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Burden and Anxiety among Informal Caregivers of Cancer Patients: Evidence from a Cancer Specialty Hospital, Mumbai, India

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Abstract

Background

Informal caregivers of patients with cancer may experience substantial psychological and caregiving burden. This study aimed to estimate the prevalence of caregiver burden and anxiety and examine their associations with patient functional status, caregiving support, and treatment-related socioeconomic factors.

Methods

This study used a cross-sectional design nested within a prospective, non-interventional cohort conducted at a tertiary cancer centre in Mumbai, India. Data were collected through structured interviews with 149 primary informal caregivers during patients' active treatment. We assessed caregiver burden using the 22-item Zarit Burden Interview (ZBI), anxiety symptoms using the Anxiety Symptoms Questionnaire (ASQ), and patient functional status using the Karnofsky Performance Status (KPS). We examined associations using chi-square tests and logistic regression.

Results

Overall, 78.5% of caregivers experienced high burden, and 38.3% experienced high anxiety. High burden was more prevalent among caregivers of patients requiring assistance than among those caring for patients requiring minimal or no assistance (90.2% vs. 74.1%). High anxiety was also more prevalent among caregivers of patients requiring assistance (44.2% vs. 31.9%), patients who underwent surgery (52.5% vs. 28.9%), and caregivers without additional support at home (48.2% vs. 32.3%). High caregiver burden remained strongly associated with high anxiety (AOR: 7.60, 95% CI:1.76–32.59), whereas the association between patient functional status and anxiety was no longer statistically significant (AOR: 2.00, 95% CI:0.75–5.20). Higher log-transformed out-of-pocket expenditure was also associated with higher anxiety scores.

Conclusions

Caregiver burden and anxiety were common among informal caregivers of patients with gastric and pancreatic cancer. Caregiver burden, patient functional status, treatment-related demands, and caregiving support should be considered when developing psychosocial and financial support strategies within cancer care.

Introduction

Cancer care relies heavily on informal caregivers, particularly family members and close relatives who provide unpaid physical, emotional, and practical support throughout the cancer trajectory (WHO, 2020). In low- and middle-income countries, informal caregivers often assume responsibility for symptom management, treatment coordination, assistance with activities of daily living, and other aspects of patient care, frequently without formal training or adequate institutional support (Ranganathan et al., 2023; WHO, 2020). Although this family-based model of care is essential to sustaining cancer treatment, the demands placed on caregivers can adversely affect their own physical and psychological well-being (Ranganathan et al., 2023).

Informal caregiving in cancer is associated with substantial psychological and financial challenges, including caregiver burden, anxiety, and depression (Mishra et al., 2021; Ranganathan et al., 2023). Caregiver burden represents the multidimensional strain associated with the responsibilities of providing care and has been linked to poorer quality of life, greater psychological distress, and adverse physical health (Bedaso et al., 2022; Mishra et al., 2021; Ranganathan et al., 2023). Evidence from a systematic review and meta-analysis suggests that anxiety and depressive symptoms are common among cancer caregivers, with pooled prevalence estimates of approximately 47% and 42%, respectively (Bedaso et al., 2022). The literature depicts the psychological consequences of cancer caregiving and the need to consider caregiver well-being as an integral component of cancer care.

These challenges may be particularly pronounced among caregivers of patients with gastrointestinal cancers, including gastric and pancreatic cancer, which can involve advanced disease, intensive treatment, substantial symptom burden, and deterioration in functional status (Chong et al., 2022; ICMR, 2020). Such clinical and treatment-related demands may increase caregivers' involvement in daily activities, treatment coordination, and support during hospitalization and recovery, thereby intensifying the physical and psychological demands of caregiving. Despite the substantial care needs associated with these cancers, evidence on the psychological burden experienced by their informal caregivers, particularly in low- and middle-income countries, remains limited.

