

Care Burden among Family Caregivers of Children with Cancer at Pediatric Oncology Unit of Tertiary Cancer Hospital of Nepal

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Abstract

Background: Cancer is one of the most common diseases in children, leading to major challenges for caregivers and imposing a substantial caregiving burden. This burden can lead to negative health outcomes for the parents. The chronic nature of pediatric cancer places considerable demands on caregivers, severely impacting their well-being.

Materials and Methods: A descriptive cross-sectional study design was used to assess the level of care burden among 100 family caregivers of children with cancer at pediatric oncology unit of B.P. Koirala Memorial Cancer Hospital, Chitwan, Nepal. Sample was selected through non-probability purposive sampling method and data were collected through modified Zarit Care Burden Interview Scale. Both descriptive and inferential statistics were used for data analysis with SPSS 22 version.

Findings: Findings of the study revealed that 41% of the respondents had moderate level of care burden whereas 30% had low care burden, 28% had high care burden and only 1% had no care burden. There was significant association between level of care burden with the relationship with patient (p-value= 0.031) and the economic status of the family (p-value= 0.01).

Conclusion: This study concludes that almost all of the family caregivers of children with cancer at BPKMCH had care burden. So, concerned health authorities need to provide family-centered measures and services to address caregiver burden ultimately improving their well-being and reduce the burden of caregivers.

Keywords: Care Burden, Children Cancer, Cancer Hospital, Family Care Givers

Introduction

Cancer is a global burden, with around 2,80,000 children and adolescents diagnosed with cancer, and in 2020, about 1.10,000 children died from cancer worldwide.¹ More than 300 new patients with different types of pediatric malignancies are treated each year in Nepal.² As the cancer is chronic and long-lasting in nature that may lead to chronic care burden among parents.^{3,4} Physical, psychological, social or financial reaction characterized by persistent worry, stress or negative experiences occurred while providing care is known as care burden.^{5,6} Caregivers of cancer patients experience exhaustive emotional and physiological stress while providing care and, they are prone to have various physiological and psychological health problems.^{7,8}

In Asian societies, the family members are the

caregivers of cancer children who exist at all stages from diagnosis to treatment period.^{9,10} Due to advancement of medical sciences, there has been unfortunately increased in survival rate, medical costs and psychological problems not only in patients but also to their families.¹¹ Improvement in treatment modalities has led to shifting of medical care from hospital to home which has further increased the burden to caregivers.¹²

Some parents may lose their job because of the insufficient time, lengthy treatment process and the burden of obligation. Furthermore, the parents may undergo the emotional instability, uncertainty and tension because of cancer in their children.¹³ Providing care is a difficult situation for caregivers and it is especially occurred when caregivers are not properly addressed.¹⁴ The incidence of pediatric

malignancies is in growing trend as per different research studies carried out in different parts of the world, which eventually results growing burden among caregivers of cancer children. Despite being the emerging issue very limited study has been carried out regarding care burden of family caregivers. Therefore, the researcher was attentive in conducting a study to explore this aspect furthermore.

Materials and Methods

A cross-sectional study design was used to assess the level of care burden among family caregivers of children with cancer at pediatric oncology unit of B.P. Koirala Memorial Cancer Hospital. A total of 100 respondents were selected through non-probability purposive sampling method. Family caregivers who have been providing care to the children with cancer for a duration exceeding 3 months were included for the study. A well-structured interview guide was prepared with the help of Zarit Care Burden Interview Scale¹⁵ to measure the family care burden. Level of family care burden was measured by using well-structured interview guide by 5 - point Likert Scale prepared with the help of Zarit Care Burden Interview Scale.¹⁵ The modified scale was initially created in English and later translated into Nepali version after that it was used as a research instrument to measure the level of family care burden.

