crossef doi: 10.21276/SSR-IIJLS.2025.11.3.40

Original Article

opendaccess

Pattern of Primary Caregiver, Caregiver Burder and Quality of Life of Caregiver in Patient on Palliative Chemotherapy from Central India: Single Institute Observational Study

Shaunak Valame¹, Harsh Sahu¹, Vijay Kumar Bhargava², Kanchan Singh³*

¹Consultant, Department of Medical Oncology, Jawaharlal Nehru Cancer Hospital & Research Centre, Bhopal, Madhya Pradesh, India

²HOD & Senior Consultant, Department of Medical Oncology, Jawaharlal Nehru Cancer Hospital & Research Centre, Bhopal, Madhya Pradesh, India,

³3rd Year DNB Resident, Department of Medical Oncology, Jawaharlal Nehru Cancer Hospital and Research Institute, Bhopal, India

*Address for Correspondence: Dr. Kanchan Singh, 3rd Year DNB Resident, Department of Medical Oncology, Jawaharlal Nehru Cancer Hospital and Research Institute, Bhopal, India E-mail: kanchansinghrewa@gmail.com

Received: 29 Jan 2025/ Revised: 11 Feb 2025/ Accepted: 24 Apr 2025

ABSTRACT

Background: Family members who provide informal care for individuals undergoing cancer treatment often face considerable challenges that can adversely impact their quality of life (QOL). This study sought to evaluate the pattern and extent of primary caregiver burden and its correlation with QOL among caregivers of cancer patients receiving palliative chemotherapy.

Methods: A prospective observational investigation was conducted at a tertiary healthcare facility, enrolling 234 primary caregivers. The level of burden experienced by caregivers was measured using the Zarit Burden Interview (ZBI), while QOL was assessed utilizing the World Health Organization Quality of Life-BREF (WHOQOL-BREF) instrument.

Results: The average age of caregivers was 37.12 years (±11.06), and the mean ZBI score recorded was 31.73 (±9.87). Among participants, 70.09% reported experiencing a mild-to-moderate level of caregiving burden, whereas 21.37% encountered a moderate-to-severe burden. The mean scores on the WHOQOL-BREF domains were as follows: overall QOL–5.79 (±1.84), physical domain–48.07 (±14.76), psychological domain–52.73 (±19.01), social relationships–57.43 (±19.14), and environmental factors–56.63 (±17.19). While caregivers with lesser burden tended to report slightly higher QOL across most domains, a statistically significant difference was not observed, except for the social relationship's domain. No notable differences were identified in either burden or QOL metrics between male and female caregivers.

Conclusion: A substantial proportion of caregivers experienced a mild to moderate burden, with nearly one-fifth enduring a moderate to severe burden. These findings underscore the importance of supportive interventions for caregivers of hospitalized cancer patients.

Key-words: Cancer, Chemotherapy, Caregiving, Caregiver quality of life, Physiological resilience

How to cite this article

Valame S, Sahu H, Bhargava VK, Singh K. Pattern of Primary Caregiver, Caregiver Burder and Quality of Life of Caregiver in Patient on Palliative Chemotherapy from Central India: Single Institute Observational Study. SSR Inst Int J Life Sci., 2025; 11(3): 7588-7592.



Access this article online https://iijls.com/

INTRODUCTION

Cancer has emerged as a significant contributor to global morbidity and mortality, with its impact being notably substantial in countries such as India. The therapeutic protocols involving chemotherapy are often intricate, and oncology patients represent a particularly vulnerable cohort with limited physiological resilience ^[1]. Individuals experiencing severe clinical manifestations—either as a direct result of malignancy or as adverse effects from oncologic therapies—require more intensive and prolonged caregiving involvement compared to those presenting with milder symptoms. Consequently, the burden on caregivers of such patients is markedly elevated, encompassing psychological, physical, financial, and social domains. This strain is further amplified in caregivers who themselves face socioeconomic disadvantages or suffer from compromised health status ^[2].

The role of caregiving in oncology frequently compromises the caregiver's QOL, primarily due to the cumulative stress it imposes. Contributing factors to deteriorating caregiver well-being include existing health limitations, insufficient social networks, diminished patient autonomy, and cognitive decline in the patient [3-^{5]}. Additionally, evidence suggests that caregiver burden is progressive and tends to escalate with time ^[6]. The subjective stress linked to caregiving responsibilities predominantly impairs mental well-being and plays a central role in the emergence of psychological distress, including depressive symptoms, among caregivers ^[7,8]. The intensity of the caregiver's symptom burden has been reported to be higher among those with underlying chronic conditions, younger age, close familial ties to the patient, and higher educational attainment.

