

Assessment of Caregiver Burden in Family Caregivers of Patients with Advanced Cancer in Palliative Care Settings: A Prospective Observational Study Using the Zarit Burden Interview

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ABSTRACT

Objective: Quantify caregiver burden among 600 family caregivers of adult cancer patients, using the 22-item Zarit Burden Interview (ZBI).

Methods: Cross-sectional study (July–December 2024). ZBI scores (0–88) were categorized: 0–20 (little/no), 21–40 (mild–moderate), >40 (moderate–severe/severe). Demographics and caregiving profiles were recorded. SPSS v25 was used for descriptive analyses.

Results: Most caregivers were male (90%), with a mean age of 45.3 ± 12.2 years, and nearly all were co-residing with the patient; sons constituted the largest group (36.6%). Overall, 40% reported moderate–severe burden (mean ZBI 23.35 ± 5.28). ZBI scores showed strong positive correlations with household income (r = 0.72) and caregiver age (r = 0.60).

Conclusions: A significant 40% of caregivers are in moderate–severe distress. Regular ZBI screening and tailored support—counseling, information, respite—are crucial to mitigate burden.

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INTRODUCTION

Cancer has emerged as one of the most formidable global health crises of the 21st century. In 2022 alone, the world witnessed an estimated 19.3 million new cases and approximately 9.7 million deaths^[1,2]

The trajectory of this disease is set for a dramatic escalation; by 2040, the annual incidence of new cases is projected to reach 28.4 million, representing a 47% increase. This surge is largely driven by a combination of global population aging and shifting lifestyle factors^[3] Crucially, the highest relative rise is anticipated in low- and middle-income regions, where healthcare infrastructures are already significantly strained and may struggle to keep pace with the growing demand for oncology services^[1,5]

In India, the oncology landscape mirrors these global trends with alarming precision. The national cancer incidence rose from 1.46 million cases in 2022 and is expected to reach 1.57 million by 2025, maintaining a crude rate of 100.4 per 100,000 population^[1,3,7,9]

Lung cancer remains the most prevalent site among men, while breast cancer continues to be the leading site in women. Despite the implementation of various national health initiatives, the distribution of formal palliative care and specialized caregiver support remains starkly uneven, often concentrated in metropolitan hubs while leaving rural and semi-urban areas underserved^[2,6,7]

The deficiency in formal support systems necessitates a heavy reliance on family caregivers, who serve as the "invisible backbone" of the healthcare system. These individuals provide unpaid, often intensive support—

ranging from physical assistance and symptom management to complex emotional guidance—frequently over long durations^[11,13] Such high-demand roles place these caregivers at significant risk for psychological morbidity. Indeed, a recent meta-analysis of 35 studies involving over 11,000 caregivers reported a pooled 42% prevalence of depressive symptoms among those caring for cancer patients^[14,17]

Furthermore, systematic reviews have highlighted a critical gap in research: many existing measures for quantifying this strain, including the Zarit Burden Interview (ZBI), lack comprehensive psychometric validation within diverse cultural settings. This underscores a pressing need for robust, context-specific data to understand the unique socioeconomic and cultural stressors inherent in the Indian caregiving experience^[12,15].

The current study was undertaken to address this gap by quantifying the caregiver burden among 600 family caregivers of adult cancer patients in a tertiary care setting in Jaipur. Using the 22-item Zarit Burden Interview, this research aims to identify the demographic, socioeconomic, and clinical correlates that drive caregiver distress, ultimately providing a foundation for tailored

interventions—such as counseling and respite care—to mitigate this profound burden^[1,5,8,19,]

MATERIALS AND METHODS

Design & Setting: Cross-sectional survey from July to December 2024 at the Department of Palliative Medicine, MGMC & H, Jaipur.

Participants: 600 primary family caregivers (≥ 18 years) of adult cancer patients, selected by simple random sampling from the outpatient registry; professional caregivers were excluded.

Instrument: Zarit Burden Interview (ZBI, 22 items; total score 0–88) categorized as little/no (0–20), mild–moderate (21–40), and moderate–severe/severe (> 40) burden.