Before data collection, ethical approval was obtained from BPKMCH, Institutional Review Committee (IRC) and administrative approval was taken from concerned authority of BPKMCH. Written informed consent was obtained from all participants, outlining the study objectives. Privacy was maintained through secure data storage and the obtained data was used for the research purposes only. Anonymity of the participants was maintained by giving the code number. Collected data was analyzed by using Statistical Package for Social Science (SPSS) version 22 and interpreted by using descriptive statistics in terms of mean, frequency and percentage and presented in different tables. Inferential statistics, Chi square test was used to find the association between level of care burden with selected socio-demographic variables. P-value <0.05 was considered statistically significant.

Findings

Mean age of caregivers was 34.60 and majority (60%) were female. Most of the respondents (79%) were

Hindu. Furthermore, 32% were Janajati followed by Brahmin/Chhetri (23%), Madhesi and Dalit (21%) respectively. Similarly, more than half (51%) had nuclear family, 44% had secondary education, basic education (25%), no education (23%). Furthermore, more than half (53%) of caregivers were mother and majority (63%) of respondents reported that their financial situation was not adequate for less than 1 year (Table 1).

Table 1: Socio-demographic Characteristics of the Respondents: Age, Sex, Religion, Ethnicity, Family Type, Educational Status, Relationship with Patient, Economic Status of the Family(n=100)

Variables	Frequency	Percentage
Age (year)		
15-25	17	17
25-35	40	40
35-45	27	27
45-55	9	9
55-65	5	5
65-75	2	2
Mean±SD	34.60 ±10.972	
Min (Max)	18(72)	
Sex		
Male	40	40
Female	60	60
Religion		
Hindu	79	79
Buddhist	6	6
Muslim	11	11
Christian	4	4
Ethnicity		
Brahmin/ Chhetri	23	23
Dalit	11	11
Janajati	32	32
Madhesi	21	21
Muslim	11	11
Others	2	2
Family type		
Nuclear family	51	51
Joint family	49	49
Educational status		
No education	23	23
Basic education	25	25
Secondary education	44	44
More than secondary	8	8
Relationship with child		
Grand father	5	5
Grand mother	3	3
Father	28	28
Mother	53	53

Variables	Frequency	Percentage
Siblings	4	4
Others	7	7
Economic status of the family		
Not adequate for less than 1 year	63	63
Adequate for 1 year	34	34
Adequate for more than 1 year	3	3

Table 2 reveals that among 100 family members, majority (62%) reported always feeling stressed while balancing childcare and other responsibilities. When it comes to feeling embarrassed due to the child's condition, 58% never felt embarrassed and 6% always felt embarrassed. Likewise, majority (79%) caregivers never felt angry while being around the child. In terms of the child's condition affecting relationships, 43% reported never and 12% reported rarely. Regarding unable to take care of their child much longer, 43% reported never, 21% reported sometimes. Likewise, concerning the feeling strained while being around the child, majority (60%) reported always and in terms of the health suffering due to involvement with the child 34% reported never followed by sometimes (26%) and rarely (9%) respectively. Furthermore, regarding feeling about afraid of child's future, most of them (82%) reported always feeling afraid.

Table 2: Information related to Care Burden (n=100)

Statement	Never	Rarely	Sometimes	Often	Always
Stressed balancing child care and other responsibilities	9 (9.0)	3 (3.0)	13 (13.0)	13 (13.0)	62 (62.0)
Embarrassed by child's condition and behavior	58 (58.0)	8 (8.0)	10 (10.0)	18 (18.0)	6 (6.0)
Angry when around child	79 (79.0)	11 (11.0)	8 (8.0)	2 (2.0)	0 (0.0)
Child's condition negatively affecting relationships	43 (43.0)	12 (12.0)	16 (16.0)	16 (16.0)	13 (13.0)
Unable to take care of child much longer	43 (43.0)	9 (9.0)	21 (21.0)	15 (15.0)	12 (12.0)
Strained while being around child	12 (12.0)	7 (7.0)	9 (9.0)	12 (12.0)	60 (60.0)
Health suffered due to involvement with child	34 (34.0)	9 (9.0)	26 (26.0)	20 (20.0)	11 (11.0)
Afraid of child's future	0 (0.0)	2 (2.0)	1 (1.0)	15 (15.0)	82 (82.0)

