Burden of Care Among Mothers Having Children with Congenital Heart Diseases

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ABSTRACT

Introduction: Congenital Heart Disease (CHD) is a problem with structure and function of the heart that is present at birth. Children with CHD require special care, treatment and follow up for a number of common conditions which may be quite straining to the care givers. The objective of the study was to find out the burden of care among mothers having children with CHD.

Methods: This descriptive cross-sectional study was carried out in a cardiac centre of Nepal. A total of 95 mothers having children with CHD attending outpatient department of our institute were selected as the sample for the study using non-probability purposive sampling technique. A semi structured interview questionnaire consisting of the Modified Caregiver Strain Index was used to assess the burden of care among mothers having children with CHD. Frequency and percent were used to describe the variables and chi- square test at 0.05 significance level was used to analyse associations.

Results: Most (77.9%) of the mothers were regularly strained to find that their children's health condition was deteriorating due to CHD. Nearly half (44.2%) of the mothers always had financial constrain while giving care to the child, nearly half (40%) of the mothers had done emotional adjustments to take care of their children with CHD, another two-fifths (28.4%) of the mothers sometimes had disturbed sleep and almost half (46.3%) of the mothers were always upset due to some behaviour of their child with CHD. Half (50.5%) of the mothers had high level of burden of care. Statistically significant association were found between age of the mother and level of burden of care (p value = 0.05). Similarly, the type of family (p value = 0.005), age of the children (p value = 0.000) and type of CHD (p value = 0.002) were significantly associated with the level of burden of care among the mothers.

Conclusion: The study concluded that mothers tend to feel less burden of care as the child grows older, mothers having children with cyanotic heart disease tend to experience more burden of care. Mothers of less than thirty years of age and living in a joint family also experience more burden of care.

Key words: Burden of Care; Child; Congenital Heart Disease; Mothers

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INTRODUCTION

Congenital Heart Disease (CHD) is one of the commonest forms of chronic congenital anomalies in children involving the chambers, valves of the heart, blood vessels arising from the heart that causes physical, psychological, social, and financial challenges among the family members.[1,2] Caregivers of chronically ill children often have higher levels of depression and anxiety than parents of healthy children, and often experience financial and marital troubles.[3]

Caregivers experience certain problems such as somatisation, depression and anxiety, as well as distress, hopelessness, and social isolation.[4,5] They also feel guilt and wrongly blame themselves.[6] In addition to serious complications of this disease, heavy medical expenses and frequent hospitalisations impose other challenges among the caregivers.[7,8] All mothers experienced heavy burden of care for their children with CHD and faced multiple tensions and problems in care process.[9] Patient's age and CHD severity and psychosocial support seem to be related to self-assessed state of health and impairments in everyday life.[10]

Most children with CHD are diagnosed in the perinatal period or in early infancy and families must concurrently deal with the stress of a normative transition and the stress of diagnosis of a chronic illness. Caregiving demands are very high, especially in the early stages of illness. Parental psychosocial coping varies over time from diagnosis, through surgery to childhood. Common themes were evident but individuals employed their own styles and strategies based on prior experience, availability of social support, personal characteristics and belief.[11] Mothers are the primary care givers to children in most situations. The specific care giving issues in children with CHD include difficulties with nutrition and feedings and intensive medication regimens.[9] Despite the fact that CHD is the second most prevalent chronic illness in childhood little research has examined the family impact of CHD. Therefore, the objective of this study was to identify the burden of care among the mothers of children with CHD.

