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A Cross-sectional Analysis of Caregiver Burden of Cancer Patients in North India's Urban Private Healthcare

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Abstract

Introduction: Cancer is a public health concern globally, affecting patients, their families, and caregivers facing multifaceted burdens encompassing physical, emotional, and financial aspects. Recognizing caregivers› well-being as integral to effective caregiving, the research aims to provide a comprehensive analysis of caregiver burden in two urban private hospital settings in urban India, employing a descriptive approach.

Methods: This study was conducted using a cross-sectional design. 89 pairs of cancer patients and their caregivers were interviewed one-on-one to collect data. Sociodemographic details were collected with a structured questionnaires and caregiving burdens were assessed by using the Zarit Burden Interview (ZBI-22). Statistical analysis of the results was done using SPSS software.

Results: Demographics revealed 71.9% of patients aged 50-75 years, 70% live in joint families, half unemployed, and over 1/3rd retired. Caregivers, 79.7% were primary caregivers with the majority between the age of 25-50. More than 80% lived with the patients and one-third had no employment. The mean caregiver burden score using ZBI-22 was 24.78 ± 13.88, with 41.6% experiencing mild to moderate burden and 11.2% facing moderate to severe burden. Significant burdens reported by caregivers were concerns regarding patients' future, caregiver dependency, work, and family responsibilities, personal expectations, lack of time for oneself, and poor social life.

Discussion: The findings indicated a comprehensive picture, with a significant proportion of caregivers reporting little to no burden and a substantial percentage experiencing mild to moderate burden. The study highlighted caregivers neglecting self-care, and financial issues were less prominent, with reliance on government-funded schemes. In the familial structure of Indian caregiving, ties are central, but caregivers may hesitate to acknowledge the burden.

Keywords: Cancer Patients; Caregivers; Caregiver Burden

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Introduction

Cancer is a significant public health concern with poor prognosis and high morbidity and mortality, affecting more than 1.7 million people globally. It compromises the well-being of the patient as well as their families [1]. The cancer illness trajectory is long and complex, and it is frequently difficult for both patients and caregivers, resulting in a plethora of care needs requiring constant attention from caregivers posing a burden on the caregivers [2-4]. Caregiver burden is a multidimensional concept encompassing physical, emotional, and financial aspects that can significantly impact the well-being of those providing care. Caregivers tending to highly symptomatic cancer patients are at an elevated risk of experiencing psychological, physical, financial, and social challenges. The burden on caregivers intensifies, particularly when they have limited resources, come from underprivileged backgrounds, or are in poor health. The burden was found highest on the caregivers providing care for more than six hours per day and generally increases over time [5-9]. Care giver burden increases if they have; health issues, younger, more close to the person they're caring for, and more educated. Implying, that caregivers may find it harder to manage the needs of the person they're looking after. Acknowledging and addressing these challenges is important to make sure caregivers get the support they need [6,10-12].

The familial ties establish the foundation for the caregiving process and give meaning to their role as caregivers which is beyond routine responsibilities. Furthermore, caregivers who are family members are integral contributors to the care and may not want to attract attention to their concerns or seek help because they do not want to acknowledge caregiving as a burden. Indian families are more active participants in caregiving and act as a central support system for the patient and therefore suffer a significant burden of care than their Western counterparts [9,13-15]. Despite the WHO's emphasis, current healthcare systems worldwide still do not adequately address family health qualitatively in care planning. There has been considerable research to address the needs of cancer patients in Western countries. Still, the present literature is deficient in addressing the needs of cancer patients' families and caregivers in developing countries. Also, significantly less data on the challenges experienced by caregivers at home in managing patients which compounds the burdens associated with caregiving roles [2,16,17]. Given the current state, the research provides sufficient evidence that caregivers' well-being is as significant as patients' for the effective caregiving process and establishes the need for research in this field in India. This study is aimed to further explore the caregiving burdens faced by the caregivers of cancer patients in India. So, that the results can be utilized to address these burdens and plan interventions accordingly.

Methods

Study Design

This study employed a descriptive cross-sectional design to assess caregiving burden among caregivers of cancer patients. This approach was selected for its ability to provide a comprehensive overview of caregiver burden at a specific point in time, facilitating an efficient and cost-effective analysis. While this design offers valuable insights, it does not allow for causal inferences, which is acknowledged as a study limitation.

