

## Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study

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### Abstract

**Introduction:** Congenital heart defects are the most common, pervasive and serious chronic illness of all congenital malformations. The birth of a child can be stressful enough for many parents, turn into one of dashed joy and feeling of distress so there may be necessary for parents to obtain enough support from health professionals.

**Methods:** A descriptive Correlational study was conducted among 142 parents of children with Congenital Heart Disease attending Pediatric Medical Out Patient Department in Shahid Gangalal National Heart Center, Bansbari, Kathmandu. Data were collected using pre-tested structured interview schedule in Nepali version. The obtained data were analyzed by descriptive statistics (frequency, percentage, mean and standard deviation) and inferential statistics (chi-square and Karl Pearson's coefficient of correlation).

**Results:** The findings of the study revealed that near about three forth (71.8%) of parents had moderately level of stress whereas 28.2% had low level of stress and 79.6% had moderately helpful level of coping and 20.4% had minimally helpful level of coping. There was negative correlation between stress and coping ( $r=-0.076$  and  $p\text{-value}=0.367$ ) of parents. There were no any statistical association between socio-demographic characteristics of parents and stress level. Similarly, there were statistically significant association of level of coping with relationship with child, religion and occupation of parents ( $p\text{-value}$  0.004, 0.002 and 0.005) respectively.

**Conclusion:** The study concluded that with increased level of stress, there is decreased level of coping among the parents. Further, the findings suggest that health personnel must assess parenting stress at each visit to provide appropriate support and anticipatory guidance to families of children with Congenital Heart Disease.

**Keywords:** Stress; Coping; Parents; Children with congenital heart disease

### Introduction

A new baby is the beginning of wonders, hopes and dreams and becoming parents is one of life's greatest blessings. A parent's dream of giving birth to the perfect child but the birth of a child with congenital heart disease challenges those dreams. This forces families to deal with a crisis for which they may be completely unprepared. Discovering one's child has a disability causes major stress, this can disrupt the total family functioning [1].

Congenital heart disease (CHD) is now estimated to be the second most prevalent chronic illness may have effects that pervasive consequence for family life. Recently, focused on resiliency variables, especially support and coping strategy, regulating the impact of stress. In the resiliency model of family stress, adjustment and adaptation, social support is viewed as one of the primary mediators between stress and well-being [2].

India has a large population with a perceived incidence of congenital heart disease in 8 per 1000 live births in children; nearly 180,000 kids are born yearly with this problem. Of these 60,000 to 90,000 are critical and need early treatment. Nearly 10% of the infant mortality seen is due to congenital heart defects. As the number of centers capable of handling this is very few, a huge number of children are added to this pool each year of Congenital Heart Disease [3].

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. Mothers might also feel guilt and might wrongly blame themselves or they might feel frustration over not having a healthy baby. Those who have multiple children might additionally experience neglecting the healthy children [4].

Parents of children with heart disease were more likely than the normative population to report excessive parenting stress, especially related to characteristics of the child that make them difficult to parent. These parents expressed difficulty with setting limits or discipline of the child with heart disease. Parenting stress was related to the severity of the child's heart disease, family socioeconomic status, or time since most recent surgery. Clinicians must assess parenting stress at each health care visit to provide appropriate support and anticipatory guidance to families of children with heart disease [5].

The objectives of the present study were to find out the level of stress and coping, to determine the relationship between stress and coping among the parents of children with Congenital Heart Disease and to find out the association of level of stress and level of coping with selected socio demographic variables.

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## Materials and Methods

A descriptive Correlational study was conducted among 142 parents of children with Congenital Heart Disease attending Pediatric Medical Out Patient Department in Shahid Gangalal National Heart Center, (SGNHC) Bansbari, Kathmandu. Non-probability purposive sampling technique was adopted to select 142 parents as a sample for this study. Sample size was calculated at 95% confidence level and 5% confidence interval. The prevalence of children with Congenital Heart Disease (AVSD) being 10.3% [6]. The Inclusion criteria for the sample were Parents of children with the age of 6 months - 15 years having Congenital Heart Disease, who were able to speak and understand Nepali and had stayed at least for 6 months with the child as a primary caregiver. A total of 142 parents were interviewed from dated 31<sup>st</sup> January 2016 to 27<sup>th</sup> February 2016 by using pretested structured interview schedule which was developed in consultation with eleven expertise in the related field. Data were collected after getting ethical clearance from Institutional Review Committee (IRC) National Medical College and Teaching Hospital, (NMCTH) Birgunj and IRC of SGNHC, Bansbari, Kathmandu. The collected data were organized and coded and entered in Epi.data 3.1 and export to IBM Statistical Package for Social Science (SPSS 20) version and appropriate statistical tests were performed to draw the inference

