Stress and Coping Styles among Parents of Children undergoing Heart Surgery

Hossam Mohamed Abdallah, Ghada Mohamed Mourad², Fatma ata³

Clinical instructor of institute of Nursing1, Professor of Psychiatric/Mental Health Nursing2, and Assist Prof of Psychiatric/Mental Health Nursing 3, Faculty of Nursing Ain Shams University.

Abstract

Aim: this study aimed to assess stress and coping styles among parents of children undergoing heart surgery. A descriptive study was used. Sample: A convenient sample of 132 parents. Setting: This study was conducted at pediatric intensive care unit (PICU) and in-patient pediatric ward to open heart surgery at El-Demerdash hospital that affiliated to Ain Shams University. Tools of data collection: 1) General characteristics questionnaire containing the following parts: A) Socio-demographic characteristics and clinical data of child, B) Sociodemographic characteristics of parents; 2) Parent Stress Scale; and 3) Jalowiec Coping Scale (JCS). Results of the study: revealed that, the majority of the studied parents of children with heart surgery experienced moderate level of stress and two thirds of them had ineffective coping. Conclusion: The majority of the studied parents of children with heart surgery experienced moderate level of stress and two thirds of them had ineffective coping .also; this study concluded that there was a negative correlation between stress level and coping behaviors among the studied parents of children undergoing heart surgery. Recommendation: Applying educational interventional program for enhancement of stress and coping styles of parents of children with heart surgery.

Key words: stress, coping styles, parents, children, heart surgery.

Introduction

ongenital Heart Disease (CHD) is one of the most common types of birth defects, affecting 8 per 1000 child born globally and prevalence has increased over time. As there are many variations of CHD which sometimes occur in combination and with differing severities, prognosis and treatment may vary between individuals (Lumsden, Smith, and Wittkowski, 2019).

Congenital heart disease (CHD) is now estimated to be the second most prevalent chronic illness may have effects that pervasive consequence for family life. It can be a great burden for parents to be informed that their child is suffering from heart disease. The whole family might be affected and might undergo a stressful adjustment process, experiencing challenges such as attempting to understand the disease's effects, coping with uncertainty, and seeking reassurance from healthcare providers, experiences such as somatization, depression, anxiety, distress, hopelessness, and social isolation can also arise (Singh and Ghimire, 2017).

Parents of CHD children try to tolerate difficult conditions of care giving stress, control themselves, and behave patiently with the child and family members. Mothers attempt to resist hard feelings despite their worries about the future of their child's disease. Some parents use maladaptive (negative) coping strategies like crying to release their emotions, denying, worrying, and adopting aggressive behavior with medical staff. On the other hand, some parents use other coping strategies such as watching T.V, reading books, spending time out of home while their child was staying in cardiac intensive care unit (Dalir, Heydari, Kareshki, and Manzari, 2020).

Parents who have children born with CHD experience profound stress, from the time of diagnosis, through the infant's hospitalization for cardiac surgery, and in months and years that follow diagnosis. Survival for neonatal cardiac surgery has dramatically improved. Many children must return for additional surgeries or interventions throughout childhood, compounding the stress experience for parents (Woolf-King, Anger, Arnold, Weiss, and Teitel, 2017).

Parental stress can also affect the parent's own physical health, mental health, overall well-being, and quality of life. Furthermore, the parents of children with CHD experience more intense stress than parents of other pediatric populations, and that stress may be of particular concern when the child is less than one year of age (Vrijmoet-Wiersma, Klink, Kolk, and Koopman, 2019).

Coping is the cognitive, behavioral and emotional efforts to manage particular external and/or internal demands that are appraised as taxing or exceeding the resources of the person. Cognitive appraisal of the stress is affected by the nature of the stress, internal coping resources, and external social resources (AL-Sagarat, Barmawi, Al Hadid, 2017).

Involuntary engagement responses are characterized by intrusive or unregulated thoughts and emotions, such as rumination, physiological arousal, or emotional arousal. Involuntary disengagement responses involve uncontrolled withdrawal from stress, such as emotional numbing, cognitive withdrawal, and unregulated escape behaviors. Involuntary engagement and involuntary disengagement have been conceptualized as stress reactivity because the parents are non-deliberate or uncontrolled reactions to stress that occur in addition to voluntary efforts to cope with stressors (Nakazuru, Sato, and Nakamura, 2019).

Nurses, as social support personnel for sick children and their caregivers should provide empowerment-based health care education to parents of CHD children, improve parents 'caring knowledge and skills. Nurses should inform caregivers about the medical treatment, surgery, and nursing information, and promptly appease any anxiety and confusion. In addition, nurses should offer lectures on nursing knowledge in the ward, establish a follow-up system, and select appropriate ways to answer questions from caregivers of different educational backgrounds (Ni, Lv, Ding, and Yao, 2019).

Significance of the study:

Parents of children undergoing heart surgery are at a greater risk of developing acute stress reaction (ASR) or acute stress disorder (ASD) (16–30%) and post-traumatic stress disorder (PTSD) (15–34%) or presenting with clinically significant symptoms of trauma (32– 80%) (Woolf-King, Anger, Arnold, Weiss, Teitel, 2019).

The incidence in Egypt children has been estimated to be 5-6/1000 live births. In our studied neonates with congenital malformations, the incidence of significant cardiac malformation was found to be 37% studied children with congenital heart disease (Saleh, Salem, Abo-El fotoh, Soliman & Abo-Haded, 2020).

As a nurse observed, stress among parents of children undergoing heart surgery that increased and parents fear to lost their children so that should be followed coping style to decrease stress, anxiety, promotes adequate support to parent to adapt with the problem, maintain normal life for both parent and children, decrease psychological, physical, emotional and social stress and give hope to the patient and parents to children still survive.

