

Caring for the caregivers: A cross-sectional study of the burden experienced by family caregivers of children with cancer in South Gujarat



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Submission: 21-02-2024

Revision: 29-03-2024

Publication: 01-05-2024

ABSTRACT

Background: In India, family members undertake the care of a considerable number of patients with chronic illnesses like cancer at home, yet despite the recognition of their pivotal role as caregivers, scant attention is given to the suffering they endure. **Aims and Objectives:** The aim of the study is to study the sociodemographic characteristics of caregivers and children/adolescents with cancer undergoing cancer treatment and assess the caregiver's burden of children/adolescents suffering from cancer. **Materials and Methods:** A cross-sectional study involving caregivers of children having cancer who were availing services at Cancer Institute (Lions Cancer Detection Center), New Civil Hospital, Surat, to identify the burden among caregivers of children of 0–19 years of age group. A total of 237 participants were enrolled in the study from June 2019 to November 2019. Using a standardized, validated version of the Zarit Burden Interview was used for data collection. Data entry into Microsoft Excel and analysis was done by Epi Info. Univariate analysis was done to calculate mean and standard deviation while bivariate analysis by Chi-square test. **Results:** The study population consisted of 99 (41.8%) males and 138 (58.2%) female caregivers aged 18–58 years. One hundred and twenty-five (52.7%) caregivers reported no or minimal burden while 64 (27.0%) caregivers reported mild-to-moderate burden. **Conclusion:** In view of the substantial burden on family caregivers coupled with the lack of an adequate number of cancer hospitals, there is a public health imperative to recognize this important group. All levels of health staff in cancer hospitals in developing countries should be sensitized to the various burdens faced by family caregivers.

Key words: Family caregivers; Zarit Caregiver burden scale; Caregiver burden; Cross-sectional study

INTRODUCTION

India's cancer growth pattern closely resembles that of other European and American nations. In India, there are about 2.5 million cases of cancer, with nearly 900,000 cases being diagnosed and 400,000 people passing away each year.¹

With rising urbanization and the adoption of Western lifestyle and nutritional norms, India's cancer incidence has

kept pace. However, there has not been a corresponding rise in the number of hospitals with a focus on treating cancer. As a result, many of these patients receive care at home from family members.

The family is mostly the carers when a child has cancer. There is a significant amount of suffering, agony, mental anguish, and trauma involved in the entire disease detection, diagnosis, and treatment process. The lives of an entire family alter

Access this article online

Website:

<http://nepjol.info/index.php/AJMS>

DOI: 10.3126/ajms.v15i5.62925

E-ISSN: 2091-0576

P-ISSN: 2467-9100

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overnight. The trauma is further exacerbated by the cost of medical operations. Caregivers frequently have significant psychological, behavioral, and physiological repercussions on their everyday lives and health as a result of this experience, which is frequently seen as a chronic stressor.²

The needs and demands of these family members and primary caregivers are frequently disregarded and neglected when delivering care and treatment because the whole attention is on the patient. Although the crucial role provided by these family caregivers is widely acknowledged, little is known about the suffering they bear.³ As a “multi-dimensional biophysical reaction resulting from an imbalance of care demands relative to caregiver’s time, social roles, physical and emotional states, financial resources, and formal care resources given the other roles they fulfill,” caregiver load is seen to be a burden on the carer.³

The result of the caregiver load varies on a wide range of factors. Numerous sociodemographic characteristics, such as age, gender, relationship to the patient, work status, and income of caregivers, have been linked to the strain placed on families of cancer patients.^{4,5} A lack of social and familial support, the amount of time spent providing care, disruptions to daily activities,^{6,7} and the stage of the disease. Support in daily living activities and instrumental daily living tasks in cancer patients also significantly affect caregiver strain.^{5,6,8}

At various stages of the disease’s progression, the patient’s expectations and needs change, as does the load placed on the caregiver. The negative effects of caregiving have become a significant public health concern given the scope of services offered and the sacrifices made by family caregivers. The present study is planned to understand the caregivers’ burden which is crucial for successful adherence by pediatric cancer patients. Findings from this study will help assess factors contributing to the additional burden of looking after children with cancer. The present study aims to study the sociodemographic characteristics of caregivers and children/adolescents with cancer undergoing cancer treatment and assess the caregiver’s burden of children/adolescents suffering from cancer.

