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## Care burden among the caregivers of children with cancer attending tertiary hospital, Bharatpur

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### Abstract

**Introduction:** Caring for the child with cancer is associated with tremendous physical, psychological, social, and financial pressure upon the family. Early detection of burden of care among caregivers is preeminent in promoting their quality of life. The aim of this study was to identify care burden among the caregivers of children with cancer attending a tertiary hospital, Bharatpur.

**Method:** A cross-sectional study was carried out among caregivers of children attending B. P. Koirala Memorial Cancer Hospital, Bharatpur, Nepal. Non-probability consecutive sampling technique was used to select the desired sample. Data were collected from 10 Aug to 05 Nov 2020 by an interview schedule using a standardised caregiver burden scale. Data were analysed by using descriptive and inferential (chi-square and correlation) tests. A  $p \leq 0.05$  was considered statistically significant.

**Result:** Out of 110 caregivers, 61(55.5%) had a moderate level of care burden. Mean score of care burden was  $52.22 \pm 12.820$ . There was a statistically significant association between caregivers' level of care burden with economic status ( $p=0.023$ ), health problem of the caregivers ( $p=0.008$ ) and duration of disease diagnosis ( $p=0.019$ ). There was a statistically significant positive relationship between all domains of care burden.

**Conclusion:** Caregivers had a moderate level of care burden. Numerous factors associated with care burden were found. Healthcare professionals should show concern towards reducing the burden among the caregivers and carry out educational programs that help them cope with their problems.

### How to cite

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## Introduction

Globally, Cancer is the second leading cause of death and is estimated to account for 9.6 million deaths in 2018.<sup>1</sup> It is expected that 1,100-1,600 new cases of childhood cancer are diagnosed every year in Nepal.<sup>2</sup> Childhood cancer generally cannot be prevented, but early and accurate diagnosis, followed by effective treatment, can improve the outcomes of most childhood cancers.<sup>3</sup> The complexities in the treatment process and the prognosis of cancer heighten the caregiver's role.<sup>4</sup> The burden of caregiving is a complex experience that includes both objective and subjective elements.<sup>5</sup>

Several studies conducted to assess the level of care burden among the caregivers of children with cancer have shown a moderate to high level of care burden, and the association of burden have been shown on family caregivers with many factors.<sup>6-9</sup> Care burden is one of the most common psychological problems.<sup>10,11</sup> The major challenges in Nepal include inconsistent access to quality health services, unavailability of modern equipment and specialised doctors, lack of education, late diagnosis, advanced disease at presentation, finance, and inconsistent supply of chemotherapy medicines.<sup>2,12</sup>

Healthcare personnel have a unique position to identify stress and the psychological burden of caregivers, and take appropriate action to reduce the burden on caregivers and improve their method of coping.<sup>11</sup> The present study was conducted to find out the care burden among the caregivers of children with cancer attending a tertiary hospital, Bharatpur.

## Method

A descriptive cross-sectional study was conducted among caregivers who came for follow up during the one-month period at outpatient department, paediatric oncology ward, day care and hospice of B. P. Koirala Memorial Cancer Hospital (BPKMCH), Bharatpur-7, Chitwan, Nepal, from 10 Aug to 05 Nov 2020. Non-probability consecutive sampling technique was used to select the desired sample. The data was collected from the caregivers of children aged 1 to 18 years who had provided

care to the child for at least 3 months since the diagnosis of disease of the child as cancer.