Aim of the study:

The present study aimed to assess the stress and coping styles among parents of children undergoing heart surgery through:

- Assess the stress among parents of children undergoing heart surgery.
- Assess the coping styles among parents of children undergoing heart surgery.

Research question:

This study was conducted to answer the following questions:

- What are the levels of stress among parents of children undergoing heart surgery?
- What are the coping styles among parents of children undergoing heart surgery?

• What are the relationships between stress and coping styles among parents of children undergoing heart surgery?

Subject and Methods Research Design:

A descriptive design was utilized to achieve the aim of this study. Descriptive research is designed to describe a group of individual on a set of variables to document their characteristics. It provides a basis for further investigation (**Portney**, 2020).

Setting of the Study: This study was conducted in pediatric intensive care unit (PICU) and in-patient pediatric ward to open heart surgery at El-Demerdash hospital that affiliated to Ain Shams University. The PICU contains 12 beds and in-patient pediatric ward contain 20 bed divided in 8 rooms.

Subjects:

A convenient sample of 132 parents of children undergoing heart surgery was recruited in this study based on retrospective statistic, which revealed that the number of children undergoing heart surgery who admitted to the previous mentioned setting was (234) child in 2020.

Data Collection tools:

Data was collected using the following tools:-

Tool(I)-General characteristics questionnaire (appendix-...):-

This tool was developed by the researcher after reviewing of the related literatures (Said, 2006; Badry, 2008 and Simeone, et al, 2018) and it included two parts:

First part: Socio-demographic characteristics and clinical data of child.

It aimed to assess the child's age, gender, level of education, number of brother, child arrangement, previous hospital admission, duration of illness and type of surgery.

Second part: Socio-demographic characteristics of parents.

It aimed to assess the parent's age, gender, marital status, level of education, relationship between father and mother, monthly income, residence and housing condition (accommodation type, number of rooms, electricity, sanitation, ventilation and good water).

Tool (II) - Parent Stress Scale (appendix-....):

This tool was developed bv researcher after reviewing of the related literatures (Said, 2006, Smith, et al, 2017 and Ghimire, 2017). It was used to assess 4 different domains of stress (physical. psychological, social and financial stress) among parents of children undergoing heart surgery. It was composed of 67 closed ended questions divided into four subscales as following:

- Physical "19 question".
- Psychological "20 question".
- Social "21 question".
- Financial "7 question".

This scale was translated into Arabic then back translation to English to assure its accuracy.

***** Scoring system:

The parent's responses for every statement were as follows:

• No = 1

• Yes = 2

All responses of each subscale were summed up to get its total scores where the higher scores representing the high stress, they were categorized as follow:

Stress	Range	Low	Moderate	High
subscales		Stress	stress	stress
Physical	1-38	1-12	13-25	26-38
Psychological	1-40	1-13	14-26	27-40
Social	1-42	1-14	15-28	29-42
Financial	1-14	1-4	5-9	10-14

All responses of subscales were summed-up and converted into a percentage score (%).The total score was 134 scores which represent (100%). It was categorized as follow:

• Less than 50 % was considered "Low Stress".

- 50% 75% was considered "Moderate Stress".
- More than 75% was considered "High Stress".

Tool (III) - Jalowiec Coping Scale (JCS) (appendix-....):

This tool was adapted from (Original Version of JCS, 1977 and Revised Version of JCS, 1987) and modified by the researcher to assess 8 different domains of situation-specific coping behavior (Confrontive, Evasive, Optimistic, Fatalistic, Emotive, Palliative, Supportant and Self-reliant) among parents of children undergoing heart surgery.

It was composed of 60 closed ended questions divided into four subscales as following:

- Confrontive "10 question".
- Evasive "13 question".
- Optimistic "9 question".
- Fatalistic "4 question".
- Emotive "5 question".
- Palliative "7 question".
- Supportant "5 question".
- Self-reliant "7 question".

This scale was translated into Arabic then back translation to English to assure its accuracy.

Scoring system:

The parent's responses for every statement were as follows:

- Never = 1
- Rare = 2
- Sometimes =3
- Usually =4

All responses of each subscale were summed-up and converted into a percentage score (%).The total score was 240 scores which represent (100%). It was categorized as follow:

- ≤ 60 % was considered "Ineffective coping".
- > 60% was considered "Effective coping".

Tools validity and reliability: (1)Validity:

The face and content validity was done through a panel of three experts from psychiatric mental health nursing department, faculty of nursing, Ain Shams University (two professors and one assistant professors). Their opinions were regarding comprehensiveness, accuracy, clarity, relevance and appropriateness of the study tools. Modifications were done based on expert's judgment and the final form was developed.

(2)-Reliability:

Testing reliability of the proposed tools was done statistically by Cronbach's alpha test. The coefficient alpha for the tools was as follow:

- Parent Stress Scale =0.86.
- Jalowiec coping scale = 0.77.

Pilot study:

A pilot study was carried out on 10% of the sample to test clarity, applicability of the data collection tools. The subjects who were included in the pilot study were excluded from the study sample because minor modification was done after conducting the pilot study.

Field work:

A written informed consent was obtained from each participant prior to the data collection after explaining the aim of the study. Data collection started and completed within six months from the beginning of April (2021) until the end of September (2021). Data collection was done at the previous mentioned setting two days per week (Saturday and Monday) by the researcher in the morning or afternoon shift between 8.00 AM to 2.00 PM. Parent's interviewing questionnaire data were collected from the parents themselves while child's data were collected from their medical records and their parents. Each parent took about 50-60 minutes for interviewing and completing the questionnaires data as the following; General characteristics sheet took about 10 minutes. Parent Stress Scale took about 20-25 minutes and Jalowiec coping scale took about 20-25 minutes.