The context of cancer care in India may further amplify these challenges. Family members commonly assume a central role in providing care, with caregiving responsibilities extending across physical, psychological, social, and financial domains (Lukhmana & Bhasin, 2015; Menon et al., 2022; Mishra et al., 2021; Ranganathan et al., 2023). These responsibilities occur within a healthcare system characterized by substantial reliance on out-of-pocket health expenditure, variable insurance coverage, and relatively limited public health expenditure (NFHS, 2021; NHA, 2022). Consequently, the financial consequences of cancer treatment may extend beyond direct medical costs to include travel, accommodation, food, and other non-medical expenses, as well as borrowing or asset sales to finance care. Recent evidence from India indicates substantial financial hardship among households affected by cancer, including catastrophic health expenditure and distress financing (Pandey et al., 2024; Prinja et al., 2023). Such financial pressures may compound the psychological demands of caregiving and represent an important contextual pathway through which cancer care can affect caregiver well-being.

Despite these challenges, evidence on caregiver burden and anxiety among primary informal caregivers of patients with gastric and pancreatic cancer in India remains limited. Pancreatic cancer is associated with substantial symptom burden and complex physical and psychological care needs, yet relatively little attention has been given to the psychological well-being of the family members who provide primary care. Existing Indian research on cancer caregiving has largely focused on individual cancer types or broader cancer populations, with comparatively limited evidence examining caregiver burden and anxiety together among caregivers of gastrointestinal cancer patients. In addition, few studies have simultaneously considered patient functional status, caregiving support, and the financial demands of cancer treatment in relation to caregiver psychological outcomes.

Against this background, this study aimed to estimate the prevalence of caregiver burden and anxiety and examine their associations with patient functional status, caregiving support, and treatment-related socioeconomic factors among primary informal caregivers of patients with gastric and pancreatic cancer attending a tertiary cancer centre in India. Specifically, we examined whether patient functional status and caregiver burden were associated with caregiver anxiety and assessed the role of treatment and financial factors in these outcomes.

Data and Methods

This study used a cross-sectional survey of primary informal caregivers nested within a prospective, non-interventional cohort study conducted at the Gastrointestinal and Hepato-Pancreato-Biliary (GI and HPB) service of Tata Memorial Hospital (TMH), Mumbai, India. The parent cohort comprised patients receiving care for gastric or pancreatic cancer. Data collection in the parent study consisted of three modules: (1) patient recruitment, (2) follow-up to collect information on treatment expenditure and time spent in the hospital, and (3) caregiver assessment. For the present study, caregiver interviews were conducted approximately three months after patient recruitment, during the patients' active treatment period. The caregiver survey captured information on caregiving experiences, caregiver burden, anxiety, and relevant socioeconomic and caregiving characteristics at the time of assessment. A total of 244 patients were recruited into the parent study. Of these, 200 caregivers were targeted for the caregiver survey. Fifty-one caregivers were subsequently excluded because of refusal to participate, loss to follow-up, or incomplete information. The final analytic sample comprised 149 primary informal caregivers.

Ethics approval

The study was approved by the Institutional Ethics Committees of Tata Memorial Centre (TMC) and the International Institute for Population Sciences (IIPS). The parent study was registered with the Clinical Trials Registry of India (CTRI) under registration number CTRI/2023/04/051523, registered on 12 April 2023. Written informed consent was obtained from all the participants before participation in the study.

Data collection and follow-up

A structured questionnaire was developed through a research collaboration between investigators at TMH and the International Institute for Population Sciences (IIPS) and was pre-tested before implementation. The questionnaire was prepared in Marathi, Hindi, and English and administered by trained project staff. It included questions on patients' demographic and socioeconomic characteristics, clinical characteristics and comorbidities, treatment-related expenditure, healthcare utilization, and caregiving experiences.

For the caregiver component, information was collected on time spent providing care at home, caregiving responsibilities, caregiver burden, anxiety symptoms, and the availability of additional caregiving support. The parent cohort collected information prospectively from the time of patients' first registration through their subsequent treatment and hospital visits. The caregiver assessment used in the present analysis was conducted approximately three months after patient recruitment and therefore represents a cross-sectional assessment of caregivers during the active treatment period. The conceptual framework guiding the selection and organization of variables was based on the Stress Process Model proposed by Pearlin et al. (Pearlin et al., 1990).

Primary informal caregiver

A cancer patient can have multiple informal care givers during treatment spread over long duration and a challenge here is in determining the primary one among them. For this study, a primary informal caregiver was defined as an individual who provided care to a cancer patient without monetary compensation. The primary informal caregiver was identified as the family member who devoted the most time to caregiving responsibilities, typically a spouse, child, friend, or other close relative residing with the patient and assuming primary responsibility for care. In this study, we have considered the primary informal caregiver at home.

