



## ORIGINAL ARTICLE

# Caregivers' Stress and Burden among Mothers of Children with Cancer: A Cross-Sectional Feasibility Study

Chavan Seema S<sup>1\*</sup>, Mendonca Theresa L<sup>2</sup>

<sup>1</sup>Department of Pediatric Nursing, Father Muller College of Nursing, Mangalore.

<sup>2</sup>Department of Pediatric Nursing, Laxmi Memorial College of Nursing, Mangalore.

### \*Corresponding author:

Prof. Seema S Chavan, Department of Pediatric Nursing, Father Muller College of Nursing, Mangalore-02.

E-mail: seemaschavan23@gmail.com

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### Abstract

**Background:** In India, cancer is rated as 9th among the causes of death in children aged 5-14 years. Cancer and its management has always been challenging in all dimensions including physical, social, psychological and spiritual, with mothers majorly facing disturbing family experiences. Parents experience shock, denial and the quality of life of the family gets affected.

**Objective:** To determine stress and burden among mothers of children with cancer.

**Methodology:** The study was conducted using a cross sectional survey design among 60 mothers of children with cancer. The sample was selected using simple random sampling technique according to the inclusion criteria. The data was collected using Kingston Caregiver Stress Scale (KCSS) and Caregiver Burden Self-Assessment (CBSA) scale.

**Results:** Majority of mothers included in the study were above 30 years of age with a mean age of 33.74±6.51 years, a monthly family income of less than Rs 29,000/- with mean income of 18200±9788.80 per month and belonged to upper lower class. Majority of children with cancer were less than 10 years of age with mean age of 7.51±5.44 years. More than 50% of children were males, diagnosed with ALL. A significant association between caregiver's stress and educational qualification of mothers of children with cancer ( $p=0.041$ ) was observed. A positive correlation was found between caregiver's stress and burden among mothers of children with cancer.

**Conclusion:** Majority of mothers experienced stress and burden due to their child's diagnosis. Hence interventions should be developed and implemented to help mothers deal with their stress.

**Keywords:** Mother, Cancer children, Stress and burden

### Introduction

Cancer in children is different from that of adults. According to estimates, over 1,48,000 cases of cancer in children in the age range of 0 to 14 years were reported in 2008 in less developed areas. In India, cancer is rated as 9th among the causes of death in children aged 5-14

years. The Indian cancer registry reported 0.8 to 5.8% cases in boys and 0.5% to 3.4% cases in girls.<sup>1</sup>

Advancements in paediatric oncology can be considered as one of the major success stories of oncology in the millennium in India. India is battling as a resource challenge country; however, it is satisfying that the

pediatric oncology prognosis was 75-80% in the last five years. India has a long way to go to match the international standards in treatment of pediatric oncology cases which makes it vital to introspect and analyse our challenges, thus contributing to education, research and service.<sup>2</sup>

To comfort sick children at home, the parents, who are the primary caregivers, must assume the role of a caregiver. They control the child's symptoms, offer pertinent nursing care, visit doctor for follow-up appointments, and so on. Parent-child relationship is close-knit. Reciprocal determinism, is a dynamic theory which assumes that a parent and child may both influence one another, thus governing how parent-child connection works.<sup>3</sup> The level of parental stress rises in proportion to the intensity of symptom burden, which directly decreases the child's quality of life.<sup>4,5</sup> The load of caretaking on the parents increases as the child's symptom burden increases. Compared to other chronic diseases, cancer causes greater worry, anxiety, and fear in parents.

Cancer and its management has always been challenging in all dimensions, including physical, social, psychological and spiritual, with the mothers majorly facing disturbing family experiences. Parents experience shock, denial and the quality of life of family gets affected.<sup>6</sup>

Limited available literature on stress and burden faced by mothers of children suffering with cancer in Indian population highlights the need and importance of the study undertaken. It is important that we have an understanding about the concerns of mothers of children with cancer, that can enable us to attend to their therapeutic needs.

### Objectives of the study

1. To assess the stress and burden among mothers of children with cancer.
2. To evaluate the association between stress and burden among mothers of children with cancer and the selected baseline variables.
3. To find the correlation between caregiver's stress and burden among mothers of children with cancer

**Hypothesis:** All hypotheses are tested at 0.05 level of significance.

H<sub>1</sub>: There will be a significant association between stress and burden among mothers of children with cancer and the selected baseline variables.

H<sub>2</sub>: There will be significant correlation between stress and burden among mothers of children with cancer.