Ethical Considerations:

Approval to conduct the study was obtained from the ethical committee in the faculty of nursing, Ain Shams University before starting the study. The researcher explained and clarified the study aim and conducting way to the subjects before taking the consent of participation. The researcher assured maintaining anonymity and confidentiality of data of subjects included in the study. The participants were informed about their right to withdraw from the study at any time without giving any reason. The researcher clarified the objective and aim of the study to the family caregiver included in the study .the researcher assured maintaining anonymity and confidentiality of the subject data with reassurance about of the information given and that it will be used for scientific research only.

Administrative design:

Approval to carry out this study was obtained from the faculty of nursing, Ain Shams University to the medical and nursing directors of PICU and in-patient pediatric open heart surgery ward at El-Demerdash hospital that affiliated to Ain Shams University.

Statistical design:

The collected data were organized, categorized, tabulated and statistically analyzed using the statistical package for social science (SPSS) version 20 and Microsoft Excel version 2010. Quantitative data were presented as mean and standard deviation (SD) while qualitative data were expressed as frequency and percentage. Chi-square test used as a test of significance to test relations between quantitative variables as the variables were not normally distributed.

The observed differences and associations were considered as follows:

- P > 0.05 was considered non- significant (NS).
- $P \le 0.05$ was considered Significant (S) **Results:**

Table (1): revealed that; 50.0 % of the studied children were in age group Day- 3 years with mean age 5.11 ± 1.8 . Owing to gender and educational level, 59.1% of them were males and 59.1% of them were not read or write. Regarding number of brothers, it was revealed that 36.4% of them had 2 brothers. Additionally, 45.5% of the studied children were the 2nd children in their families.

Table (2): reveals that; 68.2 % of the studied parents were in age group 18 - 35 years with mean age 32.5 ± 3.68 and 59.1% of them were

females. Also, this table showed that, 90.9 % of parents were married and 54.5% of them had university education. Regarding monthly income, it was revealed that 45.5% of parents had enough monthly income and 40.9 % of them had fairly enough income.

Table (3): reveals that; 45.5 % of the studied children had been admitted to hospital 2 times. Concerning the duration of illness, this table shows that, 45.5 % of the studied children had the CHD since one year. Regarding type of surgery, it was revealed that 43.2 % of child had VSD.

Figure (1): illustrates that, regarding physical stress, 50.0% the studied parents had moderate level and 45.0% of them had low level of stress. Concerning psychological stress, 59.0% the studied parents had high level and 32.0% of them had moderate level of stress. In relation to social stress, 46.0% the studied parents had moderate level and 36.0% of them had high level of stress. Additionally, 91.0% the studied parents had high level of financial stress

Figure (2): clarifies that, 59.70% the studied parents had ineffective coping behavior while, 41.30% of them had effective coping behavior.

Table (4): shows that there was a statistical significant differences between coping behavior of parents understudy and their age, gender, marital status, educational level, residence and monthly income at P-value =0.000

Table (5): shows that there was a statistical significant differences between coping behavior of parents understudy and their marital status, educational level and residence at P-value =0.001, 0.003 and 0.36 respectively. While, there was no statistical significance differences between coping behavior of parents understudy and their age, gender and monthly income at P value = 0.262, 0.288 and 0.264 respectively.

Table (6): clarifies that there was a negative correlation between stress level and coping behavior among the studied parents of children undergoing heart surgery at P value 0.032.

Part (I): Socio-demographic characteristics of the studied subjects

Table (1): Distribution of socio-demographic characteristics_of Children undergoing heart surgery (n=132).

Socio-Demographic variables	Items	Ν	%
Child age	Day - 3 years	66	50.0
	>3-8 years	36	27.3
	More than 8 years	30	22.7
	Mean \pm SD	5.	11 ± 1.8
Child gender	Male	78	59.1
-	Female	54	40.9
Child education	Not read or write	78	59.1
	Read and write	18	13.6
	Primary school	36	27.3
Number of brothers	Nothing	42	31.8
	1	42	31.8
	2	48	36.4
Child arrangement	1	54	40.9
-	2	60	45.5
	3	18	13.6

Table (2): Distribution of socio-demographic characteristics_of parents having children undergoing heart surgery (n=132).

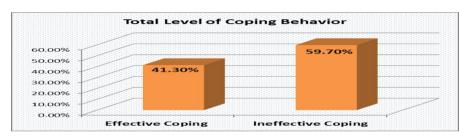
Socio-Demographic variables	Items	Ν	%
Parents age	18-35 > 35-55	90 42	68.2 31.8
	Mean \pm SD	32	5 ± 3.68
Deverteender	Male	54	40.9
Parent gender	Female	78	59.1
Marital status	Married	120	90.9
Iviaritai status	Widowed	6	4.5
	Divorced	6	4.5
	Primary	12	9.1
Parent education	Prep	24	18.2
	Secondary	24	18.2
	University	72	54.5
Relationship between father and	Yes	66	50.0
mother	No	66	50.0
Monthly income	Enough	60	45.5
	Fairly enough	54	40.9
	Not enough	18	13.6
Table (3): Distribution of clinical	data of Children undergoing hear	t surgery (n=132)).
Clinical data	Items	Ν	%
Pervious hospital admission	1	48	36.4
	2	60	45.5
	3	18	13.6
	More than 3	6	4.5
Duration of illness	From birth	30	22.7
	6 months	36	27.3

	2	60	45.5
	3	18	13.6
	More than 3	6	4.5
Duration of illness	From birth	30	22.7
	6 months	36	27.3
	1 year	60	45.5
	Others	6	4.5
Type of surgery	ASD	51	38.6
	VSD	57	43.2
	TOF	24	18.2



Part (II): Parent's stress among parents of children undergoing heart surgery

Figure (1): Comparison between total levels of stress subscales among parents of children undergoing heart surgery (n=132).



Part (III): coping behavior among parents of children undergoing heart surgery.

