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Article

Analysis of the psychosocial and functional impact of patients' illness on primary caregivers in a tertiary care hospital in South Gujarat

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Abstract: Family caregivers play a foundational role in patient care, but they often face high physical, psychosocial and financial burden, especially in areas where resources are limited, and this burden remains underrecognised. As the patient's disease progresses further, this burden increases and harms the primary caregiver's well-being, which ultimately affects patient care. This study aimed to assess these burdens, identify unmet needs and support gaps faced by primary caregivers during the period of the patient's hospitalisation. This cross-sectional survey was conducted from September 2025 to October 2025 in a tertiary care hospital. 107 caregivers were recruited using non-probability sampling, and data were collected by interviewing participants. The interview questionnaire contained items assessing emotional, physical, financial and social burden. Appropriate descriptive and inferential statistical methods were used to analyse the data. Most caregivers were men (57.94%) and between 31 and 50 years old (47.66%). Many caregivers reported feeling anxious or worried (66.35%) and sad or depressed (34.58%). Some caregivers reported that their health was affected (21.50%), and many occasionally neglected their health (59.81%). Financial strain was a concern for 38.31%, and 11.21% had to reduce or quit their jobs. The survey found that monthly income was significantly linked to burden (p = 0.046). Findings suggest caregiver burden is a public health issue that is often ignored, and caregivers should be screened and provided with support. Caregivers are like "invisible patients," and their well-being directly affects patient outcomes; hence, we need to pay more attention to them in clinics and policy-making.

Keywords: caregiver burden; family caregivers; financial stress; psychosocial impact; quality of life; social support

1. Introduction

As the global population ages, the prevalence of non-communicable diseases (NCDs) such as neurodegenerative conditions, cardiovascular diseases, renal failure and malignancies increases. The pace of this transition is accelerated in developing nations due to the shifting in lifestyle paradigms, rapid urbanization and an increased burden of environmental and behavioural risk factors. Consequently, rehabilitative and palliative patient care are also increasingly moving from hospitals to community and home settings. However, in both of these scenarios, family members play a central role, serving as primary caregivers of long-term care and assistance for patients (Liu et al., 2020). The prevalence of these chronic diseases is increasing more rapidly in developing and least developed countries than in developed countries, which is

impelled by longer life expectancy and a greater burden of risk factors. Family members as primary caregivers of patients form a foundational pillar of the healthcare system. They provide as much as 90% of the in-home long-term care required by adults (Lian et al., 2022). In India, traditional societal structures and cultural understandings have historically relied upon the joint family system to distribute the physical and emotional demands of patient care and chronic disease management. But the nuclearization of families, shifting occupational dynamics and rapid economic migrations have weakened these support foundations. This results in the concentration of exhaustive demands of caregiving onto single individuals, which in turn generates psychosocial and financial consequences (Baishya, 2024).

Caregiver burden is a complex and multifaceted issue as their health and well-being directly influence their own lives and indirectly the quality of care received by patients. Theoretical frameworks like the Stress Process Model postulate that caregiving stress proliferates through primary stressors, i.e., directly related to the patient's condition and care requirements; and secondary stressors, i.e., indirect effects on the caregiver's occupational, social and financial life (Pearlin et al., 1990). As a disease advances, patients experience decreased quality of life. Along with that, informal caregivers face increased emotional and psychological strain, which can increase as the illness progresses (Lian et al., 2022; Tang et al., 2021).

