1.22 $\pm$ .416
Communication with health team	74	74	26	26	1.26 $\pm$ .440
Children needs					
Physical care	95	95	5	5	1.05 $\pm$ .219
Nutrition	44	44	56	56	1.40 $\pm$ .492
Learning	77	77	23	23	1.23 $\pm$ .422
Child and mother closeness	57	57	43	43	1.41 $\pm$ .494
Emotional and psychological support	85	85	15	15	1.30 $\pm$ .460
Guidance	78	78	22	22	1.20 $\pm$ .413
Play	70	70	30	30	1.15 $\pm$ .358

Concerning needs as perceived by mothers, table (3) illustrates that the highest mothers' need mean score was emotional support; communication with health team, participation in child care (1.31 $\pm$ .464, 1.26 $\pm$ .440 and 1.22  $\pm$  .416 respectively). The lower mothers' need mean score was information about CA, physical comfort (1.14 $\pm$  .348 and 1.09 $\pm$ .287 respectively). The same table clarified

that; the highest children need mean score was child and mother closeness, nutrition, emotional and psychological support, learning and guidance (1.41 $\pm$ .494, 1.40 $\pm$ .492, 1.30 $\pm$ .460, 1.23 $\pm$ .422 and 1.20 $\pm$ .413 respectively). The lower children need mean score were play, physical care (1.15 $\pm$ .358 and 1.05 $\pm$ .219).

**Table 4:** Percentage Distribution of Challenges as Perceived by the mothers (n=100).

Items	Yes		No		Mean $\pm$ SD
	No	%	No	%	
Knowledge about surgical management	92	92	8	8	1.08 $\pm$ .272
Poor mothers bonding	74	74	26	26	1.26 $\pm$ .440
Parent stress	86	86	14	14	1.20 $\pm$ .368
Social stigma	68	68	32	32	1.32 $\pm$ .468
Financial responsibility	89	89	11	11	1.19 $\pm$ .314
Family acceptance	63	63	37	37	1.36 $\pm$ .482
Home care	87	87	13	13	1.13 $\pm$ .338
Health team communication	60	60	40	40	1.37 $\pm$ .485

Table (4) illustrates that the highest mothers' challenges mean score was health team communication, family acceptance, social stigma, poor mothers bonding, parent stress, and financial responsibility (1.37 $\pm$ .485, 1.36 $\pm$ .482,

1.32±.468, 1.26±.440, 1.20±.368 and 1.19±.314 respectively). The lower mothers' challenges mean score

was home care and Knowledge about surgical management (1.13±.338 and 1.08 ±.272 respectively).

**Table 5:** Percentage Distribution of Challenges as perceived by Children with CA (n=100).

Items	Yes		No		Mean ±SD
	No	%	No	%	
Position	86	86	14	14	1.14±.348
Daily care	80	80	20	20	1.20±.402
Bathing	83	83	17	17	1.17±.377
Daily activities	57	57	43	43	1.43±.497
Medications	69	69	31	31	1.31±.464
Tubes and child connections	63	63	37	37	1.37±.485
Pain	88	88	12	12	1.15±.358

Apparently, table (5) showed that the highest children challenges mean score was daily activities, tubes and child connections, medication, daily care and bathing (1.43±.497, 1.37±.485, 1.31±.464, 1.20±.402 and 1.17±.377

respectively). The lower children's challenges mean score was pain and position (1.15±.358 and 1.14±.348 respectively).

**Table 6:** Correlation between Mothers' Needs and Challenges and their Selected Personal Data

Items	Mothers' Age		Residence		Education	
	R	P	R		PR	P
<b>Mothers' needs</b>						
Emotional support	.964	.540	3.21	.076	2.67	.062
Participation in child care	.770	.804	26.58.000*		8.27	.000*
Communication with health team	1.35	.141	25.96.011*		6.85	.012*
<b>Mothers' Challenges</b>						
Knowledge about surgical management	1.74	.005*	10.19	.002*	4.36	.006*
Poor mothers bonding	1.53	.005*	6.63	.011	3.16	.028*
Parent stress	1.41	.001*	25.48	.000*	11.42	.000*
Stigma	1.73	.007*	6.09	.015	3.50	.068
Financial challenges	1.47	.056	15.15	.000*	6.58	.000*
Family acceptance	1.38	.012	1.28	.098	4.92	.003*

\* Statistically significant P < 0.05.

\* Statistically significant P < 0.01.

It is evident from table (6) that there was a statistically significant correlation between mothers' needs and place of residence and education level to participation in child care and communication with health team ( $p < 0.05$ ,  $p < 0.01$ ). There were no statistical significant correlations between mother's needs and mother's ages with emotional support, participation in child care and communication with health team. The same table revealed that there were statistical significant correlation between mothers' challenges and

their ages related, place of residence and education level to knowledge about surgical management, poor mothers bonding, parent stress, stigma, financial challenges and family acceptance at ( $p < 0.05$ ,  $p < 0.01$ ). There were no statistical significant correlations between mother's challenges and mother's ages with financial challenges, family acceptance. Also, place of residence with family acceptance, poor mothers bonding and education level with stigma.