Figure (2): Total level of coping behavior among parents of children undergoing heart surgery (n=132).

Socio-			1	Level of tot	tal Stress				
Demographic	Items	Low	stress	Moderat	e stress	High	stress	x2	p-value
variables		Ν	%	Ν	%	Ν	%		p fuite
Age	18-35	18	100	54	81.8	18	37.5	118.1	0.000*
	>35-55	0	0	12	18.2	30	62.5	110.1	(HS)
Gender	Male	12	66.7	24	36.4	18	37.5	119.5	0.000*
	Female	6	33.3	42	63.6	30	62.5	119.5	(S)
Marital status	Married	18	100	60	90.9	42	87.5		0.000*
	Widowed	0	0	6	9.1	0	0	125.4	
	Divorced	0	0	0	0	6	12.5		(S)
Educational	Primary	0	0	6	9.1	6	12.5		
level	Prep	0	0	0	0	24	50	273.1	0.000*
	Secondary	0	0	18	27.3	6	12.5	275.1	(S)
	University	18	100	42	63.6	12	25		
Residence	Urban	18	100	42	63.6	12	25	91.6	0.000*
	Rural	0	0	24	36.4	36	75	91.0	(S)
Monthly	Enough	6	33.3	30	45.5	24	50		
income	Not enough	0	0	12	18.2	6	12.5	168.6	0.000*
	Fairly	12	66.7	24	36.4	18	37.5	108.0	(S)
	enough								

Part (IV): Relation and correlations between the studied variables among parents of children <u>undergoing heart surgery</u> Table (4): Relationship between total level of stress and parents socio-demographic data (n=132).

* P-value ≤ 0.05 Significant (S)

Socio-	Total Level of Coping Behavior						
Demographic variables	Items		ve coping =33)		ve coping =141)	x2	p-value
		Ν	%	Ν	%		
Age	18-35	42	63.6	48	72.7	1.25	0.262
	>35-55	24	36.4	18	27.3	1.23	(NS)
Gender	Male	24	36.4	30	45.5	1.12	0.288
	Female	42	63.6	36	54.5	1.12	(NS)
Marital status	Married	54	81.8	66	100		0.001*
	Widowed	6	9.1	0	0	13.20	
	Divorced	6	9.1	0	0		(S)
Educational level	Primary	12	18.2	0	0		
	Prep	12	18.2	12	18.2	14.00	0.003*
	Secondary	12	18.2	12	18.2	14.00	(S)
	University	30	45.5	42	63.6		
Residence	Urban	30	45.5	42	63.6	4 40	0.036*
	Rural	36	54.5	24	36.4	4.40	(S)
Monthly income	Enough	30	45.5	30	45.5		
-	Not enough	6	9	12	18.2	2.66	0.264
	Fairly enough	30	45.5	24	36.3		(NS)

P-value > 0.05 Non-significant (NS)., * P-value ≤ 0.05 Significant (S).

Table (6): Correlation between stress and co	ping behavior am	ong parents under study.
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Depent's veriables	Level of stress				
Parent's variables	r	P-value			
Coping pattern	- 0.707	0.032*			
* P value < 0.05 Significant					

* P-value ≤ 0.05 Significant

Discussion

Worldwide, congenital heart disease (CHD) is the most prevalent congenital disease and the second most prevalent chronic illness in children. Surgical intervention remains the mainstay treatment for CHD. Approximately, 70% of infants with CHD require surgery (Ni, 2019).

Having a child with CHD undergoing heart surgery is known as a stressful experience for parents. However, parents are the most important source of support for children with CHD, and studies have reported that parents directly influence the health of children with CHD. The psychological well-being of these children undergoing CHD surgeries is highly dependent on their parent's psychological state and coping abilities (Vainberg, Vardia and Jacoby, 2019).

Therefore, this study aimed to assess the stress and coping styles among parents of children undergoing heart surgery through answering the following research questions:

1. What are the levels of stress among parents of children undergoing heart surgery?

2. What are the coping styles among parents of children undergoing heart surgery?

3. What are the relationships between stress and coping styles among parents of children undergoing heart surgery?

The discussion of the findings covered four main parts-:

Part I: Socio-demographic characteristics of the study subjects.

Part II: Parent's stress among parents of children undergoing heart surgery.

Part III: Coping behavior among parents of children undergoing heart surgery.

Part IV: Relationships and correlation between the studied variables of the parents under study.

Part I: Socio-demographic characteristics of the study subjects.

Pertaining to child's age, the findings of the present study revealed that half of the studied children were in age group 0-3 year with mean age 5.11 ± 1.8 . This result was consistent with **Bajracharya and Shrestha**, **2016**, in a study entitled "Parental coping mechanisms in children with congenital heart disease at tertiary cardiac Centre" who found that slightly less than half of children with CHD were in age group from birth -3 years.

Also, this result was supported by **Maneekunwong**, **Srichantaranit and Thampanichawat**, **2021**, in a study entitled" Factors influencing caregivers' uncertainty of children undergoing cardiac surgery in Bangkok, Thailand" who found that three quarters of child were in age group 0-3 years.

Additionally, in the same line with this study, **Khoshhal, et al, 2019**, in a study entitled "Assessment of quality of life among parents of children with congenital heart disease using WHOQOL-BREF: a cross-sectional study from Northwest Saudi Arabia" reported that the median age of participating children was 5.2 years and mean age was 6.3 ± 4.8 years.

On the other hand, this result was inconsistent with Nakazuru, Sato and Nakamura, 2019, in a study entitled "Stress and coping in Japanese mothers whose infants required congenital heart disease surgery" who found that the mean age of children was $2.0\pm$ 0.8 years.

Related to child's gender, the findings of the present study revealed that about three fifths of the studied children were males. This result was in agreement with **Ghimire, 2017**, in a study entitled "Stress and coping among the parents of children with congenital heart disease: a hospital based Study" who found that less than three fifths of child were male.