Aims and objectives

The present study aims to study the sociodemographic characteristics of caregivers and children/adolescents with cancer undergoing cancer treatment and assess the caregiver’s burden of children/adolescents suffering from cancer.

MATERIALS AND METHODS

A cross-sectional study, conducted at Cancer Institute (Lions Cancer Detection Centre), New Civil Hospital,

Surat, from June to November 2019, enrolled 237 caregivers of children aged 0–19 undergoing cancer treatment for at least 2 months. The sample size calculation was based on data from the previous year, estimating approximately 500 children receiving cancer treatment within the 6-month duration. Using Epi Info, with a population of 500 and a 50% anticipated rate, the sample size was calculated to be 215 at a 95% confidence interval. All caregivers aged 18 or above, providing care for children/adolescents for the past 2 months, residing in the same household, and consenting to participate were included in the study. Exclusion criteria involved caregivers who did not attend planned visits or had children/adolescents with serious illnesses.

Prior written consent was obtained from caregivers of children with confirmed cancer diagnoses. A pre-tested, semi-structured questionnaire, including the Zerit–Burden Interview Scale (ZBI-22), was used to collect the data. The ZBI-22, validated in various populations, measures subjective burden, with higher scores indicating greater burden (range: 0–88).⁹

The original ZBI, which has 29 items on a four-point Likert scale, was later changed to the ZBI-22, which has 22 items on a five-point Likert scale. With the exception of item 22 (0=not at all, 1=a little, 2=moderately, 3=quite a bit, 4=extremely), each item of the ZBI-22 asks, “Do you feel or do you wish.” and offers optional answers with scores ranging from 0 to 4 (0=never, 1=rarely, 2=sometimes, 3=quite frequently, 4=nearly always). The ZBI-22 has been widely used and well-validated in numerous previous studies, with a Cronbach’s α of 0.92 in the original scale.¹⁰⁻¹²

According to a recent study, the ideal cutoff score for psychological distress risk is 48, with sensitivity being 73% and specificity being 80% for depression as determined by the PHQ-9.¹³ The ZBI-22, which is available in the majority of languages, has been validated across many populations of caregivers (such as spouses/partners, children, and parents) and care-recipients (such as AD/dementia, physical illness, and mental illness).

Data were entered into Microsoft Excel and analyzed using Epi Info, univariate and bivariate analyses were conducted on normally distributed data, presenting results as mean and standard deviation, alongside parametric tests. For categorical data, non-parametric tests like the Chi-square test were employed. A significance level of $P < 0.05$ was adopted for statistical significance.

RESULTS

The present study was conducted at Shri Devarajbhai Bavabhai Tejani Cancer Institute, which is managed by

D. B. Tejani Trust, and is located on the campus of New Civil Hospital, Surat. It is a diagnostic and treatment center, which provides free-of-cost services to all types of cancer. It is the only center in South Gujarat which is providing free treatment to cancer patients. They are providing cancer diagnosis as well as cancer treatment facilities. They are giving chemotherapy and radiotherapy according to patient's condition and requirements. Due to the free treatment facility, this center has a lot of patients. Needy and poor people can take the help of this center for treatment of cancer. Furthermore, cancer patients are getting residence at a very cheap rate in hospital campus which is run by one trust.