Setting

The study was conducted in two private tertiary care hospitals in Punjab, India, recognized for their specialized oncology services and substantial patient inflow. These hospitals were deliberately chosen to ensure a diverse and representative sample of caregivers from an urban healthcare setting.

Participants

Cancer patients and their primary caregivers were recruited as dyads (paired participants) to ensure a holistic assessment of caregiving burden. The eligibility criteria were as follows:
Patients: Individuals diagnosed with cancer, attending the outpatient department (OPD) of the selected hospitals, irrespective of age, gender, or cancer type, and willing to participate.
Caregivers:

- Individuals accompanying the cancer patients, regardless of cohabitation status.
- Male or female adults aged 18 years and above.
- Those willing to provide informed consent and participate in the study.

Sampling Method

The convenience sampling method was used to collect data from eligible caregivers who were available and willing to participate during the study period. This method is chosen due to its practicality and efficiency in accessing participants who are readily available and willing to participate in the study. Although this sampling method may limit the generalizability of the findings, it allows for the timely and cost-effective collection of data necessary to achieve the study's objectives. To enhance the representativeness of the sample, efforts were made to include caregivers from diverse socio-demographic backgrounds.

Study Period

The study was conducted over three months, ensuring sufficient data collection while maintaining feasibility within the study constraints.

Sample Size

89 caregiver-patient pairs/dyads were included in the study. The decision to stop data collection at the given sample size was guided by the saturation point, indicating that the researchers stopped encountering new caregivers within the study period, at the selected research settings.

Data Collection Tools

Structured questionnaires were utilized to collect socio-demographic information from both patients and caregivers. Caregiver burden was assessed using the Zarit Burden Interview (ZBI-22), a validated and widely used tool developed by Zarit, Reever, and Bach-Peterson (1980) [14,18-20]. The present study utilized the most recent version of the scale which included 22 questions and scored the level of burden as "little or no burden (0-21)", "mild to moderate (21-40)", "Moderate to severe (41-60)" and "Severe burden (61-88)". Permission to use the ZBI-22 was obtained from the relevant authorities. The tool has demonstrated strong psychometric properties and has been extensively used in caregiving research.

Data Collection Procedure

The researchers have obtained ethical approval and institutional permissions from the concerned authorities to use the tool in the present study. After obtaining informed consent, data was collected using one-on-one interviews by the researchers over three months. To ensure confidentiality and participant comfort, interviews were conducted in a private setting within the hospital premises. Language preferences were accommodated, with interviews conducted in English or Hindi, based on participant preference. The average duration of each interview was 20-30 minutes.

Data Analysis

Data analysis was conducted using SPSS. The following statistical techniques were applied:

Descriptive Statistics: Used to summarize socio-demographic characteristics of patients and caregivers, including means, frequencies, and percentages and caregiver-burden scores.

Reliability Analysis: The internal consistency of the Zarit Burden Interview (ZBI-22) was evaluated using Cronbach's alpha (0.804) and the Spearman-Brown coefficient (0.834), both of which indicated strong reliability.

Ethical Consideration

This study was conducted as a part of a thesis for M.Sc. Nursing (Oncology Nursing) after acceptance from the ethical committee of the university. (Letter no. BFUHS/2K22/p-TH/3903). The data was collected from the participants after securing informed consent.

Results

Socio-Demographic Characteristics of Patients

The majority of the patients (61.8%) had 1-5 members in the family. Almost 2/3rd of the subjects, (71.9%), were from 50-75 years. More than half of the subjects were female (53.9%). Only 33.7% of patients were educated up to the secondary level. 92% of the patients were married. Almost 70 percent belonged to a joint family. Nearly half of the study subjects were not employed and more than one-third were retired. More than 60% of the patients had a monthly family income of 10000-50000. Although, 80.9% of the patients did not have any health insurance for 67.4% of the patients the treatment was funded through government health schemes like CGHS and EHIS. For the complete demographic profile of the patient refer to Table 1.