Also, this result was consistent with Ni, et al, 2019, in a study entitled "Home care experience and nursing needs of caregivers of children undergoing congenital heart disease operations" who documented that about three fifths of child underwent cardiac surgeries were males.

This result was contradicted by Coşkuntürk and Gözen, 2018, in a study entitled "The Effect of Interactive Therapeutic Play Education Program on Anxiety Levels of Children Undergoing Cardiac Surgery and Their Mothers" who found that more than half of the participating children were girls.

Concerning to child education, the findings of the present study revealed that about three fifths of the studied child were not read or write. From the researcher point of view, this result could be attributed to that half of child under study were in age group 0- 3 years which is still not the age of learning to read and write.

Owing to number of children in family, the findings of the present study revealed that two thirds of the studied child had two brothers. This result was consistent with **Ghimire**, 2017, in a study entitled "Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study" who found that more than half of child had two siblings.

This result was in disagreement with Ni, et al, 2019; in a study entitled "Home care experience and nursing needs of caregivers of children undergoing congenital heart disease operations" who found that more than three quarters of child had no siblings (were the only child).

Concerning to child arrangement, the findings of the present study revealed that more than two fifths of the studied child were the 2nd children. This result went in the same line with Bajracharya and Shrestha, 2016, in a study entitled "Parental coping mechanisms in children with congenital heart disease at tertiary cardiac Centre" who found that half of children with CHD were the second birth order.

In relation to parent's age, the findings of the present study revealed that more than two thirds of the studied parents were in age group 18-35 years with mean age 32.5 ± 3.68 . This result was in the same line with Wei, et al, 2016, in a study entitled "Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing" who found that majority of parents were in age group 19-39 years.

Also, Maneekunwong, Srichantaranit and Thampanichawat, 2021, in a study entitled "Factors influencing caregivers' uncertainty of children undergoing cardiac surgery in Bangkok, Thailand" found that majority of parents were in age group 18-39 years.

This result was supported by **Dalir, et al, 2020,** in a study entitled "Coping with Caregiving Stress in Families of Children with Congenital Heart Disease: A Qualitative Study" who found that the mean age of participants parents was 32.48±6.47.

Related to parent's gender, the findings of the present study revealed that about three fifths of the studied parents were females. This result was consistent with Simeone, et al, 2018, in a study entitled "The lived experience of parents whose children discharged to home after cardiac surgery for congenital heart disease" who found that three quarters of participants were mothers of children who underwent cardiac surgery.

This result was supported by Maneekunwong, Srichantaranit and Thampanichawat, 2021, in a study entitled "Factors influencing caregivers' uncertainty of children undergoing cardiac surgery in Bangkok, Thailand" who found that majority of caregivers were mothers.

This result could be attributed to the fact that historically, the main role of woman is caregiving, starting with the home, children husband and other family members especially when they get sick.

Owing to parent's marital status, the findings of the present study revealed that most of the studied parents were married. This result was agreed with **Diffin**, et al, 2016, in a study entitled "Stress and distress in parents of neonates admitted to the neonatal intensive care unit for cardiac surgery" who reported that majority of participants were married.

Also, this result was consistent with **Charumathidasarathan, et al, 2018,** in a study entitled "Efficacy of CBT on Depression among Parents with Children Undergoing Complex Congenital Heart Surgery & Prolong ICU Stay" who found that more than half of the parents were married.

Concerning to parent's education, the findings of the present study revealed that about more than half of the studied parents had university education. This result was consistent with **Simeone, et al, 2018,** in a study entitled "The lived experience of parents whose children discharged to home after cardiac surgery for congenital heart disease" who found that more than two fifths of parents had university education.

This result was contradicted by Maneekunwong, Srichantaranit and Thampanichawat, 2021, in a study entitled "Factors influencing caregivers' uncertainty of children undergoing cardiac surgery in Bangkok, Thailand" who found that more than half of parents had completed their studies up to the secondary level.

Pertaining to the relationship between father and mother, the findings of the present study revealed that there was kinship between father and mother in more than half of the studied parents. This result was supported by Fazeriandy, et al, 2018, in a study entitled "Consanguinity and congenital heart disease in offspring" who reported that there was a significant association between consanguineous marriage and CHD.

Also, This result goes in the same line with **Al-Fahham and Ali, 2021**, in a study entitled "Pattern of congenital heart disease among Egyptian children: a 3-year retrospective study" who documented that consanguinity was presented in about half of parents of children with CHD.

This result was consistent with Wei, et al, 2016, in a study entitled "Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing" who found that more than half of parents had enough monthly income.

This result was supported by **Charumathidasarathan**, et al, 2018, in a study entitled "Efficacy of CBT on Depression among

Parents with Children Undergoing Complex Congenital Heart Surgery & Prolong ICU Stay" who found that the two fifths of the parents had enough income and about one third of them had middle income.

In relation to the residence, the findings of the present study revealed that more than half of the studied parents were from urban areas. This result was agreed with Elshazali, Farah and Zaki, 2020, in a study entitled "Knowledge, attitude and practice of parents' of children with congenital heart disease in a developing country" who found that about three fifths of the parents were from urban areas.

Also, this result was consistent with Al-Fahham and Ali, 2021, in a study entitled "Pattern of congenital heart disease among Egyptian children: a 3-year retrospective study" who documented that found that about more than three quarters of parents were from urban areas.

The researcher believes that urban populations have a better access to health service compared to rural population.

Regarding previous hospital admission; the findings of the present study revealed that more than two fifths of the studied children had been admitted to hospital 2 times. disagreement This result was in with Maneekunwong, Srichantaranit and Thampanichawat, 2021, in a study entitled "Factors influencing caregivers' uncertainty of children undergoing cardiac surgery in Bangkok, Thailand" who found that less than three quarters of child had no hospitalization history due to CHD complications.