METHODS

This descriptive cross - sectional study was carried out to assess the burden of care among mothers having children with CHD using purposive sampling technique. The study was carried out in Paediatric OPD of the only tertiary level cardiac centre of our country, located in Bansbari, Kathmandu, Nepal. Sample size was calculated using the Cochrane formula, considering the prevalence of CHD as 54%[12] and allowable error as 10%. Thus a total of 95 mothers attending the paediatric OPD of our institute for their children with CHD, both cyanotic and acyanotic and aged six months to 10 years were included in the study. After getting approval from Institutional Review Committee, data was collected using a semi structured interview questionnaire consisting of the Modified Caregiver Strain Index (MCSI) along with a section on socio-demographic characteristics. MCSI tool containing 13 items on a rating scale was used with a maximum score of 26 and minimum of zero. It can be used to assess individuals of any age who have assumed the caregiving role for an older adult[13] and it has been used for children for first time. The level of caregiver strain increases with MCSI score. Burden of care was divided as high burden and low burden. High burden meant score equal to and more than mean score and low burden meant score less than mean score. An informed written consent was obtained from mother prior to data collection. The data was collected by interviewing mothers in a separate area of the OPD by investigators. The collected data were edited, classified, coded and entered into Statistical Package for Social Science (SPSS) version 16.00. The data was analysed by using descriptive statistics such as frequency, percentage and inferential statistic such as Chi-square test.

RESULTS

Majority (56.8%) of the mothers were of 21 - 30 years of age. Highest proportion (36.8%) of the mothers had studied up to primary level only. Highest proportion (45.3%) of the mothers had their main occupation as agriculture for their living. Majority (70.5%) of the mothers were residing in rural area. Majority (57.9%) of the mothers were

Table 1. Extent of strain experienced by the mothers in caring for their children with CHD (n = 95)

Items	Yes, Always No. (%)	Yes, Sometimes No. (%)	No No. (%)
Disturbed sleep	27 (28.4)	39 (41.1)	29 (30.5)
Care giving is inconvenient	18 (18.9)	41 (43.2)	36 (37.9)
Care giving is a physical strain	25 (26.3)	45 (47.4)	25 (26.3)
Care giving is confining	19 (20.0)	34 (35.8)	42 (44.2)
There have been family adjustments	14 (14.7)	36 (37.9)	45 (47.4)
There have been changes in personal plans	29 (30.5)	31 (32.6)	35 (36.8)
There have been other demands at the same time	19 (20.0)	31 (32.6)	45 (47.4)
There have been emotional adjustments	38 (40.0)	46 (48.4)	11 (11.6)
Some behavior of the child is upsetting	44 (46.3)	38 (40.0)	13 (13.7)
It is upsetting to find the child's health condition has changed to be worse	74 (77.9)	20 (21.1)	1 (1.1)
There have been work adjustments	15 (15.8)	42 (44.2)	38 (40.0)
Care giving is a financial strain	42 (44.2)	29 (30.5)	24 (25.3)
Overwhelmed feeling	16 (16.8)	31 (32.6)	48 (50.5)

living in nuclear families. Majority (54.7%) of the children having CHD were males, 57.3% were consecutive born children and operation was done in 31.6% children. More than one third (38.9%) children had ventricular septal defect.

Table 1 shows the extent of strain experienced by the mothers in caring for their children with CHD. Most (77.9%) of the participants always found it upsetting to see their chlild's health condition getting worse. They also experienced emotional adjustment and financial strain.

Table 2 shows that just above half (50.5%) of the mothers had high level of care burden and less than half (49.5%) mothers had low level of burden of care. Mean score is 12.72 and High burden is more or equal to 12.72 and low burden is less than 12.72.

Table 2. Mothers' level of burden (n=95)

Level of burden	Frequency	Percent
High	48	50.5
Low	47	49.5
Total	95	100

Table 3 depicts that age of the mother was significantly associated with burden of care (p value = 0.05) revealing that younger mothers of up to 30 years of age had significantly higher level of burden of care than the older mothers of above 30 years. Type of family was also significantly associated with burden of care (p value = 0.005) indicating that significantly higher proportion of mothers from joint family had higher level of burden than those from nuclear family. Remaining socio- demographic variables such as occupation of mother, religion followed, area of living and educational status of mother were not significantly associated with level of burden of care.