### Material and Methods

This study used a cross-sectional descriptive design and was carried out at few hospitals in Mangalore. Each year, 200 patients came to the hospital, and 60 of them were chosen through simple random sampling. Kingston Caregiver Stress Scale (KCSS), Caregiver Burden Self-Assessment (CBSA), and baseline proforma were employed by the researcher. The CBSA scale had 20 elements with a minimum score of 0 and a maximum score of 88, while the KCSS rating scale had 10 items with a minimum score of 10 and a maximum score of 50. The CBSA scale was graded into little or no burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41-60), and severe burden (61-88), whereas the KCSS rating scale was classified into light stress (16), moderate stress (16-24), and severe stress (>24). Test re-test method & Cronbach's alpha was used to assess the language reliability and the score was 0.84 & 0.87, respectively. The study was carried out at a chosen hospital in Mangalore between June 20, 2022, and September 15, 2022. Before collecting data, formal authorization was acquired from the relevant authorities. The researcher introduced herself and provided the subjects with an explanation about the goals of the study. Participants gave their informed consent before the instrument was used on them. The tool was finished by the participants in about 15-20 minutes. After thanking the subjects for their cooperation and involvement, the data gathering came to an end. The data was compiled and subjected to statistical analysis.

### Results

#### Baseline characteristics of mothers of children with cancer

Majority of women in the present study were over 30 years of age, with a mean age of 33.74±6.51 years. About half of them had completed high school education, belonged to joint families and had two children. Majority of the participants reported to be living within 50 kilometers of a health care facility, with a mean distance and standard deviation of 86.13±85.67 km and a treatment cost of less than Rs 30,000 per month was reported. A mean monthly income of 18200±9788.80 was reported with majority of the participants belonging to the upper lower class (Table 1).

**Table 1:** Baseline characteristics of mothers of children with cancer in terms of frequency and percentage (n=60)

Variables	Intervention			Chi-square	p-value
	f	%	Mean±SD		
<b>Age in years</b>					
<30	24	40.0%	33.74±6.51	0.278	0.598
>30	36	60.0%			
<b>Occupation</b>					
Unemployed	49	81.7%		1.002	0.317
Skilled	11	18.3%			
<b>Educational qualification</b>					
Middle school	9	15.0%		-	0.845
High school	28	46.7%			
Intermediate / Diploma	8	13.3%			
Graduate	8	13.3%			
Professional degree	7	11.7%			
<b>Family type</b>					
Nuclear family	16	26.7%		1.393	0.498
Joint family	28	46.7%			
Extended family	16	26.7%			
<b>Place of residence</b>					
Rural	30	50.0%		0.267	0.606
Urban	30	50.0%			
<b>Proximity of the health care setting (in Kilometres).</b>					
<50	22	36.7%		0.404	0.817
51-100	20	33.3%	86.13±85.67		
>100	18	30.0%			
<b>Number of children</b>					
One	17	28.3%		0.802	0.670
Two	28	46.7%			
Three	15	25.0%			
<b>Treatment Expenditure in Rupees per month</b>					
≤30,000	41	68.3%		0.077	0.781
>30,000	19	31.7%	30741.94±24516.62		
<b>Information on Cancer &amp; its management</b>					
Yes	30	50.0%		0.267	0.606
No	30	50.0%			
<b>Source of Information on Cancer</b>					
Media	12	20.0%		0.356	0.837
Health personal	30	50.0%			
Never received any information	18	30.0%			

Challenges experienced due to the child cancer diagnosis				0.577	0.448
Yes	52	86.7%			
No	8	13.3%			
Family members diagnosed with Cancer				0.218	0.640
Yes	5	8.3%			
No	55	91.7%			
Monthly income (Acc. to kuppuswamy scale)				18200±9788.80	0.795
< 10000	3	5.0%			
10000-29000	47	78.3%			
29000-49000	8	13.3%			
>50000	2	3.3%			
Financial status (Acc. to kuppuswamy scale)				-	0.412
Upper Middle class	8	13.3%			
Lower Middle class	15	25.0%			
Upper Lower class	37	61.7%			

#### Baseline characteristics of children with cancer

More than 50% of the children diagnosed with ALL were males, and age of the children with cancer was less than 10 years, with a mean±SD of 7.51±5.44 years. More than 90% of the children only underwent chemotherapy

and were mostly in stage II. It was also stated that the disease had not expanded aggressively from the time of diagnosis in majority of children (90%), which was less than two years, with a mean±SD of 0.61±0.49 years (Table 2).