A structured interview schedule was developed by the researcher on the basis of a literature review to gather information on socio demographic factors of caregivers, family related information, child related information. Care burden of caregiver was measured by using standardised Caregiver Burden Scale (CBS). The CBS is a 4-point Likert scale for assessment of the subjective burden of caregivers of chronically ill persons.<sup>13</sup> It consists of 22 items and examines 5 domains, namely, general strain (8 questions), isolation (3 questions), disappointment (5 questions), emotional involvement (3 questions) and environment (3 questions). The tool has demonstrated a good kappa value (0.89 to 1.00) and Cronbach's alpha (0.70 to 0.87).<sup>13</sup> Each question has four responses: 'not at all, seldom, sometimes and often'. The mean of all the answers comprises a score for the total burden. A higher score indicates a greater burden. The total score of caregiver burden can be divided into three levels: Mean scores: low burden (1.00-1.99), moderate burden (2.00-2.99), and high burden (3.00-3.99). The same ranges can be used for the five domains, also. The English version of instrument was translated into Nepali and back-translated with the help of a linguistic expert (Nepali/English teacher).

Ethical clearance was taken from Chitwan Medical College Institution Review Committee (CMC-IRC/076/077/058). Data were collected by the researcher after taking permission from hospital director of BPKMCH. Written informed consent for literate and verbal informed consent (and thumbprint) for illiterate caregivers was obtained before data collection. First of all, respondent was identified. The purpose of the study and data collection process was explained to the respondents. A structured interview schedule was conducted in a separate room/corner in the OPD. In a day, 4-5 respondents were interviewed, taking 30-35 minutes. Some of the information related to the child's disease condition and treatment was collected from the client's record file.

Data were reviewed and checked for completeness, consistency and accuracy. The

data were edited, organised, coded and entered into IBM SPSS 20.0 version. Descriptive (frequency, percentage, mean, median and standard deviation) and inferential (chi-square and correlation) statistics were used. Spearman's rank correlation coefficient was calculated to find out the relationship between the various domains of care burden. A  $p \leq 0.05$  was considered statistically significant.

## Result

Out of 110 caregivers, median age was 32 years, female 59(53.6%), 96(87.3%) followed Hindu religion, 102(92.7%) were married, 38(34.5%) had completed secondary level of education, 52(52.7%) were unemployed, 64(58.2%) had inadequate income and 8(7.3%) had chronic health problem, Table 1.

**Table 1. Socio-demographic characteristics of the caregivers of children with cancer, n=110**

Variables	n(%)
<b>Age (in years)</b>	
20-40	80(72.7)
40-60	28(25.5)
≥ 60	2(1.8)
Median-32, IQR=Q <sub>3</sub> -Q <sub>1</sub> =40-26, min-20, max-76	
<b>Sex</b>	
Male	51(46.4)
Female	59(53.6)
<b>Religion</b>	
Hindu	96(87.3)
Other than Hindu	14(12.7)
<b>Ethnicity</b>	
Dalit	19(17.3)
Janajati	45(40.9)
Brahmin	13(11.8)
Chettri	26(23.6)
Muslim	7(6.4)
<b>Marital status</b>	
Married	102(92.7)
Unmarried	8(7.3)
<b>Educational status</b>	
Illiterate	19(17.3)
General literate	7(6.4)
Basic education	35(31.8)
Secondary education	38(34.5)
Bachelor and above	11(10.0)
<b>Occupation</b>	
Employed	52(47.3)
Unemployed	58(52.7)
<b>Economic status</b>	
Adequate	39(35.5)
Inadequate	64(58.2)
Extra saving	7(6.4)
<b>Health problem of respondents</b>	
Yes	8(7.3)
No	102(92.7)

The median duration of disease diagnosed and treatment received was 12 years; majority (70.9%) of children received chemotherapy, and 45(40.9%) were hospitalised more than three times, Table 2.

We found that more than fifty per cent (55.5%) of caregivers had moderate burden, and 16.4% had high care burden, Table 3.

We found that the highest care burden was found in the general strain domain (19.19±5.383) and the lowest in the emotional involvement domain (4.93±1.902), Table 4.

There was a statistically significant association between the caregiver's level of care burden and economic status ( $p=0.023$ ), health problem of the respondents ( $p=0.008$ ) and duration of disease diagnosis ( $p=0.019$ ), Table 5.