Caregivers of mental disorder patients such as schizophrenia, dementia, etc., play a very important role in providing emotional support, maintaining medication adherence and assisting with daily activities. This responsibility brings heavy physical, emotional and social burdens to caregivers, which may further be escalated by unpredictable symptoms, limited awareness, and societal stigma (Syarif et al., 2025). Most individuals with neurodegenerative disorders such as Amyotrophic Lateral Sclerosis (ALS) and Parkinson's disease (PD) are cared for primarily at home, mostly by their partners or children. Caregivers' personal and professional lives are affected, which often leads to fatigue, sleep disturbances and other health challenges to maintain their own health because these diseases require long-term care (Tang et al., 2021). Due to the sudden onset leading to lasting effects, vascular disorders, stroke, and renal diseases profoundly affect both patients and their families. Patients and caregivers often face psychosocial consequences such as anxiety, depression, social isolation and major lifestyle changes that diminish quality of life (QOL) (Maggio et al., 2024). In the case of caregivers for end-stage renal disease patients, they encounter rigid schedules associated with hemodialysis, which directly affect their employment hours (Syarif et al., 2025). Moreover, cancer has also emerged as a major cause of morbidity and mortality across the globe, including in India, which has raised substantial demands on caregivers.

Those caring for and supporting highly symptomatic patients face high psychosocial, physical and financial burdens that are further intensified when caregivers themselves have limited resources or poor health (Mishra et al., 2021). Additionally, the burden falls disproportionately on women, who often balance caregiving with domestic responsibilities and employment (Goyal-Honavar et al., 2025). Rural female caregivers face further critical challenges as they live in an

environment with limited healthcare access, constrained economic opportunities, rigid gender roles and the absence of formal caregiving infrastructure (Lalani et al., 2025).

In a developing nation like India, the financial landscape of the majority of families always stays on the verge of undergoing high distress if they encounter a hefty out-of-pocket health expenditure, and families are routinely compelled to liquidate generational assets or receive high-interest debt to mitigate chronic illnesses, which forces them to slip into poverty (Wagle et al., 2024).

This study aimed to systematically evaluate the demographic details, emotional, physical, financial, social and occupational burden experienced by caregivers of patients at a tertiary care teaching hospital in South Gujarat. Additionally, unmet needs and support gaps faced by family caregivers during the period of hospitalisation were identified. To nurture clinical empathy among undergraduate medical students, this study was integrated with the 'Attitude, Ethics, and Communication (AETCOM) Module 2.8—What does it mean to be a family member of a sick patient?' This education module inculcates an understanding of a family's support systems, coping mechanisms and emotions in order to develop empathy and compassion during encounters with patients and their caregivers. In order to enable undergraduate students to conduct direct interviews with patient caregivers and data collection, they were systematically trained in empathetic communication first. This exercise allowed students to gather research data while simultaneously fulfilling the module's objective of demonstrating empathy in patient encounters.

2. Materials and methods

This questionnaire-based, cross-sectional survey with an embedded qualitative component was conducted after approval of the Institutional Ethics Committee (IEC) and reported in accordance with the STROBE guidelines, as part of the AETCOM 2.8 module training for undergraduate medical students at a tertiary care teaching hospital in South Gujarat . The study population was the primary family caregiver of patients who were admitted to various inpatient departments of the hospital, including Medicine, Surgery, Pediatrics, Obstetrics and Gynaecology and others.

It was expected that the relatives cum caregivers would have adequate knowledge of the diagnosis and line of treatment being administered to the patient. Those who could not understand and comprehend the questionnaire because of cognitive disabilities or extreme psychological stress were excluded from the study.

A non-probability, convenience sampling technique was utilised for participant recruitment. While formal sample size calculation was not performed for this exploratory cross-sectional survey, the sample size was deemed adequate to provide preliminary estimates of caregiver burden prevalence in this setting. Participants were enrolled as per inclusion and exclusion criteria after obtaining written informed consent. Data was collected by interviewing participants in real time by medical students. The interview was composed of the following aspects:

1) Sociodemographic details of both the patient and the caregiver.
2) A series of Likert-scale and categorical questions assessing the impact of the patient's illness on the caregiver's emotional well-being, physical health, financial

status, professional life, and social activities.

3) Questions related to the level of caregiving involvement and the perceived adequacy of support systems.
4) Two open-ended questions to gather qualitative insights regarding the caregivers' crucial challenges and their coping strategies.