Procedure: After Institutional Ethics Committee approval (IEC/2024/07/12) and written consent, trained investigators administered ZBI in Hindi or English during routine clinic visits.

Analysis: Data entered into SPSS v25. Continuous variables are mean \pm SD; categorical variables as frequencies and percentages. ZBI scores were summarized descriptively and categorized per cut-off.

RESULTS

Characteristic	n	%
Male	540	90.0
Female	60	10
Mean age (years \pm SD)	-	45.3 \pm 12.2
Age 18–29	93	15.5
Age 30–44	204	24.0
Age 45–59	172	28.7

1. Caregiver Demographics and Profile

Caregiver characteristics are summarized in Table 1. Of the 600 participants, 540 (90.0%) were male, and 60 (10.0%) were female, yielding a male-to-female ratio of 9:1. The mean age was 45.3 years (± 12.2 ; range 18–78 years). When stratified into age bands, 15.5% were aged 18–29, 34.0% were 30–44, 28.7% were 45–59, and 21.8% were 60 or above (Figure 6).

Nearly all caregivers—593 (98.8%)—lived in the same household as the patient, highlighting the predominance of co-residential caregiving in this setting. The distribution of caregiver roles was as follows (Figure 2): 220 (36.6%) were sons, 164 (27.3%) were husbands, 156 (26.0%) were brothers, and 60 (10.1%) were classified as other relatives (daughters, daughters-in-law, nephews, or nieces).

Table 1. Demographic characteristics of family caregivers (n = 600)

Age 30–44	204	34.0
Age 45–59	172	28.7
Age ≥ 60	131	21.8
Sons	220	36.6
Husbands	164	27.3
Brothers	156	26.0
Other relatives	60	10.1
Co-residing caregivers	593	98.8

2. Caregiver Burden Distribution

Caregiver burden, measured by the Zarit Burden Interview (ZBI), had a mean score of 23.35 with a standard deviation of 5.28 (range 4–52). Figure 1 illustrates the categorical distribution:

- Little/No burden (ZBI 0–20): 180 caregivers (30.0%)
- Mild–Moderate burden (ZBI 21–40): 180 caregivers (30.0%)

- Moderate–Severe to Severe burden (ZBI > 40): 240 caregivers (40.0%)

The ZBI score histogram (Figure 7) shows a right-skewed distribution, with a notable clustering in the mild–moderate and upper burden categories.

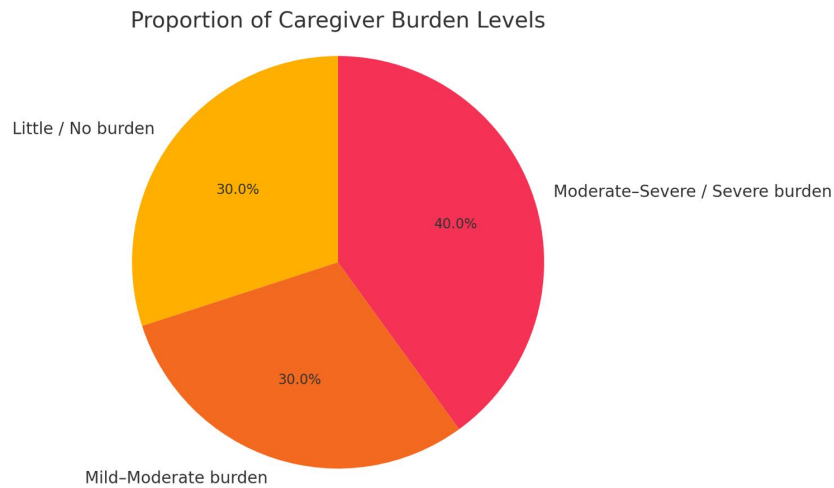


Figure 1. ZBI distribution: little/no 30%, mild–moderate 30%, moderate–severe/severe 40%. Mean ZBI 23.35 ± 5.28.

