

ORIGINAL RESEARCH ARTICLE

Psychosocial Burden in Early-Stage Cancer Caregiving: A Study from Kerala, India

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ABSTRACT

Family caregivers of cancer patients are their spouses, adult children, or close relatives; these individuals provide sustained, unpaid care typically without formal training or institutional recognition. This study examines the psychosocial challenges experienced by family caregivers of cancer patients in the early stages in the state of Kerala, India, with a specific focus on Idukki district, a region characterised by high cancer incidence and a predominantly family-based caregiving culture. Employing a quantitative descriptive research design, data were collected from 60 caregivers using a self-structured, 51-item questionnaire aligned with the study's objectives. Participants were selected through convenience non-probability sampling from both public and private hospital settings. Findings reveal substantial psychosocial burden among caregivers, particularly in the early stages of cancer care: 56.67% identified psychological difficulties as their primary burden, 78.33% reported at least occasional emotional strain, 68.33% experienced significant role changes, and pronounced economic vulnerability was evident, with 73.33% of caregivers classified as Below Poverty Line and 78.33% reporting a monthly household income below ₹20,000 (≈ US\$241 or ₱12,792.90). The study concludes that strengthening caregiver-focused interventions through counselling services, respite care, psychoeducation, and community-based support is essential to advancing holistic, equitable, and sustainable cancer care in India.

Keywords: *Early-stage Cancer Care, Family Caregivers, Informal Caregiving, Social Work, Psychosocial Burden*

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INTRODUCTION

Global and national cancer burden

Cancer is a complex, life-threatening illness characterised by the uncontrolled proliferation of abnormal cells that invade and destroy surrounding body tissue. Its aetiology is multifactorial, arising from an interplay of genetic predispositions, environmental exposures, and lifestyle behaviours. Globally, approximately 20 million new cancer cases and 9.7 million cancer-related deaths are recorded annually, with projections indicating a steady upward trajectory attributable to population ageing, shifting lifestyle patterns, and environmental risk factors (American Cancer Society, 2024; IARC, 2024). In India, the disease burden is substantial and growing: an estimated 1.56 million new cases and nearly 874,000 deaths were reported in 2024 alone (Rai, 2025). Within this national landscape, Kerala records the highest age-adjusted cancer incidence rate in India, approximately 118.5 per 100,000 population among men and 100.6 per 100,000 among women (ICMR-National Cancer Registry Programme, 2024), against a national average of roughly 110 per 100,000; a 2025 Government of India (Lok Sabha) statement placed the state's overall rate at approximately 170 per 100,000, over 50% above the national figure. Lung cancer predominates among men and breast cancer

among women in the state (Economic Times Health World, 2025). These statistics did not restrict eligibility to a single cancer site; caregivers of patients with any cancer diagnosis undergoing active treatment were eligible, reflecting the general caregiving burden associated with cancer rather than a disease-specific burden. Consistent with the state-level pattern in which lung cancer predominates among men and breast cancer among women, patients in the study sample were similarly drawn across common cancer types. These statistics underscore the urgent need to examine not only clinical management but also the broader social and psychological dimensions of cancer care, particularly as experienced by informal family caregivers.

The psychosocial burden of informal caregiving

An extensive international literature has examined psychosocial burden among informal caregivers of cancer patients (Northouse et al., 2010; Northouse et al., 2012; Girgis et al., 2013; Grosse et al., 2017; Chong et al., 2022; Secinti et al., 2023); however, significant gaps remain regarding caregivers in low- and middle-income, rural contexts (Prinja et al., 2023). Studies specifically addressing challenges faced by informal caregivers (Family caregivers, typically spouses, adult children, or other close relatives who provide sustained, unpaid care without formal training or

institutional recognition) in rural and semi-urban areas of India, where healthcare access is limited, financial resources are constrained, and formal psychosocial services are scarce, are particularly rare. This study addresses that gap by foregrounding the caregiver experience within a specific socio-cultural and regional context, thereby generating locally grounded evidence for social work practice, institutional policy, and caregiver-focused intervention design.

The study is grounded in the Stress Process Model (Pearlin et al., 1990), with complementary perspectives drawn from Family Systems Theory (Bowen, 1978) and the Transactional Model of Stress and Coping (Lazarus and Folkman, 1984). Together, these frameworks conceptualise caregiving burden as shaped by primary stressors such as patient illness severity and treatment demands (Pearlin et al., 1990; Mosher et al., 2013), secondary stressors including role strain (Kim and Schulz, 2008), financial difficulties and social disruption (Keramatikerman, 2020; Prinja et al., 2023), and mediating resources encompassing coping strategies, social support, and family dynamics (Bowen, 1978), providing a robust foundation for understanding why caregivers differ in vulnerability and outcomes.