Outcome variables

Caregiver burden

Caregiver burden was assessed using the Zarit Burden Interview (ZBI) score, one of the most widely applied instruments for evaluating the subjective impact of caregiving. Originally developed by Zarit, Reever, and Bach-Peterson (1980) for dementia caregivers, the ZBI has since been validated across diverse populations, including cancer and chronic illness caregivers (Mishra et al., 2021; O'Rourke & Tuokko, 2003; Zarit et al., 1980).

The standard ZBI-22 consists of 22 items rated on a 5-point Likert scale (0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Quite frequently, 4 = Nearly always). Total scores range from 0 to 88 and were categorized as follows:

- 0–20: Little or no burden

- 21–40: Mild to moderate burden
- 41–60: Moderate to severe burden
- 61–88: Severe burden

For analysis, scores were collapsed into two categories: Low burden (0–40) and High burden (41–88) (Lucijanić et al., 2020).

The ZBI demonstrated high internal consistency (Cronbach's α = 0.83) and strong validity in our study.

Caregiver anxiety

Caregiver anxiety was assessed using the Anxiety Symptoms Questionnaire (ASQ), a self-report instrument that measures the frequency and intensity of anxiety symptoms during the preceding week (Baker et al., 2019). The ASQ comprises 17 items covering cognitive, physiological, and affective symptoms of anxiety. Each symptom is assessed on two dimensions: frequency, ranging from 0 (none of the time) to 4 (all of the time), and intensity, ranging from 0 (none) to 4 (extreme). The instrument provides separate frequency and intensity scores as well as a combined assessment of anxiety symptoms. Previous validation work has demonstrated high internal consistency for the ASQ, with Cronbach's α of 0.90 for the total score, 0.86 for intensity, and 0.83 for frequency, together with good test–retest reliability and convergent validity with established measures of anxiety (Baker et al., 2019).

Because clinically validated ASQ cut-off values were not available for the study population, anxiety severity was classified using a data-driven clustering approach. K-means clustering was performed using the standardized ASQ frequency and intensity scores. Both dimensions were converted to z-scores before clustering to ensure that they contributed equally to the distance-based classification.

To determine the number of clusters, solutions with two, three, and four clusters were evaluated using the Calinski–Harabasz pseudo-F criterion (Caliński & Harabasz, 1974). The pseudo-F value was highest for the two-cluster solution (202.5), compared with three clusters (178.9) and four clusters (152.2). The two-cluster solution was therefore selected as the primary classification and was interpreted as representing caregivers with lower versus higher overall anxiety burden. For subsequent analyses, the resulting two-cluster classification was used as a binary outcome, categorized as low anxiety and high anxiety.

Explanatory variables

Explanatory variables were selected based on the study objectives and the conceptual framework derived from the Stress Process Model (Pearlin et al., 1990). Variables were grouped into three domains: patient clinical characteristics, patient socioeconomic and demographic characteristics, and caregiver characteristics.

Patient clinical characteristics included cancer type (gastric or pancreatic), disease stage (localized, regional, or distant), surgery (yes or no), treatment category (private or public/subsidized treatment), duration of hospitalization (no hospitalization, ≤ 1 week, or > 1 week), and functional status measured using the Karnofsky Performance Status (KPS). KPS was categorized as ≥ 60 (minimal or no assistance required) and < 60 (assistance required). was also included.

Patient socioeconomic and demographic characteristics included sex (male or female), age group (< 46, 46–60, or > 60 years), place of residence (urban or rural), employment status (unemployed, employed, or other), Maharashtra residence (yes, no), Health insurance (yes or no), and caste category (Scheduled Caste/Scheduled Tribe (SC/ST), Other Backward Class (OBC), or other). Out-of-pocket (OOP) expenditure was categorized as ₹0–100,000, ₹100,001–200,000, ₹200,001–300,000, and >₹300,000. Distress financing was defined as having borrowed money, with or without interest, or having sold assets, jewellery, or land to finance healthcare (yes or no).

Caregiver characteristics included relationship to the patient (parent, spouse, or other), employment status (unemployed, employed, or other), and availability of another caregiver at home (yes or no).