The survey instrument was developed by the investigators based on published literature on caregiver burden, established burden questionnaires and their own clinical experience. It was then refined through review by senior faculty members to ensure content validity, clarity and cultural appropriateness. The draft questionnaire was pilot-tested in a small group of primary caregivers from the same setting to assess comprehensibility, response range and completion time. Minor wording changes were made based on this feedback. For psychometric evaluation, items were grouped into a priori domains (emotional, physical, financial, social and occupational burden), and internal consistency reliability was assessed using Cronbach's alpha. The emotional-burden items demonstrated good internal consistency (Cronbach's alpha ≈ 0.81), indicating good reliability of this domain. Item–total correlations were inspected to confirm that each item contributed meaningfully to its respective scale and no items were removed at this stage. Thus, the raw data were collected using this validated questionnaire and aggregated into a centralized, anonymised database for cleaning and validation. The analysis was conducted using both descriptive and inferential statistical methods with the help of Microsoft Excel version 2021 and IBM SPSS version 26. Means, standard deviations, frequencies and valid percentages were used to describe the sociodemographic profile of patients and caregivers and to summarise emotional, physical, social and financial burden variables. For inferential analysis, burden indicators were dichotomised into "high" versus "low" categories as described above, and chi-square tests were used to examine associations between caregiver characteristics (e.g., gender, relationship to the patient, monthly household income) and high emotional or financial burden, with Cramer's V reported as a measure of effect size. In additional exploratory analyses, we constructed multivariable logistic regression models with high emotional burden as the dependent variable and caregiver age group, gender, education level, relationship to the patient, and household income as predictors; adjusted odds ratios (aORs) with 95% confidence intervals (CIs), regression coefficients and *p*-values are presented. Model fit was summarised using McFadden's pseudo R^2 (pseudo R^2 = 0.09 in the final model). Given the exploratory nature of this single-centre study and the modest sample size, no formal adjustment for multiple comparisons was applied. The alpha level was set at 0.05.

For emotional burden, caregivers who rated their emotional well-being as "moderately affected" or "severely affected" were classified as having high emotional burden, whereas those reporting "mildly affected" were classified as having low burden. For financial burden, caregivers who reported "somewhat" or "yes" to the question on financial challenges due to the patient's illness were classified as having high financial burden and all other responses were categorised as low burden. Cramer's V was calculated as a measure of effect size for chi-square tests. In additional exploratory analysis, multivariable logistic regression models were constructed with high emotional

burden as the dependent variable and key caregiver characteristics (age group, gender, education level, relationship to the patient and household income) entered as predictors to examine independent associations. Open-ended responses regarding challenges and coping strategies were summarised descriptively by grouping similar phrases into broad categories (e.g., financial strain, social support, role overload) and described.

3. Results

A total of 142 patients and their relatives were approached. 26 declined to participate in this study, and 9 were unable to comprehend the questionnaire. A total of 107 participants were included in the final analytical sample. Moreover, complete case analysis was performed. All 107 participants had complete data for variables included in the primary analysis. Hence, no imputation methods were employed.

As shown in **Figure 1**, a total of 107 participants from various departments were enrolled, with the maximum from the medicine department (23), followed by surgery (19), ENT (Ear, Nose, and Throat) (15), obstetrics and gynaecology (12), ophthalmology (10), orthopedics (2), radiology (2) and dermatology (1) departments.