To address this problem, the study pursues five interrelated objectives. It first assesses the psychological difficulties, including anxiety, depression, and emotional distress, experienced by family caregivers of cancer patients in Idukki district. It then examines the social challenges associated with cancer caregiving, such as role strain, social isolation, and relationship disruption. The study further seeks to identify the coping strategies employed by caregivers and the factors that mediate or amplify psychosocial burden. It also identifies critical gaps in the formal and informal support systems currently available to family caregivers in the region. Finally, the study aims to generate locally grounded evidence to inform social work practice, caregiver-focused interventions, and policy reform.

Most existing studies prioritise patient outcomes and treat caregivers as secondary subjects rather than as primary participants in their own right. Furthermore, the great number of research originates from high-income, Western contexts, leaving caregiving experiences in developing and regional settings substantially underexamined.

MATERIALS AND METHODS

Study design

This study adopted a quantitative descriptive research design to examine the psychosocial challenges experienced by family caregivers of cancer patients. A quantitative approach was employed to enable systematic data collection and statistical description of caregiver experiences. The descriptive design was considered appropriate given the exploratory nature of the study, particularly in a regional context where empirical evidence on early-stage caregiving burden remains limited.

Population and sampling

The study population comprised family caregivers aged 25–65 years who were actively providing unpaid care to cancer patients undergoing treatment or continuing medication during the data collection period. A sample of 60 participants was selected using convenience non-probability sampling from both public and private hospital settings in Idukki district, Kerala, following institutional permission obtained from each hospital. Formal Institutional Ethics Committee clearance was not mandated for this non-interventional, descriptive social-science survey under the affiliating university's research guidelines; all procedures nonetheless followed the ethical principles of the

Declaration of Helsinki. This approach was adopted due to the sensitive, emotionally demanding nature of caregiver recruitment in hospital settings and practical constraints on access and time. Sample size was informed by WHO guidance on sample size determination for exploratory health studies (Lwanga and Lemeshow, 1991) and is comparable to sample sizes used in similar exploratory caregiver-burden studies (Chong et al., 2022). The sample size of 60 was deemed adequate for this exploratory descriptive study, as it allows for initial assessment of psychosocial burden and is consistent with similar caregiver studies conducted in resource-constrained settings.

Inclusion and exclusion criteria

Inclusion criteria:

- Family caregivers aged 25–65 years
- Individuals providing unpaid care to cancer patients in the early stages of treatment
- Caregivers available and willing to participate during the data collection period

Exclusion criteria:

- Paid or professional caregivers
- Caregivers of terminally ill patients receiving palliative care
- Individuals unwilling or unable to provide informed consent

The 25 - 65 age band reflects the working-age demographic profile reported for family caregivers in prior Indian caregiving studies (Prinja et al., 2023). Restriction to early -stage/ongoing-treatment caregiving, with exclusion of palliative/terminal-stage caregivers, was adopted to distinguish this study from the substantially larger existing literature on end-of-life caregiver burden (Nissen et al., 2016), consistent with the study's objective of examining the comparatively under-researched early-stage phase.

Recruitment and response rate

Participants were recruited from selected public and private hospitals in Idukki district. At the public hospital, written permission was obtained from the medical officer-in-charge/superintendent following submission of the study protocol and participant information sheet. At the private hospital, equivalent written permission was obtained from the hospital administration/medical director's office through that institution's internal research-access procedure. In both settings, caregivers were approached only after institutional clearance was granted, informed about the purpose of the study, and invited to participate. A total of 130 eligible caregivers were approached, of whom 60 consented to participate, yielding a response rate of 47%.

Data collection

Primary data were collected using a self-structured questionnaire consisting of 51 items designed to assess psychological and social challenges associated with caregiving. The instrument covered domains including caregiver demographics, disease and treatment characteristics, psychological well-being, social functioning, role changes, and utilisation of support systems.

Content validity was established through an extensive review of caregiving and psycho-oncology literature and evaluation by a three-member expert panel (social work, oncology, clinical psychology) using a content validity index (CVI). The instrument was further evaluated by subject experts in social work, oncology, and clinical psychology to ensure relevance and clarity. A pilot

study was conducted to assess clarity, feasibility, and respondent comprehension. Minor modifications were made based on feedback prior to final administration. Secondary data were obtained from peer-reviewed journals to support contextual analysis.