**Table 7:** Correlation between Children Needs and Challenges with their Ages

Items	Children Age	
	r	P
<b>Children needs</b>		
<b>Learning</b>	.941	.033*
Child and mother closeness	1.367	.034*
Support and guidance	4.743	.000*
<b>Children challenges</b>		
Position	1.337	.015*
Child Care	.964	.074
Daily activates	1.190	.021*

\* Statistically significant P < 0.05.

Regarding to children needs table (7) demonstrates that there was a statistically significant correlation between children needs and their ages related to learning, child and mother closeness and support and guidance ( $p < 0.05$ ). The same table revealed that there was a statistically significant correlation between children's challenges and their ages

related to position and daily activates at ( $p < 0.05$ ). There was no statistical significant correlation between children challenges and child care.

**4. Discussion**

Concerning the personal data, it was evident from the

current study's result that more than two fifth of mothers in the study group their age ranged from 20 to less than 30 years. The same result was founded by <sup>[10]</sup> that the majority of mothers were between 26 and 35 years of age who had children with congenital anomalies. Regarding mothers' level of education, the current study found that more than two fifth of mothers had secondary school education. These results were congruent with <sup>[17]</sup> they studied 169 mothers and found that more than two thirds of mothers were low education level.

The current study revealed that it was found that more than two thirds of mothers in the study group were housewives. The same result was found by <sup>[18]</sup> they studied 70 mothers and their children with CHD and found that the majority of the mothers in the study group were housewives. As regards mothers' consanguineous, more than half of studied sample had consanguineous marriages. This result was supported with <sup>[19]</sup> they concluded that the study results proved that the highest percentage in both study and control groups had a consanguineous marriage.

In relation to children's age, according to the current study result, it was found that more than half of children their age were 6years to less than 8 years and live in rural areas. This result is congruent with <sup>[20]</sup> they studied age at diagnosis of birth defects and reported that more than two fifth of children were aged up to 3 years and more and lived in the rural areas. It could be related to mothers who live in rural areas, not following up during pregnancy and not receiving folic acid in the first three months. Regarding children's gender in the current study reported that more than half of the studied children were males <sup>[8]</sup>. They study was carried out on 100 infants and children who have congenital anomalies found that more than half were males.

Regarding hospital stays, the current study found that more than two fifth of studied children stay one week in hospital and one third of them stay two weeks in hospital. This result is congruent with <sup>[21]</sup> reports of significantly higher frequency and duration of hospital stays for children with congenital anomalies. Regarding frequent surgical correction, more than two fifth of children in the current study performed once surgical correction. This result was supported with <sup>[22]</sup> they studied seventy-nine infants and reported that the majority were referred to pediatric surgery for emergency surgical intervention and performed surgical correction. The researcher's point of view on the surgical correction stages for children with major congenital anomalies continuous through several years from child age.

Furthermore, the current study found that less than half of the children in the current study had gastrointestinal CA. Nearly one quarter of children had orthopedic CA and more than one quarter of children complained of urology CA. The results were in agreement with <sup>[23]</sup> they reported that a total of 321 cases with CA were presented. Less than one-quarter of children have GIT congenital anomalies. Regarding orthopedic and CNS anomalies found that less than one quarter of children in the study of children had developmental hip dysplasia (DHD), club foot. This result Similar to <sup>[8]</sup> they reported that less than one third of children complain from musculoskeletal anomalies.

The current result reported that the highest mother's needs for emotional support were  $1.31 \pm .464$ . This result in agreement with <sup>[24]</sup> they mentioned that, mothers of infants with birth defects are significantly different from each other in terms of psychosocial factors revealed the relationship

between inadequate perceived social Concerning mothers' needs for participation in child care had higher mean score was  $1.22 \pm .416$ . In this context <sup>[25]</sup>, reported that, mothers' mean duration of care participation increased as infants' recovery progressed at  $(15.82 \pm 8.76)$ . The researcher's point to the emotional needs importance of supporting mothers, to provide her child need and overcome all family stressors.

The current result showed that the highest child needs for mother closeness was  $1.41 \pm .494$ . The same result was founded by <sup>[26]</sup> this study demonstrated that lower in mothers attachment with infants who have congenital anomalies that cannot be cured and are liable to risk for maternal detachment. As regarding to the nutritional needs. This result supported with <sup>[27]</sup> concluded that decreased caloric intake has been shown in the majority of children with different categories of CA to be the most important cause of malnutrition in pediatric patients. It could be related to some of CA effect on child nutrition especially with GIT anomalies.

The current result concluded that the highest children's needs for emotional and psychological support, learning and guidance were  $(1.30 \pm .460, 1.23 \pm .422$  and  $1.20 \pm .413$  respectively). The results congruent with <sup>[28]</sup> and reported that children with CA needed a program to support children in coping with CA and they learned different ways of care to help themselves.