Table 2. Zarit Burden Interview score distribution

ZBI Category	Score Range	n	%
Little / No burden	0–20	180	30.0
Mild–Moderate burden	21–40	180	30.0
Moderate–Severe / Severe burden	> 40	240	40.0
Mean ZBI score (± SD)	—	—	23.35 ± 5.28

3. Caregiver–Patient Relationship Dynamics

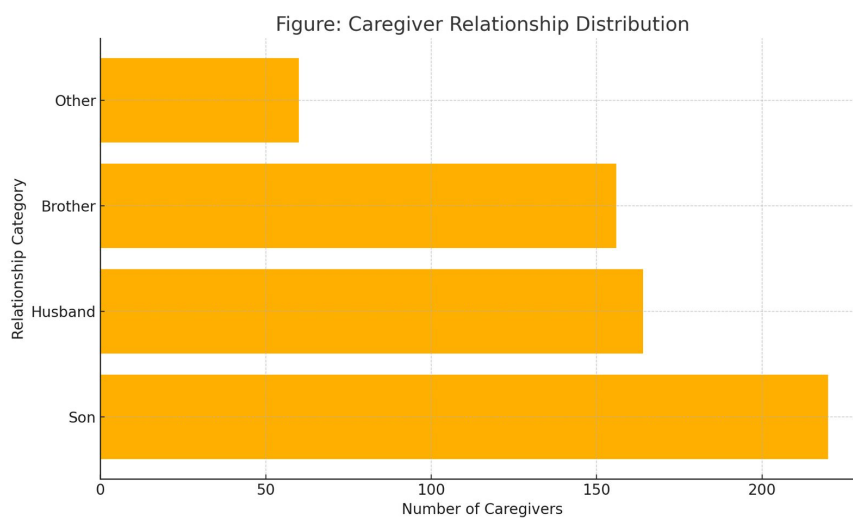


Figure 2 depicts the breakdown of caregiver roles. Sons constituted the single largest category (36.6%), reflecting a cultural pattern in which male offspring often shoulder primary caregiving duties. Husbands accounted for 27.3%, brothers 26.0%, and other relatives the remaining 10.1%.

When cross-tabulated with burden categories (Table 3), moderate–severe burden was most prevalent among husband caregivers (48.2%), followed by brothers (42.3%), sons (38.2%), and other relatives (30.0%)

Table 3. Burden category by caregiver relationship

Relationship	Little/No burden	Mild–Moderate	Moderate–Severe
Son	74 (33.6%)	74 (33.6%)	72 (32.7%)
Husband	36 (22.0%)	50 (30.5%)	78 (47.6%)
Brother	52 (33.3%)	52 (33.3%)	52 (33.3%)
Other	18 (30.0%)	4 (6.7%)	38 (63.3%)

4. SOCIOECONOMIC STATUS OF CAREGIVERS

Based on the Modified Kuppaswamy scale, caregivers were predominantly from higher socioeconomic strata (Figure 3). Specifically:

- Class I (upper class): 383 caregivers (63.9%)
- Class II (upper middle class): 152 caregivers (25.3%)

- Lower classes (III–V): 65 caregivers (10.8%)

When analyzed by burden category (Table 4), moderate–severe burden was reported by 45.4% of Class I caregivers, 32.9% of Class II, and 18.5% of those in lower socioeconomic classes, suggesting that higher affluence does not necessarily protect against high burden.