Ethical considerations

The study adhered to established ethical principles for research involving human participants. Formal Institutional Ethics Committee clearance was not required for this study category as per institutional guidelines; however, all procedures adhered to the ethical principles of the Declaration of Helsinki, including voluntary participation with the right to withdraw at any stage without consequence, written/verbal informed consent before data collection, strict anonymity and confidentiality (no personally identifiable information collected), use of data solely

for academic purposes, and heightened sensitivity to the emotional vulnerability of caregivers through private, supportive administration of the questionnaire executed to maintain the ethical standards.

Data analysis

Data analysis was performed using IBM SPSS 26 software. Descriptive statistical techniques were applied to summarise and describe the data across all study domains. Results are presented through tables to facilitate clear and accessible reporting of findings. Given the descriptive and exploratory orientation of the study, inferential statistical procedures were not employed; however, patterns and associations identified in the descriptive analysis are discussed in relation to the existing literature and the study's theoretical framework.

RESULTS

Table 1. Socio-Demographic Profile of Caregivers (USD and Philippine Peso equivalents calculated and added alongside. Using the approximate mid-market at ₹83 = US\$1, INR-PHP rate ₹1 ≈ ₱0.65; the approximate exchange rate during the data-collection period).

Variable	N	Percentage (%)
Age Group (years)		
25–35	15	25
36–45	15	25
46–55	12	20
56–65	18	30
Gender		
Female	39	65
Male	21	35
Economic status		
Below Poverty Line (BPL)	44	73.33
Above Poverty Line (APL)	16	26.67
Monthly Household Income		
Below ₹20,000 (≈ US\$241)	47	78.33
₹20,001–₹50,000 (≈ US\$241–602)	12	20
Above ₹50,000 (≈ US\$602)	1	1.67

Table 1 presents the socio-demographic characteristics of the caregivers who participated in the study. The largest age cohort was 56–65 years (30%). Female caregivers accounted for 65% of respondents and male caregivers for 35%, confirming a

gender-skewed distribution of informal caregiving responsibilities. Economic vulnerability was pronounced: 73.33% of respondents were classified as Below Poverty Line (BPL), and 78.33% reported a monthly household income below ₹20,000 (≈ US\$241).

Table 2. Caregiver patient relationship.

Variable	N	Percentage (%)
Relationship to patient		
Spouse	27	45
Child/ In-law	20	33.33
Other relative	13	21.67

Table 2 summarises the relationship between caregivers and patients. Spouses constituted the largest caregiver group

(45%), followed by children or in-laws (33.33%).

Table 3. Disease profile.

Variable	N	Percentage (%)
Cancer stage		
Early stage	24	40
Localised	20	33.33
Advanced	16	26.67
Current treatment type		
Medication only	28	46.67
Chemotherapy	17	28.33
Surgery	11	18.33
Other/ Combined	4	6.67
Treatment status		
Ongoing	54	90
Completed	6	10

Table 3 presents the disease profile data. At the time of data collection, 40% of patients were at an early stage of cancer and 33% at a localised stage; 26.67% had advanced disease. Treatment

was ongoing in 90% of patients, with medication-only regimens the most common (46.67%), followed by chemotherapy (28.33%) and surgery (18.33%).

Table 4. Psychological burden.

Indicator	N	Percentage (%)
Primary burden type reported		
Psychological challenges	34	56.67
Social difficulties	16	26.67
Physiological challenges	8	13.33
Other	2	3.33
Psychological health indicators		
Elevated stress	25	41.67
Sleep deprivation	23	38.33
Fatigue	20	33.33
Emotional strain	47	78.33
Intense stress	30	50
Patient condition affects caregiver well-being	24	40
Significant role changes reported	41	68.33

Table 4 shows psychological challenges as the primary burden for 56.67% of caregivers, with elevated stress (41.67%), sleep deprivation (38.33%), and fatigue (33.33%) forming a self-reinforcing cycle rather than independent problems. The gap between occasional emotional strain (78.33%) and intermittent intense stress (~50%) suggests distress is a near-constant baseline punctuated by acute episodes, making one-off support models inadequate. Nearly 40% linked their own well-being to the patient's

condition, reflecting the dyadic nature of illness burden (Bowen, 1978), while 68.33% reporting major role changes points to a structural renegotiation of family identity rather than simple added workload. Notably, high self-reported satisfaction (86.66%) alongside this burden likely reflects role-identity affirmation and cultural norms discouraging dissatisfaction, rather than an absence of distress, a pattern warranting more objective measures in future work.