There was a positive correlation between all domains of care burden ( $p\leq 0.001$ ). The highest correlation was found between general strain and disappointment domain ( $R=0.657$ ), and the lowest between environment and emotional involvement domain ( $R=0.361$ ), Table 6.

**Table 2. Disease and treatment-related information of children with cancer, n=110**

Variables	n(%)
<b>Duration of disease diagnosis,</b>	
≤12 months	59(53.6)
>12 months	51(46.4)
Median-12, IQR=Q <sub>3</sub> -Q <sub>1</sub> =30-5, min-3 months, max -156	
<b>Type of treatment received</b>	
Chemotherapy	78(70.9)
Combination therapy	25(22.7)
Targeted therapy	7(6.4)
<b>Duration of treatment received</b>	
≤12 months	61(55.5)
>12 months	49(44.5)
Median-12, IQR=Q <sub>3</sub> -Q <sub>1</sub> =30-4.875, min-3, max-156	
<b>Number of hospitalisations</b>	
Never hospitalized	13(11.8)
1 time	29(26.4)
2 times	23(20.9)
≥3 times	45(40.9)
Median-2, IQR=Q <sub>3</sub> -Q <sub>1</sub> =4-1, min-0, max-20	

**Table 3. Level of care burden among the caregivers of children with cancer, n=110**

Level of care burden	N(%)
High burden (3-4)	18(16.4)
Moderate burden (2-2.99)	61(55.5)
Low burden (1-1.99)	31(28.1)

**Table 4. Mean score of different domains of care burden among the caregivers of children with cancer, n=110**

Domain	Number of Items	Maximum Possible Score	Obtained Range	Mean±SD	Mean %
General strain	8	32	9-32	19.19±5.383	59.96
Isolation	3	12	3-12	6.96±2.742	58
Disappointment	5	20	6-20	15.33±3.475	76.65
Emotional involvement	3	12	3-10	4.93±1.902	41.08
Environment	3	12	3-12	5.80±2.625	48.33
<b>Total</b>	<b>22</b>	<b>88</b>	<b>29-81</b>	<b>52.22±12.820</b>	<b>59.34</b>

**Table 5. Association of the level of care burden with selected variables among the caregivers of children with cancer, n=110**

Variables	Level of burden, n(%)			X <sup>2</sup>	p-value
	Low	Moderate	Severe		
<b>Age (in years)</b>				0.688	0.709
20-40	24(30.0)	44(55.0)	12(15.0)		
≥40	7(23.3)	17(56.7)	6(20.0)		
<b>Sex</b>				0.617	0.735
Male	14(27.5)	30(58.8)	7(13.7)		
Female	17(28.8)	31(52.5)	11(8.6)		
<b>Religion</b>				-	0.735*
Hindu	28 (29.5)	53 (55.2)	15 (15.8)		
Non-Hindu	3 (21.4)	8 (57.1)	3 (21.4)		
<b>Educational status</b>				3.934	0.140
Illiterate	4(21.1)	9 (47.4)	6(31.6)		
Literate	27(29.7)	52 (57.1)	12(13.2)		
<b>Economic status</b>				-	0.023*
Adequate	16(41.0)	21(53.8)	2(5.1)		
Inadequate	12(18.8)	37(57.8)	15(23.4)		
Extra saving	3(42.9)	3(42.9)	1(14.3)		
<b>Health problems of respondents</b>				-	0.008*
Yes	3(37.5)	1(12.5)	4(50.0)		
No	28(27.5)	60(58.8)	14(13.7)		
<b>Duration of care</b>				3.449	0.178
≤12 months	13(21.3)	38(62.3)	10(16.4)		
>12 months	18(36.7)	23(46.9)	8(16.3)		
<b>Duration of disease diagnosis</b>				7.941	0.019
≤12 months	10(16.9)	38(64.4)	11(18.6)		
>12 months	21(41.2)	23(45.1)	7(13.7)		
<b>Type of treatment received</b>				-	0.662*
Chemotherapy	21(26.9)	46(59.0)	11(14.1)		
Combination therapy	8(32.0)	11(44.0)	6(24.0)		
Targeted therapy	2(28.6)	4(57.1)	1(14.3)		
<b>Number of hospitalizations</b>				-	0.595*
Never hospitalized	5(38.5)	6(46.2)	2(15.4)		
1 time	11(37.9)	13(44.8)	5(17.2)		
2 times	5(21.7)	13(56.5)	5(21.7)		
≥3 times	10(22.2)	29(64.4)	6(13.3)		