A total of 237 caregivers participated in this study, of which 99 (41.8%) were male and 138 (58.2%) were female. Their ages ranged from 18 to 58 years, with a mean age of 35.6 ± 7 years. On average, the duration of cancer treatment for children in this study was 9.1 months, with a standard deviation of 6.82. The majority (69.2%) of the children were in the initial stage of cancer treatment. Majority of caregivers (96.6%) were married, and almost half (46.6%) of the caregivers had completed education up to a higher secondary level. Almost half of the caregivers (50.8%) were employed in either skilled or unskilled jobs. The majority (60.3%) of the caregivers were living in nuclear families. About 37.1% of the caregivers belonged to class III of the modified B.G. Prasad classification, indicating a lower socioeconomic status. Most of the cancer patients (74.7%) had a family size of less than six members (excluding the patient) (Table 1).

Mothers were the primary caregivers for 56.5% of the cases, followed by fathers for 38.8%. Most of the caregivers (80.6%) had been providing care for a year, while 19.4% had been doing so for more than a year. On average, caregivers spent 13.6 h a day with the child, with a standard deviation of 6.5. Almost all (98.3%) caregivers received support from their partners or other family members. About three-fourths of the caregivers had to quit their jobs at some point. Most of the caregivers (92%) had taken their children with cancer to the doctor more than 5 times for treatment. The average age of children with cancer in this study was 8.84 years, with a standard deviation of 4.5. The majority (38.4%) of the children were between 6 and 10 years old. Boys made up the majority (56.5%) of children with cancer in this study, while girls accounted for 43.5%. Most of the children (43.5%) were not attending school, and 17.7% were below the age of 3 years. Of those who were attending school, the majority (42.6%) was in primary school and only 9.7% were in high secondary school. Only two children were illiterate, and 2.5% had dropped out of school. The majority (71.7%) of children with cancer were living in their own homes. About 12.7% of the children were provided housing by the Can Kids organization to live with their parents during cancer treatment (Table 2).

Table 1: Sociodemographic profile of caregivers (n=237)

Variables	Number	%
Age (in years)		
20–29	49	20.7
30–39	116	48.9
40–49	64	27.0
>50	8	3.4
Sex		
Male	99	41.8
Female	138	58.2
Marital status		
Married	229	96.6
Unmarried	2	0.8
Widow/Widower	6	2.6
Literacy status		
Illiterate	20	8.4
Primary	43	18.2
Secondary	110	46.4
Higher Secondary	40	16.9
Graduation	24	10.1
Occupation		
Homemaker	94	39.7
Unskilled worker	65	27.4
Skilled worker	56	23.6
Private work	10	4.3
Unemployed	8	3.4
Business	2	0.8
Student	2	0.8
Type of family		
Nuclear	143	60.3
Joint/extended	94	39.7
Socioeconomic class (Modified B. G. Prasad)		
I	0	0.0
II	55	23.2
III	88	37.1
IV	77	32.5
V	17	7.2
Number of family members		
<6	177	74.7
>6	60	25.3

The caregivers had a mean Zarit Burden Score of 25.6 (SD ± 12.9), indicating a moderate level of burden overall. Among the caregivers, the majority (52.7%) reported no or minimal burden, meanwhile, no one reported severe burden (Table 3).

Out of 229 married caregivers, 193 experienced low burden and 36 experienced high burden. The Fisher's exact test of significance shows that there is no significant association between the burden on caregivers and their marital status ($P=0.421$). Similarly, there is no significant association between the burden on caregivers and their type of family (nuclear or joint) ($P=0.266$). Among 94 caregivers living in a nuclear family, 73 who were housewives experienced a low burden, while 21 experienced a high burden. The Fisher's exact test shows that this association is marginally significant (Table 4).