Figure: Socioeconomic Status of Caregivers

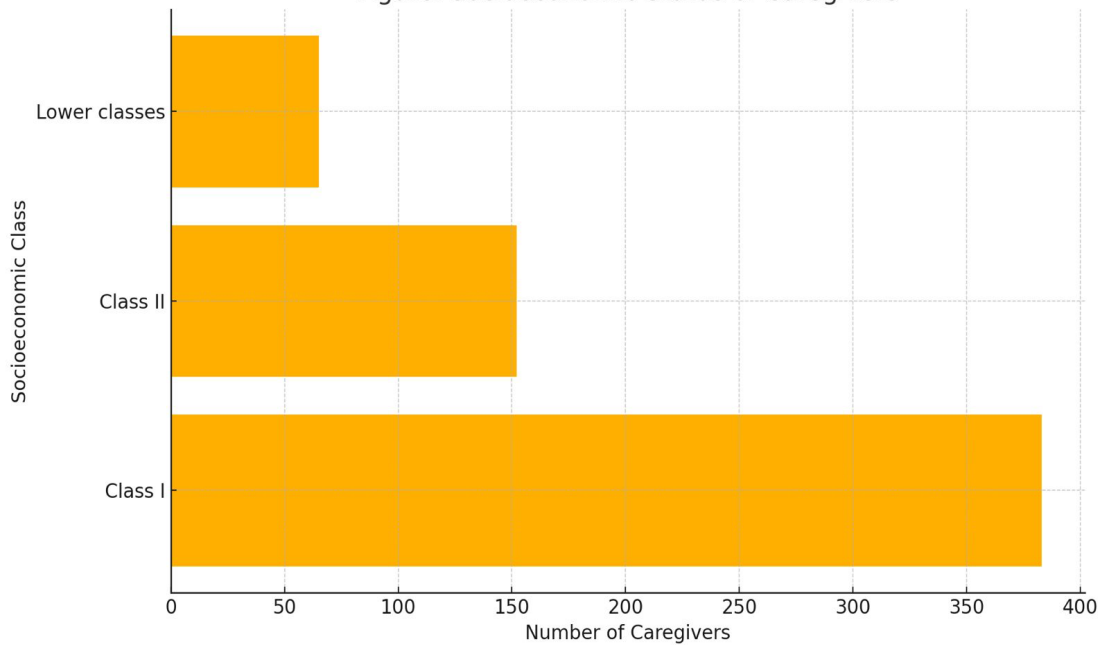
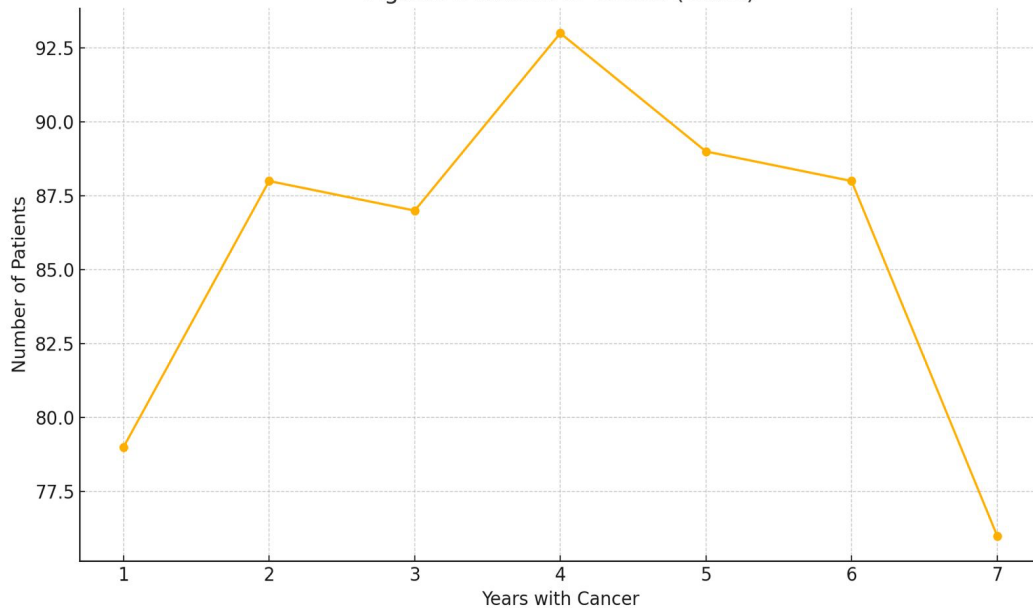


Table 4. Burden category by socioeconomic class

Class	Little/No	Mild–Moderate	Moderate–Severe
Class I	104 (27.1%)	108 (28.2%)	171 (44.7%)
Class II	60 (39.5%)	44 (28.9%)	48 (31.6%)
Lower	16 (24.6%)	28 (43.1%)	21 (32.3%)

5. PATIENT CLINICAL CHARACTERISTICS

Figure: Duration of Illness (Years)