\*Fisher exact Test

**Table 6. Relationship between various domains of care burden among the caregivers of children with cancer, n=110**

Domains	General strain	Isolation	Disappointment	Emotional involvement	Environment
General strain	1				
Isolation	R=0.567**	1			
Disappointment	R=0.657**	R=0.517**	1		
Emotional involvement	R=0.603**	R=0.372**	R=0.427**	1	
Environment	R=0.543**	R=0.434**	R=0.365**	R=0.361**	1

\*\*Correlation is significant at the 0.01 level (2-tailed).

## Discussion

The findings of this study showed that more than half of the respondents (55.5%) had moderate care burden, 28.1% low burden, and 16.4% had high burden while providing care to the children with cancer. Inconsistent findings were reported in the studies conducted in Iran in 2017 & 2019, where the majority of the parents had moderate care burden, i.e. 79.7%; 71.2%; 71.4% respectively.<sup>6,7,14</sup> The results showed that the majority of the caregivers of children with cancer are facing a moderate level of care burden. This might be due to the length of treatment and the burden of responsibility, which is causing the caregivers to suffer from care burden.<sup>7</sup>

The findings of this study revealed that the overall mean score of care burden was  $52.22 \pm 12.820$ . Consistent findings of studies conducted in Iran where care burden scores were  $56.43 \pm 9.32$ ;  $52.76 \pm 10$ ;  $54.71 \pm 11.27$ .<sup>6,7,14</sup>

Regarding the mean score for different domains of care burden, the current study revealed that the highest score was found in the general strain domain ( $19.19 \pm 5.383$ ) and the lowest score was found in the emotional involvement domain ( $4.93 \pm 1.902$ ). Similar findings were reported in a study conducted in Iran, showing the highest score in the overall pressure domain ( $19.21 \pm 5.28$ ) and the lowest score in the emotional involvement domain ( $6.24 \pm 2.55$ ).<sup>14</sup>

In other studies, it was reported that the highest score was found in the general strain domain and the lowest score was found in the environment domain.<sup>6,7</sup> The findings show that the general strain domain is the most affected domain, which is consistent with the present study. This similarity of the findings might persist because the caregivers have to encounter multiple stressful situations while delivering care to the ill child that pose physical and psychological suffering like fatigue, sleep problems, stress, depression and anxiety. Such an atmosphere of suffering can disrupt the caregiver's quality of life and quality of patient care.<sup>15</sup>

This study shows that there was a statistically significant association for the level of care burden with caregivers' economic status ( $p=0.023$ ), health problem of the caregivers ( $p=0.008$ ) and duration of disease diagnosis

( $p=0.019$ ). Consistent findings have been reported in a study that the factors associated with care burden were cancer type: Acute myeloid leukaemia and Ewing sarcoma, the number of hospitalisations, duration of disease, parents' age, parents' income, and child's age.<sup>7</sup> Another study revealed that daily care time, anxiety, general health, average monthly family income, social support, and number of co-caregivers were factors associated with care burden.<sup>16</sup> Both studies revealed an association of care burden with the income status of the caregivers, which is similar to the present study. This may be because caregivers of cancer children have many extra expenses associated with the child's disease condition and their treatment process, despite fulfilling their daily basic requirements.