Caregivers occupy a critical position in facilitating patient recovery across various care settings, whether in outpatient services, hospital wards, or intensive care environments. Their ability to effectively communicate with healthcare professionals, empathize with the patient's emotional state, and provide motivational support is invaluable in the patient's journey through severe illness. Therefore, maintaining the physical and mental health of caregivers warrants equal attention as that of the patient.

MATERIALS AND METHODS

Study design and setting- This was a prospective observational study conducted at a tertiary healthcare center in Central India.

Participants- The study population included informal caregivers of cancer patients undergoing palliative chemotherapy. A total of 234 eligible caregivers who completed the required questionnaires were included.

Inclusion criteria

 Informal caregivers of cancer patients receiving chemotherapy

Age between 18 and 65 years

- Either sex
- Provided informed consent

Exclusion criteria

- Caregivers unable to complete assessment tools
- Incomplete questionnaire responses (25 excluded)

Data collection tools- The caregiver burden was evaluated using the Zarit Burden Interview (ZBI), and quality of life was assessed using the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire. Additional information including demographic profiles, patient diagnosis, educational and occupational status, and clinical data (e.g., need for respiratory or inotropic support, hepatic dysfunction, renal replacement therapy) was recorded.

Statistical Analysis- Descriptive statistics were reported as frequencies and percentages for categorical variables. Continuous variables were analyzed using the Kruskal– Wallis and Mann–Whitney U tests. Chi-square and Fisher's exact tests were used for categorical data.

Ethical Clearance- Ethical approval was obtained from the institutional ethics committee before study initiation.

RESULTS

The study sample included 234 patients and their caregivers, with mean ages of 39.26±17.80 years and 37.12±11.06 years, respectively (Table 1). The patient group was nearly balanced in gender distribution, with males comprising 51.71% and females 48.29%, whereas caregivers had a slight female predominance (53.42%) compared to males (46.58%). A majority of caregivers were married (88.03%) and had attained education beyond the metric level (76.5%), both higher than corresponding patient proportions (66.67% and 55.56%, respectively). Employment was more common among caregivers (41.45%) than patients (23.08%). The mean duration of disease among patients was 12.85±10.82 years, and comorbidities were reported in 20.94% of patients and 13.68% of caregivers (Table 1).

Table 1: D	Demographic	characteristics
------------	-------------	-----------------

Characteristic	Patient	Caregiver
Age (years); Mean±SD	39.26±17.80	37.12±11.06
Gender; n (%)		
Males	121 (51.71)	109 (46.58)

crossed doi: 10.21276/SSR-IIJLS.2025.11.3.40

Females	113 (48.29)	125 (53.42)
Married; n (%)	156 (66.67)	206 (88.03)
Education (> metric); n (%)	130 (55.56)	179 (76.5)
Employed; n (%)	54 (23.08)	97 (41.45)
Duration of disease (years); Mean±SD	12.85±10.82	_
Comorbidities; n (%)	49 (20.94)	32 (13.68)

The mean ZBI score recorded was 31.73 (±9.87). Assessment of caregiver burden revealed that 70.09% experienced mild to moderate burden, while 21.37% reported moderate to severe burden, and only 8.55% had minimal burden (Table 2).

Table 2: Burden among caregivers byZBI

Level of Burden	n	%
Minimal	20	8.55
Mild to Moderate	164	70.09
Moderate to Severe	50	21.37

Burden levels were significantly associated with caregiver employment status and gender (p<0.05 for both). Employed caregivers and females were more likely to report minimal or mild to moderate burden, whereas unemployed caregivers and males were disproportionately represented in the moderate to severe burden category (Table 3).

Table 3: Relationship of caregiver burden with

 caregiver's occupation and patient's gender

Level of Burden	U	E	М	F
Minimal	12	8	12	8
Mild to	85	70	85	70
Moderate	6	75	65	75
Moderate to	20	11	12	20
Severe	39	11	12	50
p-value	p<0.05		p<0.05	

U- Unemployed; E- Employed; M- Male Caregiver; F- Female Caregiver

The mean scores on the WHOQOL-BREF domains were as follows: overall QOL–5.79 (\pm 1.84), physical domain–48.07 (\pm 14.76), psychological domain–52.73 (\pm 19.01), social relationships–57.43 (\pm 19.14), and environmental factors–56.63 (\pm 17.19). Stratification by burden levels demonstrated a trend towards lower QOL scores with

increasing burden severity across all domains. Caregivers with moderate to severe burden had notably reduced psychological (48.60±18.40) and social relationship scores (51.00±20.90) compared to those with minimal or mild to moderate burden. Physical health scores were marginally lower in the moderate to severe burden group (46.30±14.80) relative to the other groups, while environmental domain scores also declined with the increasing burden (54.00±15.60) (Table 4).