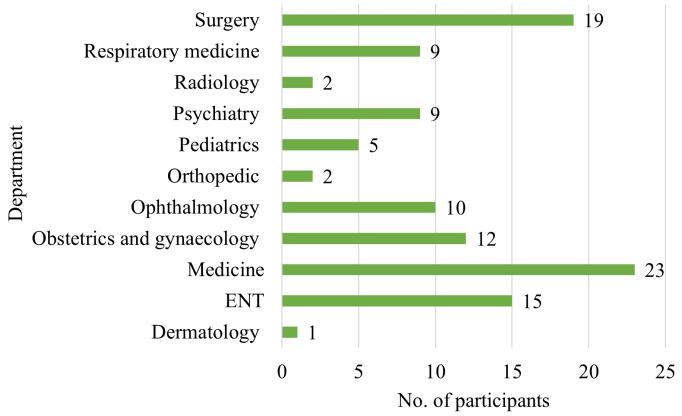

Figure 1. Number of participants from various departments.

Table 1 describes the demographic details of patients and caregivers. A maximum of 48 (44.9%) patients belonged to the ≤30 years of age group, while a maximum of 51 (47.7%) caregivers were from the 31 to 50 years of age group. Male patients dominated both the patient group (n = 74, 69.2%) and the caregiver group (n = 62, 58%). Middle school education level was more prevalent than other groups among both patients (n = 31, 29%) and caregivers (n = 36, 33.6%). The highest number of patients (n = 50, 46.7%) and caregivers (n = 39, 36.4%) were receiving a monthly income of ≤15,000 INR.

Table 1. Demographic details of patients and their caregivers.

Characteristics	Category	Patients n (%)	Caregivers n (%)
Age (years)	≤30	48 (44.85%)	41 (38.32%)
	31–50	35 (32.71%)	51 (47.66%)
	>50	24 (22.42%)	15 (14.01%)
Gender	Male	74 (69.16%)	62 (57.94%)
	Female	33 (30.84%)	45 (42.06%)

Table 1. *Cont.*

Characteristics	Category	Patients n (%)	Caregivers n (%)
Education	Illiterate	20 (18.69%)	16 (14.95%)
	Primary School	29 (27.10%)	18 (16.82%)
	Middle School	31 (28.97%)	36 (33.64%)
	High School	20 (18.69%)	23 (21.50%)
	Graduate/Professional	7 (6.54%)	14 (13.08%)
Monthly Income (INR)	Unemployed/Nil	28 (26.17%)	31 (28.98%)
	≤15,000	50 (46.73%)	39 (36.44%)
	15,001–30,000	24 (22.43%)	28 (26.17%)
	>30,000	5 (4.67%)	9 (8.41%)

Figure 2 shows that 31 (29%) caregivers had the relationship of spouse to the patient, 30 (28%) were parents and 18 (16.8%) were siblings.

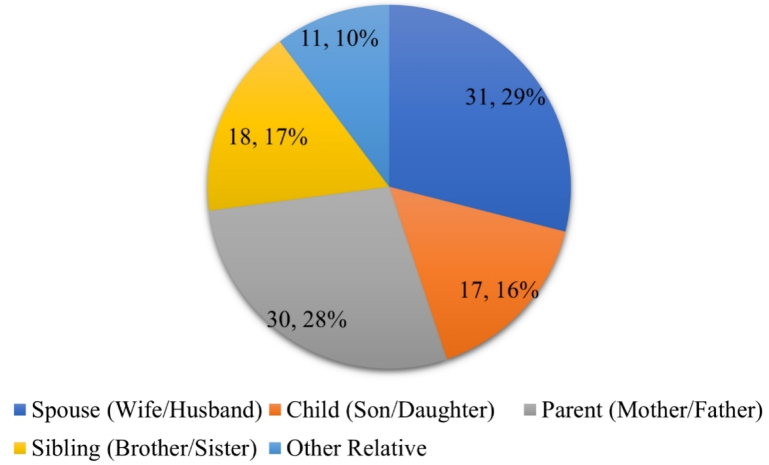

Figure 2. Relationship between patient and caregiver.

The maximum responses showed that emotional well-being was mildly affected in all types of relationships.