Sr. No.	Socio-Demographic Profile of the Patient		f	%
1.	Total number of family members	1-5	55	61.80
		6-10	31	34.80
		11-15	03	03.40
2.	Age (in years)	<25	01	01.12
		25-50	15	16.85
		50-75	64	71.91
		>75	09	10.11
3.	Gender	M	41	46.07
		F	48	53.93
4.	Religion	Hindu	65	73.03
		Muslim	0	00.00
		Sikh	23	25.84
		Christian	0	00.00
		Other	01	01.12

5.	Educational background	No formal Education	18	20.22
		Primary Education	18	20.22
		Secondary Education	30	33.71
		Graduate & above	22	24.72
6.	Marital status	Single	01	01.12
		Married	82	92.13
		Divorced	00	00.00
		Widowed	06	6.74
7.	Type of Family	Nuclear	27	30.34
		Joint	62	69.66
8.	Employment status	Not employed	44	49.44
		Self-employed	04	04.49
		Private Job	03	03.37
		Government Job	06	06.74
		Retired	32	35.95
9.	Family income (monthly)	<10000	04	04.49
		10000-50000	56	62.92
		50000-1 lac	21	23.60
		>1 lac	08	08.99
10.	H/O Co-morbidities	Yes	33	37.08
		No	56	62.92
11.	If yes, specify.	DM	20	60.60
		HTN	15	45.45
		Others	07	21.21
12.	Duration since diagnosis of cancer	<3 months	34	38.20
		3-6 months	31	34.83
		6months - 1year	09	10.11
		<3 months	15	16.85
13.	Duration since undergoing chemotherapy or radiation	3-6 months	68	76.40
		6months - 1year	15	16.85
		>1 year	04	04.49
		Yes	02	02.25
14.	Family history of cancer	No	23	25.84
		Yes	66	74.16
15.	Family history of treatment with chemotherapy or radiotherapy	No	21	23.60
		Yes	68	76.40
16.	Do you have health insurance	No	17	19.10
		Out-of-pocket expense	72	80.90
17.	If not, how do you pay for the treatment	Government-funded	10	11.24
		Assistance by	60	67.42
		community resources	0	0.00

Table 1: Socio-demographic profile of patients N=89.

Socio-Demographic Characteristics of Caregivers

Among the caregivers, 79.7% were primary caregivers of the patient. More than 75% of caregivers were from 25-50 years of age. More than half of the caregivers were male as they were accompanying the patient for the treatment. More than half (51.6%) were educated up to graduate & above level. 83.1% of caregivers lived with the patient. 1/3rd of the caregivers had no employment, and the other 1/3rd had a private job. Among the total caregivers, 34.8% devoted 2-6 hours, and 28% devoted more than 8 hours to care for the patient every day. Eighty percent of the caregivers claimed that the patient did not have health insurance (Table 2).

Sr. No.	Socio-Demographic Profile of Caregivers			%
1.	Total number of family members	**1-5**	**54**	**60.67**
		6-10	31	34.83
		11-15	04	04.49
2.	Are you the primary caregiver	**yes**	**71**	**79.78**
		no	18	20.22
3.	Availability of other caregivers	**yes**	**79**	**88.76**
	in the family	no	10	11.24
4.	Age of caregiver (in years)	<25	05	5.62
		25-50	**67**	**75.28**
		50-75	16	17.98
		>75	01	1.12
5.	Gender	**M**	**57**	**64.04**
		F	32	35.96
6.	Relationship with the patient	Parent	02	2.25
		Sibling	04	4.49
		Spouse	23	25.84
		Child	**42**	**47.19**
		Child in law	08	8.99
		Other	08	8.99
7.	Religion	**Hindu**	**66**	**74.16**
		Muslim	00	0.00
		Sikh	22	24.72
		Christian	00	0.00
		Other	01	1.12
8.	Educational background	No formal Education	02	2.25
		Primary Education	07	7.87
		Secondary Education	32	35.96
		Graduate & above	**46**	**51.69**

9.	Marital status	Single	17	19.10
		Married	**72**	**80.90**
		Divorced	0	0.00
		Widowed	0	0.00
10.	Living with the patient	**Yes**	**74**	**83.15**
		No	15	16.85
11.	Family income (monthly)	<10000	04	04.49
		10000-50000	**52**	**58.43**
		50000-1 lac	20	22.47
		>1 lac	13	14.61
12.	Employment status	**Not employed**	**30**	**33.71**
		Self-employed	07	07.87
		Private Job	**33**	**37.08**
		Government Job	11	12.36
		Retired	08	8.99
13.	Loss of job because of caregiving	**Yes**	**22**	**24.72**
		No	67	75.28
14.	Length of caregiving period	**<3 months**	**54**	**60.67**
	since diagnosis	3-6 months	16	17.98
		6months - 1year	08	08.99
		>1 year	10	11.24
15.	Approximate time devoted every day	< 2hours	14	15.73
	for care of the patient	**2-6 hours**	**31**	**34.83**
		6-8 hours	17	19.10
		>8 hours	25	28.09
16.	Does the patient have health insurance	Yes	17	19.10
		No	**72**	**80.90**

Table 2: Socio-demographic profile of caregivers N=89.