The current study revealed that mothers' challenges had higher mean score for parent stress was  $(1.20 \pm .368)$ . This result was similar to <sup>[29]</sup> they reported that all mothers had negative effects of the child's illness at birth and were overwhelmed with a particular depression, fear and stress about an unknown future. Regarding family acceptance, had higher mean score was  $1.36 \pm .482$ . In this context <sup>[30]</sup>, concluded that all mothers described having a period of depression after the child was discharged from the hospital; this changes in the mother's thoughts and feelings around the acceptance of family.

In relation to financial responsibility, the mothers' challenges had higher mean score was  $1.19 \pm .314$ . This result corresponds with <sup>[31]</sup> they concluded that the financial burden of hospital care among children with CA has an effect on all family members, specifically with number of admissions and total time spent in hospital. The researcher's point of view the financial challenges were the main element during the treatment process for children and had a negative impact on all family members

On the other hands, mothers' challenges had higher mean score for health team communication  $(1.37 \pm .485)$ . this result congruent with <sup>[32]</sup> they studied 120 mothers whose infants with CA and report that the mothers highest perceived support was respectively related to the communicational-informational with medical team and the quality of care domains of support, while the lowest perceived support was respectively related to the emotional and the self-esteem domains ( $P = 0.013$ ).

As regards mothers' challenges had higher mean score for social stigma was  $(1.32 \pm .468)$ . In a recent research study by <sup>[33]</sup> Parents' perceived knowledge and beliefs on congenital malformations that studied the majority of mothers concern the society view about the child with congenital anomalies and reported the majority of mothers concern the society view about the child with congenital anomalies is a stigma for family. It could be related to Arab society, which has a different view of the child who suffers from birth defects,

and they almost consider it a stigma in the family for them. The current study reported that the highest mothers' challenges mean score for poor mothers bonding was  $1.26 \pm .440$ . The result was in agreement with [34] and emphasis that majority of mothers have poor child bonding following after birth of a child with CA. Parents especially mothers, go through several stages of emotional reactions. The initial stages are characterized by shock, denial, sadness, and anger until adaptation that develops gaps between mothers and children.

On the other hand, mothers' challenges had higher mean score for daily activities ( $1.43 \pm .497$ ). In this context [34], they studied Challenges of congenital malformations and documented that neurological malformations of children are often dependent on their parents and caregivers for their entire lives as they may be unable to carry out basic self-care and lead to overall poor quality of life.

The results indicated that children's challenges mean score for medication, daily care and bathing was ( $1.31 \pm .464$ ,  $1.20 \pm .402$  and  $1.17 \pm .377$  respectively). This result was agreement with [35] they concluded that experiences of guilt and blame appeared in more ways. The mothers blamed themselves for their child's anomaly and kept reflecting on their behavior of daily care, medication and nutrition. The researcher's point of view child care was cornerstone for mothers and their child with CA to maintain children care in hospital and after discharge.

The current result proved that there was statistically significant correlation between mothers' needs and education level at ( $p < 0.05$ ,  $p < 0.01$ ). This result is congruent with [35] they concluded that were almost of mothers in the study had significant statistical correlation between mothers needs and level of education at  $< 0.05$ . The researcher's point of view educational background for mothers can affect on the needs arrangement to help her hospitalized child.

The current result proved that there was a statistically significant correlation between mothers' challenges and their ages, place of residence and education level ( $p < 0.05$ ,  $p < 0.01$ ). This result was congruent with [10] they found that were significant statistical correlation between mothers' age and problems developed after having a child with congenital anomalies. Majority of young mothers' complain from this challenge and them unable to facing this problem [17]. Concluded that maternal education level had correlate with birth outcomes and over coming of problem that related to anomalies.

The results indicated that there was a statistically significant correlation between children's needs and challenges with their ages ( $p < 0.05$ ). This explanation was in the same line with [36] they studied maternal age and child development and found that there were statistically significant positive correlations between child needs and their age. It could be related to child needs, fact inter-related with mothers and nurses to maintain their needs and cover all challenges for their age and gender.

## 5. Conclusion

The current study results concluded that mothers had numerous needs with their children with CA, such as needs emotional support; communication with medical team, participation in child care. Regarding mothers' challenges, the findings clarifies that mothers face some challenges like health team communication, family acceptance, social stigma, poor mothers bonding, parent

stress, and financial responsibility. While, children need such as child and mother closeness, nutrition, emotional and psychological support, learning and guidance. The findings clarifies, that children face some challenges such as daily activities, tubes and child connections, medication, daily care and bathing. The study results also concluded that, there was statistically significant correlation between mothers' challenges and their ages, place of residence and education level, and there was statistically significant correlation between children's needs and challenges with their ages. These results support the proposed study questions.

## 6. Recommendations

Based on the results of the current study, it was recommended that:

- Raising the awareness of mothers needs about caring for children with congenital anomalies through health education sessions about the nutrition, activity, treatment, and prognosis.
- Provision of simple Arabic illustrated booklets about the common congenital anomalies, nutrition, activity, treatment and prognosis should be available and distributed to mothers who had children with different congenital anomalies.
- Availability of empowerment program and supportive care for mothers and their children with congenital anomalies.
- Longitudinal study is necessary to monitor the mother's challenges and selected postoperative outcomes.

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