Table 3 illustrates 38% reported never lacking privacy due to childcare involvement and the least (6%) reported always lacking privacy. Regarding the impact on social life due to childcare responsibilities, more than one-quarter (28%) reported never experiencing a negative impact and (11% reported

rarely experiencing it. Likewise, concerning the feeling of uncomfortable having friends over because of child, nearly half (47%) reported never and 12% reported often feeling uncomfortable. In terms of losing control of their lives since their child's illness, one-quarter (25%) reported sometimes feeling this way and the least (9%) rarely felt it. Regarding the desire for someone else to care for their child, most of them (89%) reported never and the least (2%) reported sometimes. In terms of uncertainty about what to do for their child, 43% reported sometimes and the least (4%) reported never and rarely. Regarding feeling of they should do more for child, majority (84%) reported always, 12% reported often and 3% reported sometimes. Likewise, regarding they could do better for child caring, majority (86%) reported always, 11% reported often.

Table 3: Information related to Care Burden (n=100)

Statement	Never	Rarely	Sometimes	Often	Always
Lacking privacy due to childcare involvement	38(38.0)	17(17.0)	29(29.0)	10(10.0)	6(6.0)
Social life has suffered due to childcare	28(28.0)	11(11.0)	22(22.0)	19(19.0)	20(20.0)
Uncomfortable having friends over because of child	47(47.0)	13(13.0)	14(14.0)	12(12.0)	14(14.0)
Lost control of life since child's illness	21(21.0)	9(9.0)	25(25.0)	21(21.0)	24(24.0)
Want someone else to care for child	89(89.0)	3(3.0)	2(2.0)	3(3.0)	3(3.0)
Uncertain about what to do for child	4(4.0)	4(4.0)	43(43.0)	31(31.0)	18(18.0)
Feel should do more for child	0(0.0)	1(1.0)	3(3.0)	12(12.0)	84(84.0)
Feel could do better caring for child	1(1.0)	2(2.0)	0(0.0)	11(11.0)	86(86.0)

Table 4 presents that the among 100 family members, majority of them (61%) reported never feeling burdened overall and the least (6%) reported sometimes felt burdened. Regarding the perception of caring child more than needed, the majority (74%) reported always and the least (2%) reported rarely. In terms of not having enough time for themselves, 31% reported always and same percent (31%) reported never feeling this way and 8% reported rarely.

Concerning the overall burden of childcare, the majority (63%) reported always and the least (3%) who sometimes felt burdened. Regarding the statement of they feel they were the only one their child could depend on, most of them (64%)

reported always and 4% reported rarely. Regarding the concern of not having enough money to care for their child, majority of them (62%) reported always and 7%) reported rarely not having enough money.

Table 4: Information related to Care Burden (n=100)

Statement	Never	Rarely	Sometimes	Often	Always
Overall, how burdened do you feel in caring for child	61(61.0)	7(7.0)	6(6.0)	12(12.0)	14(14.0)
Feeling of caring for child more than needed	5(5.0)	2(2.0)	4(4.0)	15(15.0)	74(74.0)
Do not have enough time for yourself	31(31.0)	8(8.0)	16(16.0)	14(14.0)	31(31.0)
Feeling of overall burden of childcare	14(14.0)	5(5.0)	3(3.0)	15(15.0)	63(63.0)
Feel you are the only one the child could depend on	10(10.0)	4(4.0)	10(10.0)	12(12.0)	64(64.0)
Do not have enough money to care for child	14(14.0)	7(7.0)	8(8.0)	9(9.0)	62(62.0)

Table 5 shows the level of care burden experienced by family caregivers of children with cancer where, less than half (41%) had a moderate level of care burden, followed by low care burden (30%) and high care burden (28%) respectively. Moreover, the least (1%) had no care burden.