Table 5. Social burden.

Social burden indicator	N	Percentage (%)
Financial crisis as the primary social challenge	41	68.33
Social withdrawal reported	36	60
Difficulty balancing work and caregiving	44	73.33
Psychological support from family members	36	60

Table 5 presents findings related to the social burden experienced by caregivers. Financial crisis was the most frequently cited social challenge (68.33%), followed by difficulty

balancing work and caregiving (73.33%) and social withdrawal (60%); 60% reported receiving psychological support from family members.

Table 6. Access to support systems and identified service gaps.

Support system indicator	N	Percentage (%)
Received any caregiving training	28	46.67
Patient has medical insurance	37	61.67
Unaware of government welfare schemes	37	61.67
Accessed the Chief Minister's Relief Fund	18	30.00
Never received professional counselling	42	70.00

Table 6 presents data on caregivers' access to formal and informal support systems. Less than half of the sample (46.67%) had received any form of caregiving training, and satisfaction with the training received varied considerably among those who had. While 61.67% of patients held some form of medical insurance, caregiver awareness of available government welfare schemes was markedly low: 61.67% of respondents reported being unaware of such provisions. Approximately 30% had accessed the Chief Minister's Relief Fund. The most critical gap identified by the study concerned professional psychosocial support: 70% of caregivers reported having never received counselling from a trained professional, representing the most severe and consistent service deficiency identified across the sample.

Data quality was checked through double entry with cross-verification against original questionnaires, and logical consistency checks between related items. The pilot study served

as an initial face/content-validity check before final administration. Findings were further triangulated against the existing caregiver-burden literature discussed in the following section to assess consistency of direction and magnitude with prior studies. No formal external validation was undertaken, given the exploratory, self-structured nature of the questionnaire; this is noted as a limitation.

DISCUSSION

Socio-demographic determinants of caregiving vulnerability

The socio-demographic profile of the sample points to structural inequalities that systematically concentrate caregiving burden among older adults and women. Within the Stress Process Model (Pearlin et al., 1990), these characteristics function as background contextual factors that shape caregivers' differential

exposure to stressors and their available coping resources. The overrepresentation of female caregivers (65%) reflects not simply cultural preference but the material effect of gendered labour divisions that restrict women's occupational participation, limit their independent income, and normalise their assumption of unpaid care work

Economic status shows a similarly patterned effect. The pronounced economic vulnerability of the sample, with 73.33% classified as below the poverty line and 78.33% reporting monthly incomes below ₹20,000 (≈ US\$241, at ₹83 = US\$1), is significant beyond its descriptive value. Within the Stress Process Model, financial strain constitutes a secondary stressor: it does not arise directly from the patient's illness but from the economic consequences of caregiving, including treatment costs, income loss, and out-of-pocket expenditure (Prinja et al., 2023). These intersecting vulnerabilities suggest that caregiver burden in this context cannot be adequately understood through a psychological lens alone; a structural and socio-economic analysis is necessary.

Disease stage and the timing of burden

The finding that a majority of patients were at early or localised stages of cancer at the time of data collection, yet caregivers already reported significant psychological burden, constitutes one of the more theoretically important results of this study. It challenges a widely held assumption in the caregiving literature that psychosocial distress is primarily a late-stage or terminal-phase phenomenon (Kurtz et al., 2004), and instead suggests that the burden trajectory may begin substantially earlier, potentially at the point of diagnosis itself.

Psychological burden

Psychological challenges were identified as the primary burden by 56.67% of caregivers, with elevated stress (41.67%), sleep deprivation (38.33%), and pervasive emotional strain (78.33%) as the dominant indicators. As a primary stressor arising directly from illness severity and treatment demands, this pattern is consistent with prior evidence that subclinical psychological distress, when sustained over extended caregiving periods without intervention, is a significant predictor of progression to clinically significant impairment (Pitceathly and Maguire, 2003; Biegel et al., 1991; Secinti et al., 2023). The co-occurrence of high caregiving satisfaction (86.66%) alongside significant psychological and social burden is a finding that merits closer theoretical attention than a cultural explanation alone can offer. Two non-cultural mechanisms plausibly account for it. First, role-identity theory suggests satisfaction can coexist with burden when caregiving affirms a valued family role and sense of purpose rather than being experienced purely as an imposition (Kim et al., 2007; Blanchard et al., 1997). Second, within the Transactional Model of Stress and Coping (Lazarus and Folkman, 1984), caregivers may cognitively appraise the same demands along two simultaneous dimensions, threat/harm and meaning/benefit, such that the same caregiving experience can be appraised as both stressful and meaningful at once, producing parallel rather than contradictory emotional responses. Read this way, the satisfaction finding does not offset the burden finding; it coexists with it as a distinct appraisal process, and should not be taken to imply that high burden is benign.