**Table 2:** Baseline characteristics of children with cancer in terms of frequency and percentage (n=60)

Variables	Intervention			Chi-square	p-value
	f	%	Mean±SD		
<b>Age in years</b>				-	0.71
≤10	42	70.0%	7.51±5.44		
≥11	18	30.0%			
<b>Diagnosis</b>				0.94	
ALL	36	60.0%			
AML	5	8.3%			
Neuroblastoma	5	8.3%			
Hodgkin's	5	8.3%			
Ewing's	6	10.0%			
LCH	2	3.3%			
CML	1	1.7%			
<b>Gender</b>				0.067	0.795
Male	33	55.0%			
Female	27	45.0%			

Stage of disease					0.719
Stage I	16	26.7%			
Stage II	27	45.0%			
Stage III	11	18.3%			
Stage IV	6	10.0%			
Time duration from the time of diagnosis				1.071	0.301
0-2 yrs	56	93.3%	0.61±0.49		
>2 yrs	4	6.7%			
Modality of treatment				1.071	0.301
Chemotherapy	56	93.3%			
Combined	4	6.7%			
School dropout after the child's diagnosis				0.275	0.871
Yes	11	18.3%			
No	15	25.0%			
NA	34	56.7%			
Aggressive Spread				1.176	0.278
Yes	9	15.0%			
No	51	85.0%			

**Distribution of subjects based on their level of stress**

Majority of mothers (75%) had experienced severe stress (Table 3).

**Table 3:** Distribution of subjects based on their level of stress (n=60)

Variable	Moderate stress		Severe stress	
	f	%	f	%
Stress	15	25	45	75

**Distribution of subjects based on their level of burden**

Majority of mothers (55%) had experienced mild to moderate burden (Table 4).

**Table 4:** Distribution of subjects based on their level of burden (n=60)

Variable	Little burden		Mild to moderate burden		Moderate burden		Severe burden	
	f	%	f	%	f	%	f	%
Burden	11	18.3	33	55	15	25.0	1	1.7

**Association between caregiver's stress and burden among mothers of children with cancer and selected baseline variables**

There was a significant association observed between caregiver's stress and educational qualification of mothers of children with cancer ( $p=0.041$ ). However, no significant association was found between caregiver's burden and selected baseline variables.

**Correlation between caregiver's stress and burden among mothers of children with cancer**

A positive correlation was found between caregiver's stress and burden among mothers of children with cancer ( $r=0.277, p=0.32^*$ ) which implies that as the burden increases, there is an increase in stress and vice versa.

**Discussion**

**Demographic characteristics of mothers of children with cancer**

According to our research, majority of children with cancer were males, diagnosed with ALL, and were under the age of 10 years. In both the intervention and control groups, in majority of children, the disease had not expanded aggressively in less than two years since the diagnosis was made. In both the categories, majority of mothers were over 30 years old, had only completed

high school education, were members of joint families, and had two children. In both the categories, majority of mothers reported to be living fewer than 50 kilometres from a health care facility, had an average family income of less than Rs 29,000 per month and belonged to the upper lower class. The incurred treatment costs were reported to be less than Rs 30,000 per month.

These findings are congruent with the study conducted by Rosenberg *et al.*, where all the participants were married mothers with a median age of 35 to 38 (31-44) years and with an educational qualification of at least one college degree. All the three groups of children with cancer had median (IQR) ages of 5 to 8 (3-14) years, with leukaemia or lymphoma being the most frequent diagnoses. Males made up just over half of the children.<sup>7,8,9</sup> Mothers' education was 13.32±2.22. Fathers' education was 13.27±3.22. Sahler OJ *et al.*, reported the mean mother's age in years to be 36.3±8.1 years. The age of the children in years was 8.2±5.7. 50.6% of children were males, 50% were diagnosed with Leukemia, 13% with solid tumors and 10.8% were diagnosed with brain tumors.<sup>10,11</sup>

#### **Association between caregiver's stress and burden among mothers of children with cancer and selected baseline variables**

There was a significant association between caregiver's stress and educational qualification of mothers of children with cancer ( $p=0.041$ ).

This was congruent with the findings of a cross-sectional study conducted to estimate the symptom burden and quality of life of children with cancer, which found that parents' reported stress levels were significantly and favourably associated with children's symptom burden ratings, but adversely associated with both the children's and parents' reported quality of life. Four demographic variables—relationship and children's quality of life—were identified in bivariate analyses ( $B = 28.307$ ; 95% CI, 42.981 to 13.633).<sup>12</sup>

#### **Correlation between caregiver's stress and burden among mothers of children with cancer**

In this study, a positive correlation was found between caregiver's stress and burden among mothers of children with cancer.

This was consistent with the findings of a cross-sectional study conducted on the symptom burden and quality of life of children with cancer, which found a strong correlation between the severity of the children's symptoms and the felt stress of their parents ( $p = .001$ ).

The results of this study showed that symptom load was common in Chinese children with cancer and had a direct impact on the stress levels of their parents ( $p = .004$ ).<sup>12</sup>

### **Conclusion**

The results of this study supports the findings of previous research showing that parents of children with cancer frequently experience symptom burden. This data is crucial in clearing the way for the creation of upcoming interventions. Health authorities should prioritise addressing parents' resilience in managing stress and improving their skills in managing symptoms of their children.

### **Source(s) of support**

Nil

### **Conflicting Interest**

Nil

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