Karnofsky Performance Status (KPS)

The Karnofsky Performance Status (KPS) is a clinician-rated measure of patient functional status and independence (Karnofsky, 1949; Schag et al., 1984). Scores range from 0 to 100 in 10-point increments, with higher scores indicating better functional capacity. A score of 100 represents normal functioning, whereas 0 represents death.

KPS was assessed at the time of patient recruitment and was used to represent patients' baseline functional status before the caregiver assessment. For analysis, KPS was dichotomized as ≥ 60, indicating minimal or no assistance required, and < 60, indicating a need for assistance. This categorization was used as an explanatory variable in analyses of caregiver burden and anxiety.

Statistical analysis

Descriptive statistics were used to summarize the characteristics of patients and caregivers and the distribution of caregiver burden and anxiety. Categorical variables were summarized using frequencies and percentages. The prevalence of high caregiver burden and high anxiety was estimated overall and across patient, socioeconomic, and caregiver characteristics.

Associations between categorical explanatory variables and high caregiver burden or high anxiety were initially assessed using the chi-square (χ^2) test. Binary adjusted logistic regression models were used to examine factors associated with high caregiver anxiety and high caregiver burden. For anxiety, the outcome was dichotomized into low and high anxiety based on the two-cluster solution derived from the ASQ. For caregiver burden, the outcome was dichotomized as low burden (ZBI score 0–40) and high burden (ZBI score 41–88). In supplementary analyses, ordinary least squares (OLS) regression was used

to examine factors associated with the continuous anxiety and caregiver burden score. Out-of-pocket expenditure (OOPE) was log-transformed before inclusion in the OLS model because of its skewed distribution. Regression coefficients, 95% CIs, and p-values were reported.

Results

Figure 1 illustrates the overall prevalence of high caregiver burden and anxiety and their differential distribution by the functional status of patients. Overall, 78.5% of caregivers experienced a high burden, and 38.3% had high anxiety. Among caregivers of patients requiring minimal or no assistance, 74.1% had a high burden, and 31.9% had high anxiety. Caregivers of patients who needed assistance 90.2% experienced a high burden and 44.2% high anxiety.

Burden on the informal primary caregivers

Table 1 presents the prevalence of high caregiver burden according to patient, socioeconomic, and caregiver characteristics. Overall, 78.5% of caregivers experienced high burden. The prevalence was higher among caregivers of patients requiring assistance than among those caring for patients requiring minimal or no assistance (90.2% vs. 74.1%; $p < 0.05$). High burden was also more prevalent among caregivers of patients receiving private treatment than among those receiving public treatment (88.1% vs. 66.2%; $p < 0.05$).

Table 1
Caregiving burden among primary informal caregivers by patients' and caregivers' characteristics, (N = 149)

Treatment/patient/ caregiver characteristics	Percentage with high ZBI score(n)	N	P-Value
Patients characteristic's			
Assistance requirement (KPS)			
Minimal or no assistance	74.1 (80)	108	0.03
Need assistance	90.2 (37)	41	
Cancer Type			
Gastric	79.2 (57)	72	0.90
Pancreatic	77.9 (60)	77	
Stage of detection			
Local	81.1 (30)	37	0.80
Regional	75.0 (30)	40	
Distant	79.2 (57)	72	
Patients categories			
Private	88.1 (74)	84	0.00
Public	66.2 (43)	65	
Surgery			
No	80.0 (72)	90	0.59
Yes	76.3 (45)	59	
Duration of hospitalisation			
No hospitalisation	78.3 (54)	69	0.29
<=One week	68.0 (17)	25	
>One week	83.6 (46)	55	
Sex			
Male	76.2 (81)	108	0.13
Female	87.5 (36)	41	
Note – P-values were obtained using the chi-square (χ^2) test.			