Table 2: Sociodemographic profile of care recipients (n=237)

Variables	Frequency	%
Age (in years)		
0–5	66	27.8
6–10	91	38.5
11–19	80	33.7
Sex		
Boy	134	56.5
Girl	103	43.5
Education		
Illiterate	2	0.8
Pre-school	28	11.8
Primary	101	42.6
Secondary	41	17.3
Higher Secondary	23	9.7
NA	36	15.3
Drop out	6	2.5
Currently school going		
Yes	92	38.8
No	103	43.5
NA	42	17.7
Current living status		
Own house	170	71.7
Relative's house	37	15.6
Other (Can kids home)	30	12.7
Relation of caregiver		
Mother	134	56.6
Father	92	38.8
Maternal grandfather	5	2.1
Maternal grandmother	4	1.7
Paternal uncle	2	0.8

Table 3: Burden among family caregivers as per Zarit Burden Interview (n=237)

Score	Level of burden	Frequency	%
0–20	No or minimal burden	125	52.7
21–40	Mild-to-moderate burden	64	27.0
41–60	Moderate-to-severe burden	48	20.3
61–88	Severe burden	0	0.0

DISCUSSION

Caregiving is a multifaceted aspect of health care that has become increasingly important, evolving from an informal family activity to a significant part of health care. The cancer experience is rarely undergone alone, as cancer is known to impact the entire family who journeys together. Family members, often referred to as the “hidden sufferers” within the cancer experience, are vulnerable to emotional reactions both from the patient and themselves. Caregiving can take a significant toll on a caregiver's physical and psychological well-being. Caregivers typically prioritize the needs of their loved ones over their own, which can lead to increased health risks when providing extended and complex care without adequate rest, self-care, or medical help-seeking.

The current study found that in 56.5% of cases, the main caregiver for a child with cancer was the mother,

followed by the father in 38.8% of cases. A similar study by Olagunju et al., reported that all caregivers were parents, with a majority being mothers (83.7%). In another study by Andrew Toyin Olagunju et al., among parents of long-term survivors of childhood acute lymphoblastic leukemia, it was found that 79% of participating caregivers were mothers.¹⁴

The mean age of participants in the present study was 36 years \pm 7.07, with a range of 18–58 years. The largest proportion of caregivers, 48.9%, fell in the age group of 30–39 years, only 3.37% of the caregivers were aged 50 years or above. In a previous study by Olagunju et al., on “the symptom burden and depressive symptoms among caregivers of children with cancers”, the average age of parents was 39 \pm 2 years.¹⁴ Another study conducted by Sharma et al., in 2018, on coping strategies used by parents of children diagnosed with cancer reported an average age of 38.76 (SD-3.58) years for the parents.¹⁵

The differences between the current study and previous studies could be attributed to changing social dynamics, cultural factors, medical advances, research methodology, and sample diversity.

According to Sharma et al., women are often the primary informal caregivers for family members with chronic medical conditions due to societal and cultural expectations placed on them.¹⁶ In the current study, the majority of caregivers (58.2%) were female, while males accounted for 41.2%. Similarly, Sharma et al., found that out of the 60 parents included in their study, 28 (46%) were female and 32 (54%) were male. This gender disparity may be attributed to traditional gender roles in Indian society.

Education has a significant impact on the performance of caregivers. As per the present study, 8.4% of the caregivers were found to be illiterate, and only 10.1% were graduates. In contrast, Sharma et al., found that about half of the parents (48.3%) of children with cancer were educated up to or beyond graduation.¹⁵

According to the current study, the average age of children with cancer whose caregivers were included in the study was 8.84 years (SD \pm 4.5). The majority of these children, 38.4%, were between the ages of 6 and 10 years. A study conducted by Melur Sukumar Gautham et al., in Bangladesh reported that 35.7% of the respondents were aged 1–5 years, 43.4% were aged 5–10 years, and 20.9% were aged 10–15 years.¹⁷

According to the present study, the mean Zarit burden score of caregivers was 25 with a standard deviation of 7.08. Among the participants, 52.7% reported little or no burden and 20.25% reported moderate to severe burden. Studies by Mahnaz Chaghazardi et al., Shirin Hasanvand