The findings of the present study showed that there was a statistically significant positive relationship between all the domains of care burden. Among the domains, the highest correlation was found between general strain and disappointment domain ( $R=0.657$ ), whereas lowest correlation was found between environment and emotional involvement domain ( $R=0.361$ ). Similarly, a study revealed that the highest correlation was found between general strain and disappointment domain ( $R=0.632$ ), whereas the lowest correlation was found between isolation and environment domain ( $R=0.142$ ).<sup>6</sup>

This study adds to the information regarding the caregiver level of burden and its associated factors in the local context. This finding might be helpful for healthcare providers to plan and implement holistic activities, such as counselling, for the benefit of caregivers to reduce their burden and improve the quality of life of both the caregivers and the children. The healthcare workers should show concern towards fulfilling the needs of the caregivers and their cancer children through additional information regarding the disease condition, counselling, advanced palliative care service, and supportive care, etc. Organising interventional activities like an educational program that includes a caregiver burden-related information package will be helpful. This activity should include information regarding different types of burdens the caregivers might go through and how to handle

such burdens by using different coping strategies that will ultimately minimise their burden level.

This study has some limitations and may not be generalised to other settings; i) A non-probability sampling from only one cancer hospital in Chitwan; ii) This study did not consider the stage of cancer in the children that may affect the level of care burden for caregivers; iii) The study relied on self-reported responses on a questionnaire, which may have introduced bias into the findings. A mixed-method study on caregiver burden may be necessary.

### Conclusion

More than half of the caregivers of children with cancer had a moderate level of care burden. Economic status, health problems of the caregivers and duration of disease diagnosis were associated with care burden. Thus, healthcare workers should show concern towards fulfilling the needs of the caregivers and their cancer children and provide an educational program on caregiver burden-related information.

### Author contribution

Concept and design: SU, HKS; Literature search: SU; Data collection: SU; Data analysis: SU; Draft manuscript: SU; Final manuscript and accountability: All

### Acknowledgment

None

### Conflict of interest

None

### Funding

None

### Consent

All the appropriate patient consents have been taken in the form of verbal and written. In the consent form, the patient gave consent for her

images and other clinical information to be reported in the journal. The patient was counselled that her name and initials would not be published and that due efforts would be made to conceal her identity, but anonymity cannot be guaranteed.

### Supplementary material

The data and supplementary material that support the findings of this study are available from the corresponding author upon reasonable request.

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### Supplementary material

**Tools/Questionnaire** Structured Interview Schedule on Care Burden among the Caregivers of Children with Cancer Attending Tertiary Hospital, Bharatpur.

Respondent's code number:-.....

Date:- .....

Part I – Questions related to caregivers'		
Socio demographic information		
S.N.	Questions	Responses
Q.1	What is your age? (completed years)	..... years
Q.2	What is your sex? a) Male b) Female	
Q.3	Where is your place of residence? a) Rural area b) Urban area	
Q.4	What is your religion? a. Hindu b. Buddhist c. Christian d. Islam e. Other (please specify).....	
Q.5	What is your ethnicity? a. Dalit b. Janajati c. Brahmin d. Chettri e. Others (please specify).....	
Q. 6	What is your marital status? a) Married b) Unmarried	
Q.7	What is your educational status? a) Illiterate b) General literate (can read and write) c) Basic education	

	d) Secondary education e) Bachelor and above	
Q.8	What is your present occupation? a) Home maker b) Agriculture c) Business d) Service e) Daily wages f) Others (please specify).....	
Q.9	What is your economic status? a. Adequate b. No saving c. Extra saving	
Q.10	What is your relationship with the child? a) Father b) Mother c) Brother d) Sister If any other, please specify, .....	
Q. 11	Since how long you have been providing care to the child?	.....months
Caregiver health related questions		
Q.12	Do you have any health problem? a. Yes b. No	
Social support related questions of Caregiver		
Q. 13	Are you getting treatment support from Nepal government? a. Yes b. No	
Q. 14	Are you getting treatment support from this hospital? a. Yes b. No	
Q. 15	Are you getting treatment support from any other organization? a. Yes b. No If yes, please specify.....	
Q. 16	Do your child have health insurance? a. Yes b. No	
Q. 17	Are you getting enough information regarding your childs' health problem and treatment from the health personnel (doctors/nurses)? a. Yes b. No	
Q. 18	Do you receive help while caring your child from your other family member? a. Yes b. No	
II. Family related questions		
Q. 19	What is the type of your family? a. Nuclear b. Joint	
Q. 20	Is there any history of cancer in your family? a. Yes b. No If yes, who was suffered from it, please specify.....	