Table 5: Level of Care Burden

Level of Care Burden	Frequency	Percentage
No care burden	1	1
Low care burden	30	30
Moderate care burden	41	41
High care burden	28	28

Statistical analysis of table 6 revealed a significant association between level of care burden and socio-demographic variables: the relationship with patient (p-value=0.031), economic status of family (p-value= 0.01) but no significant association was found with family type (p-value=0.358), educational status (p-value=0.429,) and duration of illness (p-value= 0.555).

Table 6: Association between level of care burden with socio-demographic variables (n=100)

Socio-demographic variables	Level of care burden				Chi-square	p-value
	No care burden	Low care burden	Moderate care burden	High care burden		
Family type						
Nuclear family	1(2.0%)	13(25.5%)	24(47.1%)	13(25.5%)		
Joint family		17(34.7%)	17(34.7%)	15(30.6%)	3.225	0.358*
Educational status						

Socio-demographic variables	Level of care burden				Chi-square	p-value
	No care burden	Low care burden	Moderate care burden	High care burden		
No education		3(13.0)	9(39.1%)	11(47.8%)		
Basic education		8(32.0%)	11(44.0%)	6(24.0%)	9.093	0.429*
Secondary education	1(2.3%)	16(36.4%)	18(40.9%)	9(20.5%)		
More than secondary education		3(37.5%)	3(37.5%)	2(25.0%)		
Relationship with patient						
Grand father		2(40.0%)		3(60.0%)		
Grand mother			3(100.0%)			
Father	1(3.6%)	9(32.1%)	13(46.4%)	5(17.9%)	26.789	0.031*
Mother		15(28.31%)	23(43.4%)	15(28.3%)		
Siblings		2(50.0%)	2(50.0%)			
Others		2(28.6%)		5(71.4%)		
Economic status of family						
Adequate for 1 year	1(2.9%)	16(47.1%)	13(38.2%)	4(11.8%)		
Not adequate for more than 1 year		12(19.0%)	27(42.9%)	24(38.1%)	16.86	0.01*
Adequate for more than 1 year		2(66.7%)	1(33.3%)			

* Likelihood Ratio

*Level of Significance p=0.05

Discussion:

In this study regarding the statement on “feeling stressed balancing childcare with other responsibilities”, the majority (62%) reported always, 13% reported often and sometimes, 9% reported never. These findings are supported by the study of Kuscu et al. in Turkey⁷ which focused that caregivers of cancer patients face extreme emotional and physical stress during the caregiving process, leading to increased risk for both physical and mental problems. Regarding the “feeling of embarrassed due to the child’s condition”, 58% reported never and 6% reported always felt embarrassed. Likewise, majority (79%) of caregivers never felt angry while being around the child. In terms of the child’s condition affecting relationships, 43% reported never and 12% reported rarely. These findings are contrary with the study conducted in Croatia¹⁶ where high embarrassment was associated with fewer years of caregiver education (P=0.009), spending more hours of caring per week (P=0.009) and higher score on frustration was associated with more neuro-psychiatric symptoms.

Regarding the statement on “child’s condition negatively affecting relationships”43% of respondents reported never, followed by sometimes and often (16%), always (13%) and rarely (12%)

respectively. This finding is supported by the study conducted in Izmir where respondents reported diminished social relations and stress due to child's condition.¹⁷ Regarding the statement on "health suffered due to involvement with child" 34% reported never, 26% reported sometimes, 20% reported often, 11% reported always and 9% reported rarely. This finding is supported by the study conducted in Brazil in 2023 where 51.7% reported never and 18.3% reported always to the statement.¹⁸