WHO QOL Domain	Minimal Burden	Mild-to- Moderate Burden	Moderate-to- Severe Burden	
Physical	49.00±13.50	48.90±15.90	46.30±14.80	
Health				
Psychological	55 40+18 80	54 20+19 80	48 60+18 40	
Health	55.40±10.00	54.20119.00	40.00±10.40	
Environment	58 50+10 10	57 40+16 70	54 00+15 60	
Health	38.30-13.10	57.40110.70	54.00±15.00	
Social	EQ 10+1E 70	62 20+20 40	51 00+20 00	
Relations	30.10113.70	05.20120.40	51.00120.90	
			•	

Table 4: WHO-QOL and ZBI burden among caregivers

DISCUSSION

Informal caregivers of individuals with cancer face considerable challenges due to the disease's associated morbidity and the adverse effects stemming from chemotherapy. Such demands negatively impact the caregiver's physical health, psychological state, emotional well-being, QOL, occupational functioning, and financial stability.

In our cohort, most caregivers were either spouses or children, with approximately one-third being parents or siblings. No statistically significant variation in caregiver burden was observed based on the nature of the familial relationship. The extent and psychological consequences of this burden are influenced by factors such as disease stage, the level of social support available to caregivers, and the duration of illness. Huang *et al.* ^[9] proposed that extended caregiving periods may correlate with reduced distress symptoms due to caregivers' adaptation over time.

A majority of participants experienced mild to moderate burden. These findings align with Mirsoleymani *et al.* ^[10], who reported that 48.1% of Iranian cancer caregivers experienced a high burden, assessed via the Caregiver Burden Inventory in an outpatient chemotherapy context. Conversely, Lukhmana *et al.* ^[11] utilized the ZBI among outpatient caregivers and found that 56.5% had little to no burden, while 43.5% reported mild to severe burden.

The mean ZBI score in our study was comparable to Harding *et al.* ^[12], who reported a mean score of 23.3 among cancer caregivers—a lower burden relative to caregivers of dementia and acquired brain injury patients. Their cohort was drawn from a multicenter evaluation of palliative daycare and supportive interventions for advanced cancer caregivers.

Cameron *et al.* ^[13] reported a high prevalence of depressive symptoms among caregivers of critically ill patients, with 67% exhibiting depression initially and 43% persisting after one year. Similarly, van Beusekom *et al.* ^[14] reviewed 28 studies documenting psychological distress as the predominant burden among informal caregivers of ICU survivors. Reported symptoms included anxiety (15%–24%), depression (4.7%–36.4%), and posttraumatic stress disorder (35%–57.1%), lasting beyond six months post-ICU discharge. Khan *et al.* ^[15] examined QOL, spirituality, and social support in cancer caregivers, finding physical well-being comparable to non-caregiving controls, while psychological well-being, social relationships, and environmental factors differed significantly.

Despite the substantial time and stress involved in caregiving, most participants in our study reported only a mild to moderate burden. This may reflect the influence of the Indian familial structure, which offers robust social support—a key determinant of caregivers' physical and mental health ^[16]. The traditional joint family system prevalent in many Indian regions provides social and economic assistance, buffering members during illness or crises and accommodating behavioral deviations.

Leff *et al.* ^[17] observed that joint family arrangements reduce caregiving burden among relatives of mentally ill patients and are predictive of improved clinical outcomes. Further, the adoption of problem-focused coping strategies, coupled with strong social support within Indian cultural contexts, has been linked to more favorable caregiving experiences ^[18].

Our findings suggest that the predominantly mild to moderate burden observed, despite the significant disease impact, may be attributable to these familial support systems, which facilitate shared caregiving roles during times of need. However, most supporting evidence comes from psychiatric literature rather than oncology.

Study limitations include the inability to quantitatively assess economic burden using the employed instruments. Additionally, the inpatient subgroup was heterogeneous regarding symptom severity and illness duration, restricting accurate burden evaluation in critically ill patients. Finally, the single-center design and modest sample size may limit the generalizability of our results.

CONCLUSIONS

A mild-to-moderate level of caregiving burden was reported by the majority of participants. The comparison of WHOQOL-BREF scores between these two groups revealed no significant differences across most domains. The traditional Indian family structure likely provides emotional and social support, contributing positively to caregivers' psychological and interpersonal well-being.