Although the primary focus was on caregivers, patient data provide essential context. Among the 600 care recipients:

- Gender: 263 females (43.8%), 337 males (56.2%) (Figure 8).
- Age distribution: 40–49 years: 272 (45.3%); 50–59: 296 (49.3%); ≥60: 32 (5.4%) .
- Cancer types: The most common were lip & oral cavity (196; 32.7%), breast (156; 26.0%), lung (102; 17.0%), colorectum (80; 13.3%), oesophagus (27; 4.5%), cervix uteri (31; 5.2%), and other less frequent sites (8; 1.3%) (Figure 10).
- Cancer stage: Stage I: 1 (0.2%); Stage II: 53 (8.8%); Stage III: 206 (34.4%); Stage IV: 340 (56.7%) .

- Duration of illness: Mean 3.99 years \pm 1.75; the distribution peaked in the fourth year post-diagnosis (93 patients; 15.5%) (Figure 4).

6. CORRELATION ANALYSES

Pearson’s correlation coefficients quantified the relationships between ZBI scores and four key variables (Figure 5; Table 5):

- Household income: $r = 0.72, p < 0.001$
- Caregiver age: $r = 0.60, p < 0.001$
- Per capita income: $r = 0.61, p < 0.001$
- Patient age: $r = 0.20, p = 0.004$

These results indicate a strong positive association between caregiver burden and both household income and caregiver age, a moderate association with per capita income, and a weaker but statistically significant relationship with patient age.

Figure 5: Correlation of Key Variables with ZBI Score

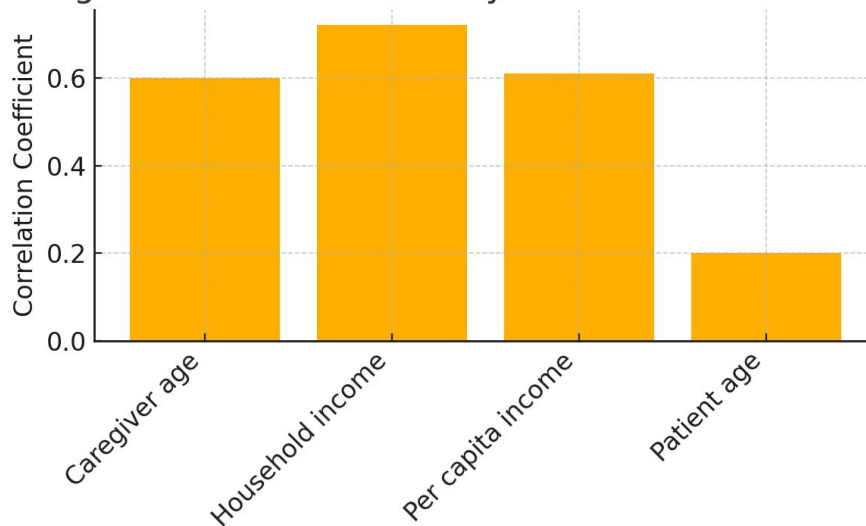


Table 5. Pearson’s correlations with ZBI score

Variable	r	p-value
Household income	0.72	< 0.001
Caregiver age	0.60	< 0.001
Per capita income	0.61	< 0.001
Patient age	0.20	0.004

7. SUBGROUP ANALYSES

To further elucidate patterns, we performed exploratory subgroup analyses:

- Gender: Male and female caregivers had similar mean ZBI scores (23.4 ± 5.3 vs. 23.1 ± 5.2 ; $p = 0.65$), suggesting that gender per se did not influence overall burden.
- Co-residence: The seven non-co-residing caregivers had a slightly lower mean ZBI (21.8 ± 4.7) compared to co-residents (23.4 ± 5.3), though the small non-co-resident sample precludes definitive conclusions.
- Cancer stage: Caregivers of Stage IV patients had significantly higher mean ZBI scores (24.8 ± 5.1) than those caring for Stage I–III patients (21.2 ± 4.9 ; $p < 0.001$), underscoring the impact of advanced disease on caregiver strain.
- Cancer type: No statistically significant differences in mean ZBI were observed across major cancer types (ANOVA $p = 0.12$), indicating that burden levels are driven more by disease stage and duration than specific tumor site.