Concerning the feeling of "strained while being around child", majority (60%) reported always followed by often (12%), sometimes (9%) and rarely (7%) respectively. Likewise, in relation to the burden of afraid of child's future, the majority (82%) reported always, 15% reported often, 2% reported rarely. Similarly, 38% reported never lacking privacy due to childcare involvement and the least (6%) reported always lacking privacy. The study of Rego Filho et al. conducted in 2023 revealed that 85% of the respondents reported never feeling strained and 10% sometimes felt strained while being around child.¹⁸ In present study, 38.3% respondents reported always feeling of afraid of child's future and 18.3% reported sometimes lacking privacy due to child care involvement. Regarding the impact on social life due to childcare responsibilities, more than one-quarter (28%) reported never experiencing a negative impact and (11% reported rarely experiencing it. This finding is consistent with the qualitative study conducted in Izmir where mothers did not engage in their previous social activities and reported that their social relations has diminished.¹⁷

Regarding the burden of "uncomfortable having friends over because of child", less than half (47%) reported never, followed by sometimes and always (14%), rarely (13%) and often (12%) respectively. In terms of losing control of their lives since their child's illness, one-quarter (25%) reported sometimes feeling this way and the least (9%) rarely. Likewise, regarding the statement on "want someone else to care for child", majority (89%) reported never, 3% reported rarely, often, always feeling it and 2% reported sometimes feeling it. Similarly, regarding the statement on "uncertain about what to do for child". 43% reported sometimes, followed by often 31%, always 18% and 4% reported never and rarely respectively. Similarly, regarding the statement on "feel should do more for child", majority (84%) reported always, 12% reported often, 3% reported

sometimes. Moreover, in relation to the statement on feel could do better caring for child, majority (86%) reported always, 11% reported often, 2% reported rarely feeling it. In the study of Brazil conducted in 2023 showed 85% of the respondents never felt uncomfortable having visitors at home, 68.4% reported never, 13.3% reported a few times regarding the feeling of losing control of their lives since their child's illness. This study of Brazil also showed that 58.4% reported never and 3.3% reported rarely on the statement of want someone else to care for child, 53.4% reported never feeling of uncertain about what to do for child, 48.3% reported always feeling of doing more for their child, and 36.7% reported always feeling of they could do better caring for their child.¹⁸

Concerning the statement on "overall, how burdened do you feel in caring for child", the majority (63%) reported always and 3% reported sometimes felt burdened. Regarding the statement of they feel they were the only one their child could depend on, most of them (64%) reported always and 4% reported rarely. The study of Rego Filho et al. revealed that 41.7% children asked for care more than needed, 43.4% reported always feeling not having enough time for themselves and 90% reported always feeling overall burden and 53.3% reported always feeling they are the only one for child's dependency for care.¹⁸

Regarding the concern of "not having enough money to care for their child", majority of them (62%) reported always and 7% reported rarely not having enough money. This finding is consistent with the finding of the study conducted by Mishra et al. in 2023¹⁹ where, more than half (55.2%) of the mothers were always financially stressed by caregiving tasks. In relation to the level of burden, 41% of the respondents had moderate level of care burden whereas 30% had low care burden, 28% had high care burden and only 1% had no care burden. The study of Sezek et al. revealed caregivers with moderate burden (46%).²⁰ Similarly, the study of Chaghazardi et al. conducted in 2022²¹ showed moderate burden in half of the respondents (50%). However, these findings are different from findings of the studies conducted in Iran, where majority (71.2%) of caregivers reported a moderate burden in one study of Ahmadi et al.²², and 79.7% in another study of Motlagh et al.²³ This study found significant association of care burden with relationship with

patient (p-value= 0.031) and economic status of the family (p-value=0.01). This finding is closely related with the study conducted in Iran by Salmani et al.²⁴ where there was significant difference between burden of care in mothers who received aid from government institutions and those who didn't receive help from state institutions (p<0.05). Likewise, there was significant difference between burden of care in mothers who take care of affected child lonely and mothers who were not alone (p<0.05).

Conclusion

Majority of the family caregivers of children with cancer at B.P. Koirala Memorial Cancer Hospital have facing care burden. Parents with higher score of care burden tend to have low economic status and lower educational status. There was significant association between level of care burden with the relationship with child and the economic status of the family. So, concerned health authorities need to provide family-centered measures and services to address caregivers' burden and ultimately improving their well-being, reducing their care burden.

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