## Results

The findings of the study revealed that majorities (54.2%) of the parents were father, 43.0% were mother, and the least (2.8%) were primary care-givers. Half of respondents (50%) belonged to the range of 31-40 age groups. Similarly, 58% were male and 41% female. More than half (57%) of them were Hindu, followed by Buddhist (26.8%) and others (0.7%). Likewise, 23% of the respondents were educated up to secondary level, 18.3% were educated up to higher secondary and the least 3.5% were master and above. Near about one forth (22.5%) parents were home-makers and 9.2% were Governmental officers. More than half (54.9 %) were living in Urban whereas 16.2% were living in Semi-urban. Half of the respondents (50.0%) were from nuclear family and 3.5% were from extended family. Similarly, 54.9% had three members in family and 41.5% parents had a monthly family income of NRs. 5000-15,000 monthly.

Regarding the socio-demographic of child, 28.2% belonged to the age group of 3-6 years. More than half (57.7%) were male and 42.3% were female. Among the number of siblings, 51.4% had two siblings. Likewise, the type of disease, 33.1% had Atrial Septal defect and 57% were diagnosed at the age of below 1 year. Similarly, numbers of hospitalization, 50.0% of the children were admitted 1-3 times.

Data presented in Table 1 depicts, area-wise stress among the parents, which shows that parents were having more physical stress with mean percentage score (45.25) followed by family and work stress with mean percentage score (35.8), psychological stress with mean percentage score (35.64) and financial stress with mean percentage score (26.66). Data presented in Table 2 reveals that near about three forth (71.8%) of parents had moderately level of stress whereas 28.2% had low level of stress.

Data presented in Table 3 shows the area-wise coping score among the parents, which shows that parents were having more coping on understanding the health care situation through communication with other parents and consultation with the health care team with mean percent score (41.22) followed by maintaining social support, self-esteem and psychological stability with mean percent score (35.77) and family integration, cooperation and an optimistic definition of the situation with mean percent score (33.41).

Data presented in Table 4 reveals that 79.6% had moderately helpful level of coping and 20.4% had minimally helpful level of coping among Parents of Children with Congenital Heart Disease.

Data presented in Table 5 illustrates that there is negative correlation between Stress and Coping among the parents of Children with Congenital Heart Disease with  $r=-0.076$  and  $p\text{-value}=0.367$  which was not statistically significant.

Data presented in Table 6, declaims that there was statistical positive correlation between financial stress and understanding health care situation as well as in family and work stress and total coping with  $r=0.189^*$  and  $r=0.212^*$  with  $p\text{-value}$  0.024 and 0.011 respectively. Likewise, there were statistical negative correlation between family and work stress and maintaining social support, self-esteem and psychological stability as well as in family and work stress and understanding health care situation with  $r=-0.210^*$  and  $r=-0.235^{**}$  with  $p\text{-value}$  0.012 and 0.005 respectively.

The study findings also revealed that there were no any statistical association between socio-demographic characteristics of parents and stress level. Similarly, there were statistically significant association of level of coping with relationship with child, religion and occupation of parents ( $p\text{-value}$  0.004, 0.002 and 0.005) respectively.

## Discussion

Regarding the socio-demographic characteristics of the parents of children with Congenital Heart Disease attending medical OPD of SGNHC revealed that 54.2% were father, 43.0% were mother and only 2.8% were primary care givers whose aged ranged from 31-40 years. More than half 58% were male and 41% female. Similarly, 57% of them were Hindu, followed by Buddhist (26.8%) and others (0.7%). Likewise, 23% of the parents were educated up to secondary level, 18.3% were educated up to higher secondary and the least 3.5% were master and above. Near about one forth (22.5%) parents were home-makers and 9.2% were Governmental officers. More than half (54.9 %) were living in Urban whereas 16.2% were living in Semi-urban. Half of the respondents (50.0%) were nuclear family and 3.5% were extended family. Similarly, 54.9% had three members in the family.