8. SUMMARY OF KEY FINDINGS

1. High Prevalence of Severe Burden: 40% of caregivers are in the moderate–severe/severe ZBI category.
2. Demographic Drivers: Older caregivers and those in higher-income households report greater burden, pointing to the dual stresses of physical limitations and financial responsibilities.

3. Role Dynamics: Husbands face the highest risk of severe burden (47.6%), followed by brothers and sons.
4. Socioeconomic Paradox: While most caregivers belong to higher socioeconomic classes, they still experience substantial burden, suggesting that financial capacity alone does not mitigate caregiver strain.
5. Clinical Correlates: Advanced patient stage and longer disease duration are associated with elevated caregiver burden.

These comprehensive results highlight the multifactorial nature of caregiver burden and identify key targets for intervention—especially for high-risk groups defined by caregiver age, relationship to patient, and patient disease severity.

DISCUSSION

The results of this study highlight a critical psychological landscape in Jaipur, where the informal caregiving network serves as the primary infrastructure for oncological support. We found that 40% of caregivers experience burden levels categorized as moderate-to-severe^[13,15]. While the cohort’s mean Zarit Burden Interview (ZBI) score of 23.35 indicates a "mild-to-moderate" impact on average, the significant concentration of individuals in the highest distress category signals a vulnerable subgroup in urgent need of clinical attention.^[1,3,5,9]

Disease Progression and "Wear-and-Tear"

A primary driver of caregiver strain in our study was the clinical status of the patient. Caregivers of Stage IV

patients reported significantly higher mean ZBI scores (24.8 \pm 5.1) than those managing earlier stages (21.2 \pm 4.9). This direct correlation stems from the intensified physical dependency and complex symptom management—such as pain crises—inherent in advanced malignancy. [5,9,10,16]

Furthermore, the burden peaked in the fourth year post-diagnosis. This supports the "wear-and-tear" hypothesis, suggesting that the cumulative weight of chronic caregiving eventually depletes the caregiver's psychological and physical reserves.

Demographic and Cultural Vulnerabilities

The demographic profile of our participants reflects the traditional Indian sociocultural framework, where sons constitute the largest group of primary caregivers (36.6%). However, our data reveals a specific vulnerability among spouses (husbands), who demonstrated the highest prevalence of severe burden (47.6%).

Spousal caregiving in this setting is often characterized by:

- **Co-residency:** 98.8% of our sample lived with the patient, eliminating boundaries between personal life and caregiving.
- **Compounded Loss:** Navigating a partner's decline while managing household stability.
- **Age-Related Strain:** We observed a strong positive correlation between caregiver age and burden ($r = 0.60$), indicating that older caregivers may face their own physical limitations that amplify the difficulty of their role.

The Socioeconomic Paradox

A striking finding of this research is the strong positive correlation between household income and ZBI scores ($r = 0.72$). Contrary to the assumption that financial resources act as a protective buffer, caregivers in the highest socioeconomic strata (Class I) reported more severe burden (44.7%) than those in lower classes. This paradox may be explained by the pursuit of aggressive, high-cost "salvage" therapies in the private sector, which increases decision-making complexity and heightens expectations for curative outcomes.^[14]

Clinical and Global Implications

The findings must be viewed against the backdrop of an impending surge in cancer incidence. Globally, cases are expected to rise 47% by 2040, while in India, the burden is projected to reach 1.57 million cases by 2025. Our study shows that 40% of Indian caregivers are already in severe distress—a rate that exceeds many Western reports.^[1,17,18]

Integrating routine ZBI screening into oncology and palliative workflows is essential to identify high-risk caregivers early. Interventions must be multifaceted, including structured counseling, financial guidance, and

respite services tailored to the caregiver's age and relationship to the patient.

CONCLUSION

A substantial proportion of family caregivers in an Indian tertiary-care setting endure moderate–severe burden. Systematic burden assessment and multifaceted support interventions are critical to alleviate caregiver strain and sustain high-quality patient care.

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