Q. 21	What is the number of children in your family? a. One b. Two c. Three d. More than three	
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Part III – Questions related to the Child's		
Sociodemographic information		
Q. 22	What is the age of your child? (Completed years)	..... years
Q. 23	What is the sex of your child? a) Male b) female	
Q. 24	What is the birth order of the child? a. First b. Second c. Third If above third, please specify .....	

Disease and treatment related questions of child (From record review)		
Q. 25	Medical diagnosis of child	.....
Q. 26	Type of treatment being received a. Surgery b. Radiotherapy c. Chemotherapy d. Immunotherapy e. Palliative care f. Combination therapy, if combination therapy, please specify.....	
Disease and treatment related questions of child (From caregiver)		
Q. 27	What is the duration of disease diagnosis?	.....months
Q. 28	Since how long your child has been receiving treatment?	.....months
Q. 29	How many times your child has been hospitalized for treatment?	..... times
Q. 30	How many times your child has made follow up visit at OPD?	..... Times
Q. 31	How long does it take for you to reach the hospital from your home?	.....

### Caregiver Burden Scale, (CBS)

Direction : Care Burden Scale is a 4 items likert scale where numbers are allocated for each response (1 - not at all, 2 - seldom, 3 - sometimes and 4 - Often). The researcher will ask the questions related to the subjective burden felt by the caregivers to the respondents and she herself will tick (✓) the appropriate number in the box.

S.No	Item	Not at all	Seldom	Sometimes	Often
1.	Do you feel tired and worn out?	1	2	3	4
2.	Do you feel lonely and isolated because of your child's problem?	1	2	3	4
3.	Do you think you have to shoulder too much responsibility for your child's welfare?	1	2	3	4

4.	Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?	1	2	3	4
5.	Do you find yourself facing purely practical problems in the care of your child that you think are difficult to solve?	1	2	3	4
6.	Do you ever feel offended and angry with your child?	1	2	3	4
7.	Do you think your own health has suffered because you have been taking care of your child?	1	2	3	4
8.	Has your social life, eg with family and friends, been lessened?	1	2	3	4
9.	Does the physical environment make it troublesome for you taking care of your child?	1	2	3	4
10.	Do you feel tied down by your child's problem?	1	2	3	4
11.	Do you feel embarrassed by your child's behavior?	1	2	3	4
12.	Has your child's problem prevented you from doing what you had planned to do in this phase of your life?	1	2	3	4
13.	Do you find it physically trying to take care of your child?	1	2	3	4
14.	Do you think you spend so much time with your child that the time for yourself is insufficient?	1	2	3	4
15.	Do you worry about not taken care of your child in the proper way?	1	2	3	4
16.	Are you sometimes ashamed of your child's behavior?	1	2	3	4
17.	Is there anything in the neighbourhood of your child's home making it troublesome for you to take care of your child?	1	2	3	4
18.	Have you experienced economic sacrifice because you have been taking care of your child?	1	2	3	4
19.	Do you find it mentally trying to take care of your child?	1	2	3	4
20.	Have you a feeling that life has treated you unfairly?	1	2	3	4
21.	Had you expected that life would be different than it is at your age?	1	2	3	4
22.	Do you avoid inviting friends and acquaintances home because of your child's problem?	1	2	3	4

Total score : .....

Thank You