Caregiver Burden of Cancer Patients

The mean score of caregiver burden based on the Zarit Burden Interview was 24.78 ± 13.88. The findings revealed that 41.6% of the caregivers experienced mild to moderate burden and only 11.2% had a caregiving burden from moderate to severe (Table 3).

Level		Frequency (f)	Percentage (%)
Little or No Burden	0 - 20	**42**	**47.2**
Mild to Moderate Burden	21 - 40	**37**	**41.6**
Moderate to Severe Burden	41 - 60	10	11.2
Severe Burden	61 - 88	0	0

Table 3: level of caregiving burden of caregivers N=89.

The significant burdens of caregivers while caregiving for a cancer patient were depicted using the total scores of each item given by 89 caregivers. The most significant burden was related to the future of the patient, followed by the dependency of the patient on the caregiver. Other significant burdens that emerged from the burden scale were caregivers being stressed between caregiving and other responsibilities of work and family, expectations from self, lack of time for self, poor social life, and overall perceived burden (Table 4).

Sr. No.	Burdens	Total Score
1.	Future of the patient	187
2.	Dependency of the patient on the caregiver	158
3.	Stress - between caregiving and other responsibilities of work and family	151
4.	Expectations from self – could do a better job in caring for the patient and should be doing more for the patient	137
5.	Lack of time for self	133
6.	Poor social life	132
7.	Overall caring burden	126

Table 4: Significant burdens of caregivers while caregiving for cancer patients.

Discussion

Caregivers, such as family members, spouses, and friends, play an essential role in handling patients' issues and meeting their needs during their disease trajectory, affecting their quality of life and rehabilitation. Therefore, this study aimed to explore the perceived burden of care in caregivers of cancer patients in Indian families. In the current study the caregivers accompanying cancer patients in OPD were included, 47.2% of caregivers reported little-no burden and 41.6% reported mild to moderate burden of caregiving. These findings correlate with the studies conducted by Chovatiya PC, et al. [21,22] which reported minimal burden in 52.7% and 56.5%, and mild to moderate burden in 20.25% and 43.5% of the family caregivers respectively. Similarly, in the study conducted by Kulkarni S, et al. [23] caregiver burden was found to be mild to moderate in 58.8% of the caregivers. Conversely, the study conducted by Mishra S, et al. [6] reported mild to moderate burden in more than 70% of the caregivers. The results of this research revealed mean score on the Zarit Burden Interview was 24.78 ± 13.88. A study conducted by Chovatiya PC, et al. [22] had similar findings with Zarit Burden Score of 25.6 ± 12.9. Another studies such as Mishra S, et al. [6] and Harding R, et al. [24] reported similar results with means of 30.697 ± 8.96 and 23.3 respectively.

In the study conducted by Joad ASK, et al. [25], most of the caregivers were in the age group of 30-60 years. These findings are also supported by the present study as the majority of the caregivers in the present study were also in the age group of 25-50 years of age. The previous study also reported the neglect of self-care by the caregivers while caring for the cancer patient, which was also identified as one of the major burdens in the present study. Aggarwal M, et al. [26], Williams SW, et al. [27], and Leff J, et al. [28] respectively in their studies reported good social support as a predictor for better caregiving and well-being of the caregiver, and that the caregiving burden can be dispersed in joint families. Another study (2015) highlighted that in the Indian subcontinent family caregiving is not considered as a specific role and a burden that's why the reporting of caregiving as a burden is far less than the western countries.21 Similarly, in this study, the majority of the patients (61.8%) and caregivers (60.6%) reported having a family of 1-5 members.

A qualitative study was conducted by Teschendorf B, et al. [29] to assess the role of stress experienced by cancer caregivers. The study revealed that lack of time for self-care among caregivers was one of the major concerns. The present study also reported a lack of time for themselves (more than 50%) as one of the main problems reported by the caregivers. This is the highest burden reported by the caregivers. In the present study, many caregivers reported availability of less time for children and other family members (more than half) because of caregiving to the patient in the family. Similarly, Emanuel N, et al. [30] suggested that caregivers were feeling burdened as they could not take care of their children/ spouses due to their responsibilities as caregivers. Hence, the findings of this study also corroborated with the present study results. Among the subjects interviewed in the present study, financial problems were inconsistent with the earlier studies as most of the subjects included in this study paid for their treatment through government-funded schemes such as CGHS and ESIC, i.e., more than 80%. The previous studies report the increased financial burden on the caregivers related to the diagnosis of cancer and its treatment. Hence the inconsistency in the results was identified because of the difference in sociodemographic characteristics of the study sample [2,16,25].