Concerning the duration of illness, the findings of the present study revealed that more than two fifths of the studied children had the CHD since one year. This result was in agreement with **Ghimire, 2017**, in a study entitled "Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study" who found that more than half of child were diagnosed since 1 year of birth. Also, this result was in disagreement with **Nakazuru**, **Sato and Nakamura**, **2017**, in a study entitled "Stress and coping in Japanese mothers whose infants required congenital heart disease surgery" who found that more than two fifths of children with CHD were diagnosed just after birth.

Regarding type of surgery, the findings of the present study revealed that more than two fifths of the studied child had VSD.This result was consistent with **Pramila and Chandniin**, **2017**, a study entitled "Knowledge of Mothers Regarding Home Care of Children undergone Cardiac Surgery with a View to Develop an Information Booklet" who documented that the most common type of heart defect is a ventricular septal defect (VSD).

This result was supported by **Aguilar-Alaniz, et al, 2021,** in a study entitled " Quality of life of children and adults following cardiac surgery for congenital heart disease: A Mexican cohort" who found that majority of children had ventricular septal defect (VSD).

In the opposite direction, this result was inconsistent with **Coşkuntürk and Gözen**, **2018**, in a study entitled "The Effect of Interactive Therapeutic Play Education Program on Anxiety Levels of Children Undergoing Cardiac Surgery and Their Mothers" who found that the higher percentages (less than two fifths) of the participating children had ASD.

Part II: Stress among parents of children undergoing heart surgery.

Related to physical stress level, the findings of the present study revealed that half of the studied parents had moderate physical stress level. This result was consistent with Lisanti, Golfenshtein and Medoff-Cooper, 2017, in a study entitled "The

Pediatric Cardiac Intensive Care Unit Parental Stress Model: Refinement Using Directed Content Analysis" found that parents experienced different level of physical symptoms related to stress. Owing to psychological stress level, the findings of the present study revealed that slightly less than three fifths of the studied parents had high psychological stress level. This result was in agreement with **Bajracharya and Shrestha, 2016**, in a study entitled "Parental coping mechanisms in children with congenital heart disease at tertiary cardiac centre" who mentioned that elevated levels of psychological stress were found in the parents of children who undergo cardiac surgery.

In the same context, **Demianczyk**, etal, 2021, in a study entitled "Coping strategies used by mothers and fathers following diagnosis of congenital heart disease" documented that parents having a child with CHD are at high risk of experiencing mental health problems, including post-traumatic stress and severe psychological distress.

Concerning to social stress level, the findings of the present study revealed that more than two fifths of the studied parents had moderate social stress level. From researcher point of view, this result could be attributed to that routine parenting life is affected by the difficult nature of the child's care, including hospitalizations and conditions associated with it. Therefore, parents are restricted from doing many social activities.

Owing to financial stress level, the findings of the present study revealed that most of the studied parents had high financial stress level. This result was supported by Nayeri, et al, 2021, in a study entitled "Being parent of a child with congenital heart disease, what does it mean? A qualitative research" who mentioned that parental role for the child with CHD is associated with high level of economic stress.

This result could be attributed to that despite, more than two fifths of the studied parents had enough income, a respected proportion still had fairly enough and not enough income. In addition, a respected proportion of studied parents don't have health insurance which increase the financial demands for treatment costs. In relation to total stress level, the findings of the present study revealed that more than half of the studied parents had moderate stress level and more than one third of them had high level of stress.

This result was consistent with **Ghimire**, **2017**, in a study entitled "Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study" who found that more than two thirds of parents had moderately level of stress.

Moreover, **De Man, et al, 2021**, in a study entitled "Parental experiences of their infant's hospital admission undergoing cardiac surgery: A systematic review" documented that parents are exposed to moderate level of stress, particularly in the first weeks and months after their child's cardiac surgery.

From researcher point of view, this result could be attributed to perceived uncertainty about child's hospital care, economic consequences of child's illness, child suffering during illness, separation from the child, lack of knowledge about the future of the disease and routine family activities.

Part III: Coping behavior among parents of children undergoing heart surgery. In relation to total coping pattern, the

findings of the present study revealed that slightly less than three fifths of the studied parents had ineffective coping pattern.

Additionally, **Dalir**, et al, 2020, in a study entitled "Coping with Caregiving Stress in Families of Children with Congenital Heart Disease: A Qualitative Study " found that parents of children with CHD used maladaptive coping behavior.

Moreover, **Demianczyk**, et al, 2021, in a study entitled "Coping strategies used by mothers and fathers following diagnosis of congenital heart disease" found that parents of children with CHD utilize maladaptive coping strategies.

On the other hand, this result was contradicted by **Ghimire**, 2017, in a study

entitled "Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study" who found that more than three quarters of parents had adequate helpful level of coping.

Part IV: Relations and correlation between the studied variables of the parents under study.

This result was consistent with **Diffin, et al, 2016**, in a study entitled "Stress and distress in parents of neonates admitted to the neonatal intensive care unit for cardiac surgery" who reported that parental age was associated with level of stress in parents of infants admitted for cardiac surgery where mothers score significantly higher stress level than fathers.

This result was supported by **Smith**, et al, 2017, in a study entitled "Effect of cardiac surgery in young children with congenital heart disease on parenting stress in central South Africa: Initial outcomes" who found that parents stress was significantly related to their economic circumstances where financial strain increased levels of parenting stress.

Also, the result of this study was agreed with **Charumathidasarathan**, et al, 2018, in a study entitled "Efficacy of CBT on Depression Among Parents with Children Undergoing Complex Congenital Heart Surgery & Prolong ICU Stay" who found that there was a significant statically differences between stress level parents and their gender and marital status where mothers experience extreme stress than fathers and single parents had higher level of stress when compared to couple parents.