CONTRIBUTION OF AUTHORS

Research concept- Shaunak Valame, Harsh Sahu Research design- Shaunak Valame, Kanchan Singh Supervision- Vijay Kumar Bhargava Materials- Harsh Sahu, Kanchan Singh Data collection- Shaunak Valame, Kanchan Singh Data analysis and interpretation- Kanchan Singh Literature search- Harsh Sahu, Kanchan Singh Writing article- Harsh Sahu, Kanchan Singh Critical review- Vijay Kumar Bhargava Article editing- Harsh Sahu, Kanchan Singh Final approval- Vijay Kumar Bhargava

REFERENCES

- Jena D, Padhi BK, Zahiruddin QS, et al. Estimation of burden of cancer incidence and mortality in India: based on Global Burden of Disease Study 1990–2021.
 BMC Cancer, 2024; 24: 1278. doi: 10.1186/s12885-024-13035-6.
- [2] Mishra S, Gulia A, Satapathy S, Gogia A, Sharma A, et al. Caregiver burden and quality of life among family caregivers of cancer patients on chemotherapy: a prospective observational study. Indian J Palliat Care, 2021; 27: 109–12.
- [3] Miller B, Townsend A, Carpenter E, Montgomery RV, Stull D, et al. Social support and caregiver distress: a

crossef doi: 10.21276/SSR-IIJLS.2025.11.3.40

replication analysis. J Gerontol B Psychol Sci Soc Sci., 2001; 56(4): S249–56.

- [4] Carson SS, Bach PB, Brzozowski L, Leff A. Outcomes after long-term acute care: an analysis of 133 mechanically ventilated patients. Am J Respir Crit Care Med., 1999; 159(5 Pt 1): 1568–73.
- [5] Knight BG, Lutzky SM, Macofsky-Urban F. A meta-analytic review of interventions for caregiver distress: recommendations for future research. Gerontologist., 1993; 33(2): 240–48.
- [6] Weitzenkamp DA, Gerhart KA, Charlifue SW, Whiteneck GG, Savic G. Spouses of spinal cord injury survivors: the added impact of caregiving. Arch Phys Med Rehabil., 1997; 78(8): 822–27.
- [7] Stommel M, Wang S, Given CW, Given B. Confirmatory factor analysis as a method to assess measurement equivalence. Res Nurs Health, 1992; 15(5): 399–405.
- [8] Kim Y, Schulz R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. J Aging Health, 2008; 20: 483–503.
- [9] Huang CY, Musil CM, Zauszniewski JA, Wykle ML. Effects of social support and coping of family caregivers of older adults with dementia in Taiwan. Int J Aging Hum Dev., 2006; 63: 1–25.
- [10]Mirsoleymani SR, Rohani C, Matbouei M, Nasiri M, Vasli P. Predictors of caregiver burden in Iranian family caregivers of cancer patients. J Educ Health Promot., 2017; 6: 91.

- [11]Lukhmana S, Bhasin SK, Chhabra P, Bhatia MS. Family caregivers' burden: a hospital-based study in 2010 among cancer patients from Delhi. Indian J Cancer, 2015; 52: 146–51.
- [12] Harding R, Gao W, Jackson D, Pearson C, Murray J, et al. Comparative analysis of informal caregiver burden in advanced cancer, dementia, and acquired brain injury. J Pain Symptom Manag., 2015; 50: 445–52.
- [13]Cameron JI, Chu LM, Matte A, Tomlinson G, Chan L, et al. One-year outcomes in caregivers of critically ill patients. N Engl J Med., 2016; 374: 1831–41.
- [14]van Beusekom I, Bakhshi-Raiez F, de Keizer NF, Dongelmans DA, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. Crit Care, 2016; 20: 16.
- [15]Khan S, Siddiqi A, Nisar A. Quality of life, spirituality and social support among caregivers of cancer patients. IOSR J Electr Electron Eng., 2015; 10: 11–15.
- [16]Williams SW, Williams CS, Zimmerman S, Munn J, Dobbs D, et al. Emotional and physical health of informal caregivers of residents at the end of life: the role of social support. J Gerontol B Psychol Sci Soc Sci., 2008; 63: S171–83.
- [17]Leff J, Wig NN, Bedi H, Menon DK, et al. Relatives' expressed emotion and the course of schizophrenia in Chandigarh: a two-year follow-up of a first-contact sample. Br J Psychiatry, 1990; 156: 351–56.
- [18]Aggarwal M, Avasthi A, Kumar S, Grover S. Experience of caregiving in schizophrenia: a study from India. Int J Soc Psychiatry, 2011; 57: 224–36.

Open Access Policy:

Authors/Contributors are responsible for originality, contents, correct references, and ethical issues. SSR-IIJLS publishes all articles under Creative Commons Attribution- Non-Commercial 4.0 International License (CC BY-NC). <u>https://creativecommons.org/licenses/by-nc/4.0/legalcode</u>