Recent studies reinforce our findings on caregiver burden in urban private healthcare settings. Our study identified emotional distress, time constraints, and disruptions in family responsibilities as major burdens, aligning with a 2024 Pune study that highlighted financial strain, increased workload, and emotional stress among caregivers, particularly spouses [31]. Similarly, a 2023 study on mental health found that younger and female caregivers faced greater burden, supporting our observation that caregiving challenges intensify with prolonged responsibilities [32]. Additionally, our study noted that caregivers struggled with neglecting self-care, consistent with a 2022 Tata Memorial Centre study, which linked patient psychological distress and caregiver education to higher burden levels. While financial burden was less pronounced in our study due to government schemes like CGHS and ESIC, other studies report significant financial stress, emphasizing the need for targeted policy interventions, caregiver training programs, and financial aid to ease caregiving challenges in diverse settings [33].

The level of caregiver burden identified in the contemporary analysis was mainly ranging from little to moderate because the family members of the patients were the primary caregivers. Moreover, the Indian familial structure is more adherent in its nature than its Western counterparts thereby dispersing the perception of caregiving as a burden. However, the supporting data provided is taken from the studies conducted in various fields and not only in cancer patients, which impedes the generalization of the findings to the caregiver burden of cancer patients. This calls for the need to conduct more research in the field of oncology.

Study Limitations

While this study provides valuable insights, several limitations must be acknowledged:

- The study was conducted in private tertiary care hospitals, potentially limiting its applicability to caregivers in government hospitals or rural settings, where caregiving burdens may differ significantly. The use of convenience sampling may have introduced selection bias, as only caregivers who were readily available and willing to participate were included.
- It was observed that the presence of their patient in the vicinity might have influenced the response of caregivers in terms of accepting caregiving as a burden, possibly leading to underreporting of burden due to social desirability bias.
- The study’s cross-sectional nature restricts the ability to assess causal relationships or changes in caregiver burden over time.
- With only 89 dyads, the findings, while informative, may not fully represent the broader population of cancer caregivers in India. 6.) Given that Indian culture often normalizes caregiving as a familial duty, caregivers might have understated their burdens, affecting the accuracy of self-reported data.

Future Research Recommendations

- A larger, multi-center study involving government hospitals and rural settings would improve generalizability.
- Longitudinal studies may follow changes in caregiver burden over time, providing more profound insights into how burden evolves over time.
- Qualitative research could explore emotional, social, and psychological aspects of caregiving, to supplement the quantitative findings.
- A comparative study comparing differences of burdens on caregiver between private and government healthcare settings could provide valuable policy insights for quality improvement.

The findings of this study highlights the need for evidence based interventions and policies for the support of cancer caregivers. Some potential recommendations include:

- Caregiver support programs: Hospitals and healthcare institutions should establish and implement structured support programs offering counselling, mental health support, and respite care to caregivers.
- Financial Support and policy integration: Expansion of government-funded schemes such as CGHS and ESIC to cover indirect caregiving costs (e.g., transportation, loss of income) would reduce the financial burdens on caregivers.
- Integration of caregiver training: Educating caregivers on patient care, stress management, and self-care strategies could improve their coping mechanisms and help reduce perceived burden.
- Community-based interventions: Creating caregiver support groups and networks among local communities can cater to emotional and social support needs of caregivers, reducing isolation and stress.
- Integration of caregiver needs into practice: Healthcare professionals should assess caregiver burden during routine patient visits and provide referrals to appropriate support services.

Conclusion

Caregiving to a patient suffering from cancer is a complex task posing numerous problems and burdens on a caregiver. This study provides important insights into the levels of burden experienced by cancer caregivers in India, highlighting that most caregivers reported little to moderate burden, likely influenced by strong family support systems. This study identifies the burdens of caregiving to cancer patients. Further research, particularly in government settings, is recommended to validate and build upon these findings, ultimately advancing our understanding of the complex dynamics of caregiver burden in the context of cancer care. By acknowledging these challenges and conducting further research, healthcare providers, policymakers, and support organizations can better design interventions to alleviate caregiver burden and enhance the well-being of those who play an indispensable role in cancer care.

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