Treatment/patient/ caregiver characteristics	Percentage with high ZBI score(n)	N	P-Value
Patients characteristic's			
Assistance requirement (KPS)			
Age			
< 46	71.4 (26)	37	0.37
46–60	83.6 (52)	62	
> 60	79.6 (39)	50	
Residential area			
Urban area	73.2 (52)	71	0.13
Rural area	83.3 (65)	78	
Maharashtra resident			
Yes	75.5 (37)	49	0.53
No	80.0 (80)	100	
Health insurance			
Yes	69.4 (50)	63	0.83
No	86.6 (67)	86	
Employment status			
Un-employed	81.5 (66)	81	0.47
Employed	72.1 (31)	43	
Others (student/retired)	80.0 (20)	25	
Out-of-Pocket expenditure			
0–1,00,000	73.9 (17)	23	0.29
1,00,000–2,00,000	91.7 (22)	24	
2,00,000–3,00,000	82.1 (23)	28	
Above 3,00,000	74.3 (55)	74	
Distress Financing			
No	78.8 (78)	99	0.91
Note – P-values were obtained using the chi-square (χ^2) test.			

Treatment/patient/ caregiver characteristics	Percentage with high ZBI score(n)	N	P-Value
Patients characteristic's			
Assistance requirement (KPS)			
Yes	78.0 (39)	50	
Caregiver characteristic's			
Relationship with patient			
Parents	72.2 (10)	14	0.66
Spouse	79.8 (82)	105	
Others	78.1 (25)	30	
Employment status			
Un-employed	72.2 (13)	18	0.77
Employed	79.8 (79)	99	
Others (student/housewife)	78.1 (25)	32	
Another caregiver			
No	91.1 (51)	56	0.00
Yes	71.0 (66)	93	
Total	78.5 (117)	149	
Note – P-values were obtained using the chi-square (χ^2) test.			

Caregiver support was also associated with burden. Among caregivers without another caregiver at home, 91.1% experienced high burden compared with 71.0% among those who had an additional caregiver ($p < .05$).

Anxiety among informal primary caregivers

Table 2 presents the prevalence of high anxiety symptoms across the same characteristics. Overall, 38.3% of caregivers experienced high anxiety. Caregivers of patients who required assistance reported higher anxiety (44.2%) than those caring for patients with minimal or no assistance needs (31.9%; $p < 0.05$). Anxiety was notably more prevalent among caregivers of patients in the private category (46.4%) compared to the public category (27.7%; $p < 0.05$), and among caregivers of surgical patients (52.5%) compared to those whose patients did not undergo surgery (28.9%; $p < 0.05$). Duration of hospitalisation was particularly influential: anxiety was highest among caregivers of patients hospitalised for more than one week (58.2%), followed by those hospitalised for up to one week (32.0%) and those with no

hospitalisation (24.6%; $p < 0.05$). Caregivers without additional support at home had higher anxiety (48.2%) than those with support (32.3%; $p < 0.05$). Caregivers of patients from outside Maharashtra reported higher anxiety (43.0%) than local residents (28.6%). Cancer type, stage, sex, health insurance, employment status, and distress financing were not significantly associated with caregiver anxiety.

Table 2
Prevalence of high anxiety among informal primary home caregivers by selected background characteristics

Treatment/patient/ caregiver characteristics	High anxiety (%)	Sample Size (n)	P-Value
Patients' Characteristics			
Assistance requirement (KPS)			
Minimal or no assistance	31.9	36	0.04
Need assistance	44.2	21	
Cancer Type			
Gastric	41.7	30	0.40
Pancreatic	35.1	27	
Stage of detection			
Local	48.7	18	0.32
Regional	35.0	14	
Distant	34.7	25	
Patients Categories			
Private	46.4	39	0.02
Public	27.7	18	
Surgery			
No	28.9	26	0.00
Yes	52.5	31	
Duration of hospitalisation			
No hospitalisation	24.6	17	0.00
<=One week	32.0	8	
>One week	58.2	32	
Sex			
Male	36.1	39	0.38
Female	43.9	18	
Age			
Note - P-values were obtained using the chi-square (χ^2) test.			