Social burden and informal support

The severity of burden observed here is better explained by an interaction between primary and secondary stressors than by their simple additive effect. Role strain was reported by 68.33%

of caregivers, with many simultaneously managing financial responsibilities, sole breadwinning, and single parenting. The absence of preparation for these role transitions functions as a critical mediating factor in the Stress Process Model: caregivers thrust into unfamiliar responsibilities without training, practical knowledge, or institutional support are likely to experience role demands as more threatening and less manageable. Against this predominantly negative burden profile, the finding that 60% of caregivers received emotional support from family members is an important counterweight. At the same time, reliance on informal networks as the primary or sole source of support may itself generate secondary burdens, including interpersonal conflict, caregiver fatigue among supporting family members, and the risk of entire family systems becoming overwhelmed, a pattern the Stress Process Model would characterise as a mediating resource under strain rather than a stable protective factor.

Formal support deficits and systemic gaps

The finding that 70% of caregivers had never received professional counselling, combined with 61.67% being unaware of available government welfare schemes, represents the most structurally significant result of this study. These are not simply individual-level deficits in awareness or help-seeking behaviour; they reflect systemic failures in the design and delivery of psychosocial support within the regional healthcare infrastructure. These deficits also carry economic implications beyond the household. Consistent with documented patterns of high out-of-pocket cancer-care expenditure in India (Prinja et al., 2023; Blanchard et al., 1997), unaddressed caregiver financial and psychological burden is associated with reduced caregiver workforce participation and productivity loss, increased caregiver healthcare utilisation from untreated distress, and poorer patient treatment adherence, which in turn raises downstream costs to the public health system. Welfare-scheme awareness and psychosocial support should therefore be understood not only as individual-welfare measures but as having system-level economic returns.

The study employed convenience non-probability sampling from a single district, and the sample is not representative of the broader caregiver population in Kerala or India. The theoretical interpretations offered above, particularly regarding the coexistence of satisfaction and burden, and the early onset of psychosocial distress, should accordingly be read as hypothesis-generating rather than as generalizable claims. This is appropriate for an exploratory design, as it provides preliminary insights into caregiver experiences; however, findings are context-specific, and future studies with larger, more representative, multi-district samples are needed to enhance external validity before these patterns can be treated as established.

The findings carry clear and actionable implications for social work practice and health policy. At the individual and family level, hospital-based social workers are well-positioned to identify caregivers at risk of psychological deterioration through early and systematic screening, particularly at the point of patient diagnosis when burden onset appears to precede late-stage disease progression. At the institutional and policy level, the systemic absence of professional psychosocial services and the widespread unawareness of welfare entitlements point to the need for structural reform rather than individual-level remediation alone. Embedding social work professionals within oncology care teams, integrating caregiver assessment into standard treatment pathways, and establishing proactive mechanisms for welfare scheme dissemination, particularly targeting below poverty line households and those with limited literacy, are priority actions indicated by these findings.

CONCLUSION

A key contribution of this study is empirical evidence that psychosocial burden is already substantial among caregivers of early-stage and localised-stage cancer patients a phase generally under-examined relative to advanced or palliative-stage caregiving in the existing literature. Set within a rural, high-incidence district, the findings further show how this early-onset burden intersects with pronounced socioeconomic vulnerability and a near-total absence of formal psychosocial support, underscoring the need for caregiver-focused interventions counselling, psychoeducation, and respite care from the point of diagnosis rather than later in the illness trajectory. Future research should adopt longitudinal and mixed-method approaches, explore regional and gender variations, and evaluate intervention models. Greater attention to policy implementation and digital support systems is also necessary to bridge existing gaps in caregiver support.

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AUTHOR CONTRIBUTIONS

Alby and Dr Jeryda contributed to the conceptualization, visualization, and methodology of the study; Alby carried out data collection, analysis, and the original draft preparation.

DECLARATION

Informed consent statement

The study was conducted in compliance with the applicable laws and ethical standards of the country in which it was performed.

Conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, or publication of this article.

AI Declaration

Generative AI and AI-Assisted Technologies in the Writing Process During the preparation of this work, the author(s) used AI-assisted tools to support grammar correction and language improvement. Following the use of these tools, the author(s) reviewed and edited all content as necessary and assume full responsibility for the accuracy and integrity of the publication.

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