Table 4 shows that the age of the children with CHD was significantly associated with the level of maternal burden of care (p value = 0.000) indicating that higher proportion of mothers with younger age group children of two years or less had higher burden than that of older age group of three to 10 years. Level of burden of mothers was also significantly associated with type of CHD (p value = 0.002) revealing that mothers having children with cyanotic CHD had experienced higher burden

Table 3. Association of mothers' burden of care with their socio-demographic variables

Variables	Level of burden		p Value
	High No. (%)	Low No. (%)	
Age of mother			
Upto 30 years	33 (58.9)	23 (41.1)	0.05
More than 30 years	15 (38.5)	24 (61.5)	
Occupation			
Agriculture	23 (53.5)	20 (46.5)	0.6
Others	25 (48.1)	27 (51.9)	
Religion			
Hindu	36 (48.6)	38 (51.4)	0.492
Others	12 (57.1)	9 (42.9)	
Area of living			
Rural	36 (53.7)	31 (46.3)	0.334
Urban	12 (42.9)	16 (57.1)	
Family type			
Nuclear	21 (38.2)	34 (61.8)	0.005
Joint	27 (67.5)	13 (32.5)	
Education status			
Cannot read and write	5 (33.3)	10 (66.7)	0.147
Can read and write	43 (53.8)	37 (46.3)	

than the mothers having children with acyanotic CHD.

DISCUSSION

Regarding the extent of strain experienced, majority (77.9%) of the mothers were regularly upset to find that child's health condition getting worse due to CHD, almost half (40%) of the mothers had done emotional adjustments to take care of their children with CHD and one fourth (28.4%) of the mothers always had disturbed sleep. This finding is consistent with the findings of a study conducted in Pakistan which stated that a caregiver has responsibility to not only look after the ill individual but also to make adjustments to his/her life.[14] Another study also had similar finding that the child's disease complexity and parent's socioeconomic status was linked to higher levels of stress experienced in terms of finances, emotional drain, and family member burden. The cost experienced by parents of children with complex CHD was described as both life changing and uncertain.[7]

Table 4. Association of mothers' burden of care with socio-demographic variables of their children

Variables	Level of burden		p Value
	High	Low	
	No. (%)	No. (%)	
Age of children			
Up to two years	20 (95.2)	1 (4.8)	0.000
Thee-10 years	28 (37.8)	46 (62.2)	
Sex of child			
Male	24 (46.2)	28 (53.8)	0.349
Female	24 (55.8)	19 (44.2)	
Birth order			
First born	19 (47.5)	21 (52.5)	0.615
Consecutive born	29 (52.7)	26 (47.3)	
Type of CHD			
Acyanotic	37 (44.6)	46 (55.4)	0.002
Cyanotic	11 (91.7)	1 (8.3)	
Surgery			
Done	31 (47.7)	34 (52.3)	0.416
Not done	17 (56.7)	13 (43.3)	

Mothers in the age group of up to 30 years had significantly higher burden of care compared to mothers of above 30 years (p = 0.05). This finding is consistent with the findings of the study which stated that younger mothers faced excessive stress due to inadequate social support network, lack of adequate knowledge of child development, are developmentally immature, and possess inappropriate child-rearing attitudes.[15]

Regarding the type of CHD, almost all (91.7%) mothers whose children had cyanotic CHD had higher level of burden of care compared to 44.6% of the mothers with children having acyanotic

CHD. This finding is consistent with the study done in Cincinnati, Ohio which concluded that parents of children with cyanotic CHD are more likely than the normative population to report excessive parenting stress, especially related to characteristics of the child that make them difficult to parent.[16]

Regarding the surgical procedure, nearly half of the mothers (47.7%) whose children had undergone surgery for CHD had high level of burden whereas more than half of those (56.7%) whose children had not undergone any surgical procedure for CHD had high level of burden. There was no significant difference between maternal burden of care and surgical status of children having CHD. This result is consistent with the findings of a study done in United Kingdom, which reported that the stability of parameters of parental functioning over time suggests that the surgical interventions are of less significance than either factor attributable to the presence of chronic illness, or the individual characteristics of the parents.[17]

CONCLUSIONS

On the basis of the study findings**,** it is concluded that half of the mothers having children with CHD experienced high burden of care. Mothers of children with CHD tend to have strain of varying extent with strain experienced regularly when child's condition deteriorates due to CHD. Mothers aged thirty years or less and belonging to joint family tend to experience more burden than the older mother of above thirty years and belonging to nuclear family. Likewise, mother having younger children of up to two years with CHD and those having cyanotic CHD are likely to experience higher burden than mothers with older children and those having children with acyanotic CHD.

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