Additionally, this result went in the same line with **Lisanti**, **2019**, in a study entitled "Parental Stress and Resilience in Congenital Heart Disease: A New Frontier for Health Disparities Research" who documented that education level influences the stress of parents of children with CHD or undergoing surgeries where lower education was associated with an increased parental stress.

Moreover, **Rajgariah**, et al, 2021, in a study entitled "Parenting stress and coping

strategies adopted among working and nonworking mothers and its association with sociodemographic variables: A cross-sectional study" reported that there was a significant statically relation between stress level parents and their residence where parents from urban areas had high level of stress compared to them from rural.

Also, the result of this study was supported by **Swathi and Padmaja**, **2020**, in a study entitled "Assessment of Stress and Coping among Caregivers of Postoperative Cerebral Palsy Children at BIRRD Hospital, Tirupati" who reported that significant association was found between coping strategies and marital status and educational status of parents. While, non-significant association was found between coping strategies and monthly income.

In the opposite direction, this result was contradicted by **Ghimire**, **2017**, in a study entitled "Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study" who found that there wasn't any statistical association between sociodemographic characteristics of parents and stress level.

Pertaining the correlation between stress and coping behavior, the findings of the present study revealed that there was a negative correlation between stress level and coping behavior among the studied parents.

This result was consistent with **Ghimire**, **2017**, in a study entitled "Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study" who found that there was negative correlation between stress and coping where with increased level of stress, there is decreased level of coping among the parents.

Also, this result was supported by **Dalir**, et al, 2020, in a study entitled "Coping with Caregiving Stress in Families of Children with Congenital Heart Disease: A Qualitative Study" who reported that there was significant negative correlation between parents stress level and coping abilities where effective coping strategies help in reducing parents distress and improve the ability to tolerate the burden of the disease and surgery. Additionally, this result went in the same line with **Demianczyk**, et al, 2021, in a study entitled "Coping strategies used by mothers and fathers following diagnosis of congenital heart disease" who documented that higher levels of parental coping were associated with fewer symptoms of stress.

Conclusion:

The findings of the present study reached to the following conclusion:

Based on the findings of the present study, it can be concluded that slightly more one half of the studied parents experienced moderate level of stress. Regarding their coping styles, it was found that two thirds of them had ineffective coping. .also; this study concluded that there was a negative correlation between stress level and coping behaviors among the studied parents of children undergoing heart surgery.

Recommendations:

Based upon the results of the current study, the following recommendations were suggested:

For nurses:

- Development of psychosocial care protocol for dealing with children with heart surgery and their parent.
- Developing awareness programs for nurses regarding psychological and social support enable them to deal with parents of children with heart surgery to enhance their psychosocial problems.
- Applying educational interventional program for enhancement of psychological problems of parents of children with heart surgery.

For researches:

- Further study to examine the level of stress, and coping styles among parents with children has heart surgery and developing a strategy of care.
- Future research to assess factors that may influence role of parents and challenges

faced by the parents in rearing different aged children with heart surgery.

For parents with children of heart surgery:

• Providing psychosocial counseling in which psychological support for parents help them to have positive adjustment and healthy outcomes.

For community:

- Establishment of counseling clinics for parents having children with heart surgery to improve their coping patterns.
- Establishing of rehabilitation program for parents of children with congenital heart disease involving their families through multidisciplinary team for enhancing their quality of life.

References

- AL-Sagarat, A.Y., Barmawi, M., Al Hadid, L.A.E. et al. Validating the psychiatric nurses methods of coping questionnaire: Arabic version. BMC Psychiatry 17, 410 (2017). https://doi.org/10.1186/s12888-017-1573-y
- Alkan, F., Sertcelik, T., Yalın Sapmaz, S., Eser, E. & Coskun, S. (2017): Responses of mothers of children with CHD: quality of life, anxiety and depression, parental attitudes, family functionality.Cardiology in the Young, 27(9), 1748–1754.
- Al-Fahham, M. and Ali, Y. (2021): Pattern of congenital heart disease among Egyptian children: a 3-year retrospective study, The Egyptian Heart Journal, 73(1), pp.2-8.
- Aguilar-Alaniz, E., Reyes-Pavón, R., Vander Ende, J., Félix- Orta, F., Servíndla Mora, I., Aroca-Peinado, A., Polo-López, L. and Moreno-Salas, J. (2021): Quality of life of children and adults following cardiac surgery for congenital heart disease: A Mexican cohort, Journal of Archivos de Cardiología de México, 91(1), PP. 34-41.

- Bajracharya, S., & Shrestha, A. (2016). Parental coping mechanisms in children with congenital heart disease at tertiary cardiac centre. *Asian Journal of Medical Sciences*, 7(4), 75–79. https://doi.org/10.3126/ajms.v7i4.14121
- Charumathidasarathan, A., Sudhakaran, M., Sivasailam, S. and Sivasankari, V. (2018): Efficacy of CBT on Depression Among Parents with Children Undergoing Complex Congenital Heart Surgery & Prolong ICU Stay, International Journal of Advances in Science Engineering and Technology, 6(3), PP.36-41.
- **Coşkuntürk, A. and Gözen, D. (2018):** The Effect of Interactive Therapeutic Play Education Program on Anxiety Levels of Children Undergoing Cardiac Surgery and Their Mothers, Journal of Perianesthesia Nursing, 33(6), PP.781-789.
- Dalir Z., Heydari A., Kareshki H., and Manzari Z.S (2020): Coping with caregiving stress in families of children with congenital heart disease, international journal of community based nursingmidwifery, 8(2):127-139.
- De Graaf, J., Hoogenboom, M., De Roos, S. and Bucx, F. (2018): Socio-demographic Correlates of Fathers' and Mothers' Parenting Behaviors, Journal of Child and Family Studies, 27(18), PP. 2315–2327.
- De Man, M., Segers, E., Schappin, R., Leeden, K., Asperen, R., Breur, H., Weerth, C., Hoogen, A., (2021): Parental experiences of their infant's hospital admission undergoing cardiac surgery: A systematic review, Journal of Acta Paediatrica, 110(6), PP. 1730- 1740.
- Demianczyk, A., Driscoll, C., Karpyn, A., Shillingford, A., Kazak, A., Sood, E. (2021): Coping strategies used by mothers and fathers following diagnosis of congenital heart disease, Child Care Health Development Journal, 10(1), PP.1-10.