Treatment/patient/ caregiver characteristics	High anxiety (%)	Sample Size (n)	P-Value
Patients' Characteristics			
Assistance requirement (KPS)			
< 46	48.7	18	0.07
46–60	27.4	17	
> 60	44.0	22	
Residential area			
Urban area	43.7	31	0.20
Rural area	33.3	26	
Local resident			
Yes	28.6	14	0.09
No	43.0	43	
Health insurance			
Yes	44.4	28	0.18
No	33.7	29	
Employment status			
Un-employed	38.3	31	0.76
Employed	34.9	15	
Others (student/retired)	44.0	11	
Out-of-Pocket expenditure			
0–1,00,000	26.1	6	0.50
1,00,000–2,00,000	41.7	10	
2,00,000–3,00,000	46.4	13	
Above 3,00,000	37.8	28	
Distress Financing			
No	36.4	36	0.50
Yes	42.0	21	
Note - P-values were obtained using the chi-square (χ^2) test.			

Treatment/patient/ caregiver characteristics	High anxiety (%)	Sample Size (n)	P-Value
Patients' Characteristics			
Assistance requirement (KPS)			
Caregiver characteristics			
Burden on caregiver			
Low	16.6	5	0.00
High	44.4	52	
Relationship with patient			
Parents	50.0	7	0.46
Spouse	35.2	37	
Others	43.3	13	
Employment status			
Un-employed	50.0	9	0.53
Employed	37.4	37	
Others (student/housewife)	34.4	11	
Another caregiver			
No	48.2	27	0.05
Yes	32.3	30	
Total	38.3	57	
Note - P-values were obtained using the chi-square (χ^2) test.			

Association between anxiety, burden, and patient functional status

Table 3 shows logistic regression estimates for the outcome of high caregiver anxiety. In the unadjusted model, caregivers of patients requiring assistance had twice the odds of high anxiety compared to those with minimal or no assistance needs (UOR: 2.1, 95% CI: 1.01–4.36; p = 0.05). Caregivers with high burden had over four times the odds of anxiety compared to those with low burden (UOR: 4.3, 95% CI: 1.55–12.0; p < 0.05). After adjustment for all patient medical, sociodemographic, and caregiver characteristics, the association between KPS and anxiety became non-significant, while high anxiety remained strongly associated with high caregiver burden (AOR: 7.6, 95% CI: 1.76–32.59; p < 0.05)

Table 3
Association of high caregiver anxiety with patient functional status and caregiver burden

Patients' Characteristics	**UOR (95% CI)**	**P-Value**	**AOR (95% CI)**	**P-Value**
Assistance requirement (KPS)				
Minimal or no assistance *(ref)*				
Need assistance	2.1 [1.01–4.36]	0.05	2.0 [0.75–5.20]	0.17
Caregiver characteristics				
Burden on caregiver				
Low *(ref)*				
High	4.3 [1.55-12.0]	0.01	7.6 [1.76–32.59]	0.01

Table 4 presents logistic regression results for the outcome of high caregiver burden. In the unadjusted model, caregivers of patients requiring assistance had over three times the odds of high burden compared to those with minimal or no assistance needs (UOR: 3.2, 95% CI: 1.06–9.90; $p < 0.05$). This association attenuated and became non-significant after full adjustment (AOR: 2.9, 95% CI: 0.65–12.93; $p = 0.16$), suggesting that other patient and caregiver characteristics account for part of the observed relationship.

Table 4
Association of high burden with functional status of patient

	Model 1		**Model 2**	
	Odds ratios (95% CI)	**P-Value**	**Odds ratios (95% CI)**	**P-Value**
Assistance requirement (KPS)				
Minimal or no assistance*(ref)*				
Need assistance	3.2 (1.06–9.90)	0.04	2.9 (0.65–12.93)	0.16
Note - UOR = unadjusted odds ratio; AOR = adjusted odds ratio; CI = confidence interval; KPS = Karnofsky Performance Status. Model 1 = unadjusted. Model 2 = adjusted for all patient medical and sociodemographic characteristics and caregiver characteristics. Reference category indicated as (ref).				

Supplementary Table S1 shows that higher out-of-pocket expenditure was significantly associated with higher anxiety scores. A one-unit increase in log-transformed OOP expenditure was associated with a 2.89-point increase in anxiety score (95% CI: 0.36–5.41; $p < 0.05$). In supplementary (Table 2) OLS analyses of the continuous ZBI score depicts that caregivers of patients requiring assistance had higher

burden scores than those caring for patients requiring minimal or no assistance (β = 7.64, 95% CI: 4.40–10.88; p < 0.05). Caregivers of patients receiving public treatment had lower burden scores than those receiving private treatment (β = −3.48, 95% CI: −6.68 to − 0.28; p = 0.05). The availability of an additional caregiver at home was also associated with lower burden scores (β = −4.61, 95% CI: −7.64 to − 1.57; p < 0.05).