Table 4: Association of burden on caregivers with caregivers' characteristics

Variable	Low (n=199)	High (n=38)	Total (n=237)	Test of significance	df	P-value
Marital status of the caregiver						
Married	193	36	229	1.732 (Fisher-exact)	1	0.421
Others	6	2	08			
Type of family of caregiver						
Nuclear	117	26	143	1.235	1	0.266
Joint	82	12	94			
Occupation of caregivers						
Housemaker	73	21	94	7.332 (Fisher-exact)	4	0.119
Unskilled, semi-skilled	104	17	121			
Private	12	0	12			
Unemployed	08	0	08			
Student	02	0	02			

et al., also found that caregivers of cancer patients experienced a moderate level of burden.^{18,19} However, a study by Chauhan et al., in 2016, reported that only 5.6% of caregivers experienced moderate to severe burden, possibly due to the perception of caring for children as a usual practice in Indian society.²⁰

Although the burden was higher among caregivers aged 30–39 years (45.5%), there was no statistically significant association between the age of caregiver and caregiver burden. This may be due to the fact that caregivers in this age group often have additional social roles, such as working and caring for other family members. In this study, 55.4% of female caregivers reported feeling burdened, but the association between gender and caregiver burden was not statistically significant ($P>0.05$). This is consistent with a report by Allegra, which noted that women tend to experience more burden than men due to their primary role in performing personal care tasks.²¹

This study reported that caregivers of children who were at the initial stage of cancer treatment (65.2%) felt more burdened. In contrast, other studies have reported that caregivers of patients who were at the initial stages of disease experienced higher levels of burden and that caregivers of children with chronic diseases who were responsible for caregiving for a longer period experienced lower levels of burden over time.^{22,23}

It appears that parents adapt to their child's illness and related limitations over time, resulting in a lower caregiving burden. For instance, Khademi et al., found that the level of care power of mothers who had a child with cancer increased with the duration of the disease.²⁴

Based on the findings, it's recommended to provide targeted support programs and resources for caregivers, especially focusing on those in the 30–39 age groups who may face additional social roles. In addition, interventions should address gender-specific caregiving challenges and adapt as caregivers adjust to their child's illness over time,

ensuring ongoing support as needed. Despite limitations including recall bias and a small sample size, this study offers valuable insights into the burden faced by caregivers of children with cancer. While unable to establish temporal relationships, its findings underscore the importance of tailored interventions and support services to alleviate caregiver burden and improve their overall well-being.

Limitations of the study

The study focused on children with cancer receiving regular treatment at LCDC, but did not examine the burden experienced by caregivers of children who left treatment.

While efforts were made to clarify the questionnaire, some participants may have found the Likert scale challenging.

Additionally, potential recall bias may have affected the findings, as participants recounted past experiences, and caregivers may have underreported their burden due to emotional attachment to their child.

CONCLUSION

Caregivers in this study, primarily mothers and fathers, experienced a moderate level of burden while caring for children with cancer, with most being married and receiving support from their families. No significant associations were found between caregiver burden and marital status or family type, indicating the need for broader support mechanisms irrespective of these factors.

ACKNOWLEDGMENTS

I would like to sincerely express my gratitude and admiration to the patients, caregivers of cancer patients, as well as the staff of LCDC, Surat, authorities, and all my friends who provided invaluable support and assistance in the successful completion of this study.

ETHICAL APPROVAL

The study has been approved by the Human Research Ethical Committee (HREC) of the Government Medical College, Surat, Gujarat, India.

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Authors Contribution:

PCC- Literature survey, implementation of study protocol, data collection, data analysis, manuscript review; **MRV**- Concept, design of study, clinical protocol, analysis, manuscript review; **KGB**- Statistical analysis, first draft of manuscript, manuscript preparation, editing, revision and submission of article.

Work attributed to:

Lions Cancer Detection Center Trust, Surat, Gujarat and Department of Community Medicine, Government Medical College, Surat, Gujarat

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Source of Support: Nil, **Conflicts of Interest:** None declared.