- Diffin, J., SpenceK., Naranian, T. Badawi, N. and Johnston, L. (2016): Stress and distress in parents of neonates admitted to the neonatal intensive care unit for cardiac surgery, Early Human Development Journal, 103(7), PP.101-107.
- Elshazali, O., Farah, T. and Zaki, M. (2020): Knowledge, attitude and practice of parents' of children with congenital heart disease in a developing country, Journal of Pediatrics and Neonatal Care, 10(5), PP.125-132.
- Fazeriandy, A., Ali, M., Saing, J., Tobing, T. and Adriansyah, R. (2018): Consanguinity and congenital heart disease in offspring, Journal of Paediatrica Indonesiana, 58(2), PP. 75-79.
- **Ghimire, P. (2017):** Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study, Journal of Health Education Research and Development, 5(7), PP.82-93.
- Khoshhal, S., Al-Harbi, K., Al-Mozainy, I.,
 Al-Ghamdi, S., Aselan, A., Allugmani, M.,
 Salem, S., El-Agamy D. and Abo- Haded,
 H. (2019): Assessment of quality of life among parents of children with congenital heart disease using WHOQOL-BREF: a cross-sectional study from Northwest Saudi Arabia, Journal of Health Quality Life Outcomes, 17, (183), PP. 2155-2170.
- Lisanti, A. (2019): Parental Stress and Resilience in Congenital Heart Disease: A New Frontier for Health Disparities Research, Journal of Cardiology in the Young, 28(9), PP. 1142–1150.
- Lisanti, A., Golfenshtein, N. and Medoff-Cooper, B. (2017): The Pediatric Cardiac Intensive Care Unit Parental Stress Model: Refinement Using Directed Content Analysis, Journal of Advances in Nursing Science, 40(4), PP. 319–336.
- Lumsden, M., Smith, D. M., & Wittkowski, A. (2019). Coping in parents of children

with congenital heart disease: a systematic review and metasynthesis. Journal of Child and Family Studies. <u>https://doi.org/10.1007/s10826-019-01406-8</u>

- Maneekunwong, K., Srichantaranit, A. and Thampanichawat, W. (2021): Factors influencing caregivers' uncertainty of children undergoing cardiac surgery in Bangkok, Thailand, Journal of Health Research, 4(6), PP.47-53.
- Maneekunwong, K., Srichantaranit, A. and Thampanichawat, W. (2021), "Factors influencing caregivers' uncertainty of children undergoing cardiac surgery in Bangkok, Thailand", Journal of Health Research, Vol. ahead-of-print No. ahead-ofprint. https://doi.org/10.1108/JHR-01-2021-0008
- Nakazuru, A., Sato, N. and Nakamura, N. (2019): Stress and coping in Japanese mothers whose infants required congenital heart disease surgery, International Journal of Nursing Practice 23(1), PP.12-25.
- Nayeri, N., Roddehghan, Z., Mahmoodi, F. and Mahmoodi, P. (2021): Being parent of a child with congenital heart disease, what does it mean? A qualitative research, BMC Psychology, 9(33), 260-268.
- **Pramila, P. and Chandniin, M. (2017):** Knowledge of Mothers Regarding Home Care of Children undergone Cardiac Surgery with a View to Develop an Information Booklet, The Medphoenix Journal, 2(1), PP.38-43.
- Rajgariah, R., Chandrashekarappa, S., Babua, K., Gopia, A., Ramaihaa, N. and Kumar, J. (2021): Parenting stress and coping strategies adopted among working and non-working mothers and its association with socio-demographic variables: A cross-sectional study, Journal of Clinical Epidemiology and Global Health, 9 (21), PP. 191–195.
- Saleh, N. Y., Salem, S. S., Abo-El fotoh, W. M., Soliman, S. E., & Abo-Haded, H.

M. (2020): Angiotensin-converting enzyme insertion/deletion (ACE I/D) gene polymorphism in Egyptian children with congenital heart disease. Birth Defects Research.

- Swathi, S. and Padmaja, A. (2020): Assessment of Stress and Coping among Caregivers of Postoperative Cerebral Palsy Children at BIRRD Hospital, Tirupati, Journal of Nursing and Health Science, 8(4), PP.41-50.
- Thakur, S. K., Acharya, R., Singh, S. K., & Ghimire, N. (2017). Ear diseases in school going children of Sunsari and Morang districts of Nepal. *Journal of Chitwan Medical College*, 7(1), 16–19. Retrieved from

https://www.nepjol.info/index.php/JCMC/a rticle/view/17364

- Vainberg, L., Vardi, A. and Jacoby, R (2019): The experiences of parents of children undergoing surgery for congenital heart defects; a holistic model of care, Fronteries in Psychology, 10(2666), PP.148-155.
- Wei, H., I Roscigno, C., Swanson, K., Black, B., Hudson-Barr, D. and Hanson, C. (2016): Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing, The Journal of Acute and Critical Care 45(2), PP.154-160.
- Woolf-King SE, Anger A, Arnold EA, Weiss SJ, Teitel D. Mental Health Among Parents of Children With Critical Congenital Heart Defects: A Systematic Review. Journal of the American Heart Association. 2017;622