Discussion

This study examined caregiver burden and anxiety among primary informal caregivers of patients with gastric and pancreatic cancer receiving care at a tertiary cancer centre in India. The findings indicate a substantial psychological and caregiving burden in this population, with high caregiver burden and anxiety observed in a large proportion of participants. Caregiver burden and anxiety were also associated with several aspects of patients' clinical and treatment-related circumstances, while the availability of additional caregiving support appeared to be associated with lower levels of burden and anxiety.

More than three-fourths of caregivers (78.5%) experienced high caregiver burden, while 38.3% experienced high anxiety. The high prevalence of caregiver burden is consistent with evidence that cancer caregiving can impose substantial physical, psychological, and social demands on family members (Bedaso et al., 2022; Cochrane et al., 2021; Kusi et al., 2023). The particularly high burden observed in this study may reflect the complex care requirements associated with gastric and pancreatic cancers, including functional limitations, intensive treatment, and prolonged hospitalization (Chong et al., 2022; ICMR, 2020). In the unadjusted analysis, caregivers of patients requiring assistance had higher odds of high anxiety than caregivers of patients requiring minimal or no assistance. This association, however, was attenuated and was no longer statistically significant after adjustment for patient and caregiver characteristics. Thus, poorer patient functional status may contribute to caregiver psychological distress, but its observed association with anxiety in this study may partly reflect other characteristics of patients, treatment, or caregivers. Prolonged hospitalization was also associated with a higher prevalence of anxiety in the descriptive analysis, potentially reflecting the disruption of household responsibilities, employment, and daily routines associated with extended hospital stays.

Caregiver burden was more prevalent among caregivers of patients requiring assistance, those whose patients received private treatment, and those without an additional caregiver at home. However, the association between patient functional status and caregiver burden was no longer statistically significant after adjustment, suggesting that the observed unadjusted relationship may partly reflect other patient and caregiver characteristics. Similarly, cancer type and disease stage were not significantly associated with either caregiver burden or high anxiety in the present study. In contrast, caregivers of patients who underwent surgery had a higher prevalence of high anxiety than caregivers of patients whose treatment did not involve surgery. This finding may reflect the greater care demands and uncertainty associated with surgical treatment, although the cross-sectional design does not allow causal conclusions to be drawn.

The availability of additional caregiving support was associated with both outcomes. Caregivers without another caregiver at home had a higher prevalence of high burden and high anxiety than those who reported additional caregiving support. This finding is consistent with the broader literature suggesting that sharing caregiving responsibilities may reduce the demands placed on individual caregivers and provide emotional and practical support (WHO, 2020). However, because caregiving support and psychological outcomes were assessed cross-sectionally, the direction of this association cannot be established. It is also possible that caregivers experiencing greater burden or anxiety were less likely to have access to additional support. These findings nevertheless highlight the potential importance of assessing caregiving support as part of routine cancer care and considering interventions such as caregiver education, peer support, and respite or community-based services.

Economic vulnerability may be an important component of the psychological burden experienced by cancer caregivers. In the supplementary analysis using the continuous anxiety score, higher log-transformed out-of-pocket expenditure was associated with higher anxiety scores (β = 2.89, 95% CI: 0.36–5.41; p<.03). Financial distress was also associated with higher continuous anxiety scores after adjustment. These findings are consistent with evidence linking financial toxicity and economic strain with adverse psychological outcomes among cancer patients and their caregivers(Abrams et al., 2021; Sadigh et al., 2022). The findings suggest that caregiver psychological well-being should be considered alongside the economic demands of cancer care. Informal caregivers may experience overlapping logistical, financial, and emotional pressures, including prolonged hospital attendance, disruption of employment, out-of-pocket expenditure, distress financing, uncertainty about the patient's prognosis, and intensive caregiving responsibilities (Basavaiah et al., 2018; Mathew et al., 2024; Pandey et al., 2024). These interconnected demands may contribute to the overall burden experienced by caregivers.