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Sub-scales	Mean Score $\pm$ SD	Percentage of mean Score	Range	Maximum Possible Score
Physical stress	9.05 $\pm$ 1.55	45.25	4-13	20
Psychological stress	16.04 $\pm$ 3.89	35.64	9-31	45
Family and work stress	12.53 $\pm$ 3.69	35.8	7-22	35
Financial stress	4.19 $\pm$ 1.58	26.66	3-11	15

**Table 1:** Stress score according to sub-scales among parents of children with congenital heart disease (n=142).

Level of stress	Frequency	Percentage
Moderate stress	102	71.8
Low stress	40	28.2

**Table 2:** Level of stress score among parents of children with congenital heart disease. n=142.

Area-wise Sub-scale	Mean score ± SD	Percent of mean Score	Range	Maximum possible score
Family Integration, Cooperation and an Optimistic Definition of the Situation	26.73 ± 3.13	33.41	21-40	80
Maintaining Social Support, Self –esteem and Psychological Stability	35.77 ± 3.32	35.77	29-44	100
Understanding the Health Care Situation through Communication with other Parents and Consultation with the Health Care Team	18.55 ± 1.86	41.22	13-24	45

**Table 3:** Coping score according to sub-scale among parents of children with congenital heart disease. n=142.

Level of Coping	Frequency	Percentage
Minimally helpful	29	20.4
Moderately helpful	113	79.6

**Table 4:** Level of Coping among parents of children with congenital heart disease. n=142.

Characteristics	Mean score ± SD	Correlation	p-value
Stress	41.83 ± 7.15	-0.076	0.367
Coping	81.07 ± 7.16		

**Table 5:** Correlation between stress and coping score among the parents of children with congenital heart disease. n=142.

Stress / Coping	Physical stress	Psychological stress	Family and work stress	Financial stress	Total stress
	<b>Family Integration, Cooperation and an Optimistic Definition of the Situation</b>	0.057 (0.501)	0.051 (0.548)	-0.122 (0.148)	-0.011 (0.896)
<b>Maintaining Social Support, Self –esteem and Psychological Stability</b>	-0.0017 (0.843)	0.028 (0.740)	-0.210* (0.012)	0.143 (0.089)	-0.065 (0.440)
<b>Understanding the Health Care Situation through Communication with other Parents and Consultation with the Health care Team</b>	-0.067 (0.426)	-0.073 (0.390)	-0.235** (0.005)	0.189* (0.024)	-0.134 (0.112)
<b>Total coping</b>	0.000 (0.997)	0.016 (0.846)	0.212* (0.011)	0.111 (0.189)	-0.076 (0.367)

\*Statistically Significant at the level of (p=0.05); \*\*Statistically Significant at the level of (p=0.01)

**Table 6:** Correlation between sub-scales of stress and coping among the parents of children with congenital heart disease. n=142.

Regarding level of stress, result revealed that majority of parents (71.8%) had moderate stress and 28.2% parents had low stress. This finding was supported by the study findings of Katherine, which showed moderate (58.3%), followed by high (25%) and low (16.7%) level of stress in parents of children with Congenital Heart Disease.

Regarding the level of coping, majority (79.6%) had moderately helpful level of coping and 20.4% had minimally helpful level of coping among parents of children with Congenital heart disease. Findings of the study is supported by the study conducted by Sullivan and Kathryn [7], which reported coping strategies related to maintaining family integration and an optimistic definition were significantly associated with spirituality. By being able to recognize factors associated with parental coping the medical and social support community able to better facilitate positive coping mechanisms for parents of children with CHD which was concluded that there was moderately helpful of the coping patterns.

Regarding the correlation between stress and coping, there were negative correlation between stress and coping with  $r=-0.076$  and  $p\text{-value}=0.367$ . The findings of the study were supported by the study

findings of Katherine Jo Greshik [8-19] which reported negative correlation between stresses and coping.

## Conclusion

On the basis of findings, it can be concluded that there was moderate level of stress and moderately helpful of coping pattern among the parents of children with Congenital Heart Disease and negative correlation between stress and coping. There were no association between stress and socio-demographic characteristics of parents and there was only significant association between coping and relation with child, religion and occupation of the parents. So, it is recommended that the health professionals must assess the parenting stress at each follow up to promote appropriate support, guidance and counseling to the parents of children with Congenital Heart Disease.

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