The study findings suggest the importance of considering informal caregivers as an integral part of cancer care. Routine assessment of caregiver burden and anxiety, particularly among caregivers of patients requiring greater assistance, may help identify individuals who need additional psychosocial support. Assessment of caregiving support and financial strain may further help identify caregivers at increased risk of psychological distress. Caregiver education, psychological counselling, peer-support programmes, and access to respite or community-based services may provide practical and emotional support during cancer treatment.

Limitations

This study has a few limitations. First, it was conducted at a single tertiary cancer centre in Mumbai and included caregivers of patients with gastric and pancreatic cancer; therefore, the findings may not be generalizable to other healthcare settings, geographic regions, or cancer populations in India. Second, the caregiver assessment was conducted during the active treatment period and was cross-sectional. Consequently, temporal relationships between caregiver characteristics, burden, anxiety, and patient-related factors could not be established, and changes in caregiver burden and anxiety across the caregiving trajectory could not be examined. Third, both caregiver burden and anxiety were assessed

using self-report instruments and may therefore be subject to reporting and social desirability bias. Fourth, clinically validated ASQ cut-off values were not available for the study population. The data-driven clustering approach provided a basis for classifying caregivers into lower- and higher-anxiety groups, but these categories may not be directly comparable with studies using clinically established thresholds. Finally, although 200 caregivers were targeted, only 149 were included in the final analysis. Non-participation due to refusal, loss to follow-up, or incomplete information may have introduced selection bias if participation was related to caregiver burden or anxiety. The relatively small sample size also resulted in wide confidence intervals for some adjusted associations, which should be considered when interpreting the magnitude and precision of the estimates.

Conclusion

Caregiver burden and anxiety were highly prevalent among primary informal caregivers of patients. Caregiver burden was strongly associated with anxiety, while the availability of additional caregiving support was associated with lower prevalence of both outcomes. Patient functional status and treatment-related factors were associated with caregiver burden or anxiety in unadjusted analyses, although some associations were attenuated after adjustment. Poorer patient functional status was associated with higher caregiver burden, while higher out-of-pocket expenditure and financial distress were associated with higher anxiety scores.

These findings highlight the importance of integrating caregiver well-being into comprehensive cancer care. Routine assessment of caregiver psychological burden, caregiving support, and financial strain may help identify caregivers who may benefit from additional support. Psychosocial interventions, including psychological counselling, peer-support programmes, and respite or community-based services, alongside measures to reduce the financial burden of cancer care, may help strengthen support for informal caregivers. Further longitudinal research is needed to examine how caregiver burden and anxiety change over the course of cancer treatment and to evaluate the effectiveness of targeted caregiver-support interventions.

Declarations

Competing interests

The authors declare no conflict of interest.

Ethics approval

The study obtained approval from the institutional review board of the Tata Memorial Centre (TMC) and was registered on the Clinical Trial Registry of India with CTRI No. CTRI/2023/04/051523 on date 12/04/2023.

Consent to participate

Written informed consent from each of the participant had been taken prior to the interviews. This study was conducted in accordance with the ethical standards outlined in the National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, published by the Indian Council of Medical Research (ICMR), 2017, and also adhered to the principles of the Declaration of Helsinki.

Consent for publication

Not applicable.

Notes

UOR = Unadjusted Odds Ratio; AOR = Adjusted Odds Ratio; CI = confidence interval; KPS = Karnofsky Performance Status. Model 1 - Unadjusted (single predictor only); Model 2 adjusted for all patient medical and sociodemographic characteristics and caregiver characteristics. Reference categories are indicated as (ref)

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Author Contribution

Conceptualization: Mohit Pandey (MP), TR Dilip (TRD), Manish Bhandare (MB), Shailesh V. Shrikhande (SVS); Methodology: MP; Data curation: MP; Formal analysis: MP; Investigation: MP, TRD, Abhishek Anand (AA), MB, SVS; Writing – original draft: MP, AA; Writing – review & editing: MP, AA, TRD, MB, SVS; Supervision: SVS, MB, TRD.

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Data Availability

All the authors involved in the study have access to the data collected as part of the International Institute for Population Sciences (IIPS0 and Tata Memorial Hospital (TMH) project. Sharing of the data

with outside parties is at the discretion of the corresponding author and may be considered on request.

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