Table 2 demonstrates that the emotional well-being of 42.0% of caregivers was moderately or severely affected, and 66.4% of caregivers were anxious or worried. 34.6% of caregivers were frequently or almost always feeling sad, depressed or helpless. 19.6% of caregivers experienced stress or frustration. Considering the physical domain, 48 (44.9%) caregivers reported physical pain/health issues. 41 (38.3%) caregivers faced financial challenges, and 12 (11.2%) had to reduce or give up their job. 34.6% of caregivers reported that their professional life was affected, and 21.5% admitted that their social life was getting hampered moderately or severely. The majority of caregivers (n = 65, 60.7%) reported reducing or giving up their hobbies.

Table 2. Descriptive analysis of various domains of caregivers.

Domain and indicator	Response category	Frequency (n)	Percentage (%)
Emotional burden			
Emotional well-being affected	Mildly	51	47.66%
	Moderately	31	28.97%
	Severely	14	13.08%

Table 2. *Cont.*

Domain and indicator	Response category	Frequency (n)	Percentage (%)
Emotional burden			
Feels anxious or worried	Yes	71	66.35%
Feels sad, depressed, or helpless	Occasionally	58	54.21%
	Frequently	31	28.97%
	Almost Always	6	5.61%
Experiences stress or frustration	Yes	21	19.62%
	Sometimes	42	39.25%
Physical burden			
Physical health impacted	Mildly	54	50.46%
	Moderately	20	18.70%
	Severely	3	2.80%
Experienced physical pain/health issues	Yes	48	44.86%
Manages own health	Sometimes Neglects	64	59.81%
	Frequently Neglects	8	7.47%
Financial burden			
Faced financial challenges	Somewhat	29	27.10%
	Yes	41	38.31%
Had to reduce or give up job	Yes	12	11.21%
	Partially	27	25.23%
Social & occupational burden			
Work or professional life affected	Yes	37	34.58%
	Occasionally	26	24.30%
Social life impacted	Mildly	65	60.74%
	Moderately	20	18.70%
	Severely	3	2.80%
Difficulty engaging in enjoyable activities	Yes	28	26.17%
	Sometimes	39	36.45%
Had to reduce/give up hobbies	Yes	65	60.74%

Prevalence of high emotional and financial burden across caregiver subgroups is summarised in **Table 3** and **Figure 3**. In bivariate analyses, caregiver gender was not significantly associated with high emotional burden ($\chi^2 = 0.77$, df = 1, $p = 0.38$, Cramer's V = 0.08) or high financial burden ($\chi^2 = 0.086$, df = 1, $p = 0.77$, Cramer's V = 0.028). Relationship to the patient (spouse, parent, child, sibling, other) similarly showed no statistically significant association with either high emotional burden ($\chi^2 = 1.92$, df = 4, $p = 0.75$, Cramer's V = 0.13) or high financial burden ($\chi^2 = 5.73$, df = 4, $p = 0.22$, Cramer's V = 0.16). The *p*-value for the monthly income and high emotional burden was statistically significant ($\chi^2 = 8.09$, df = 3, $p = 0.046$, Cramer's V = 0.28). However, no significant association was observed for high financial burden ($\chi^2 = 7.61$, df = 3, $p = 0.054$, Cramer's V = 0.27). In the multivariable logistic regression analysis, none of the caregiver characteristics remained independently associated with

high emotional burden at the 0.05 significance level. Male caregivers had lower odds of high emotional burden than female caregivers (adjusted OR 0.57, 95% CI [0.18–1.81]), although this association was not statistically significant. Compared with caregivers from households earning more than INR 30,000 per month, those with monthly income of INR 15,000 or less showed higher odds of high emotional burden (adjusted OR 2.33, 95% CI [0.69–7.85]). No significant independent associations were observed for caregiver age group, relationship to the patient, or education level, and overall model fit was modest (McFadden pseudo $R^2 = 0.09$).

Table 3. Statistical analysis between demographics and burdens (emotional & financial).

Characteristics	Category	High emotional burden (%)	*p*-value	High financial burden (%)	*p*-value
Caregiver Gender	Male (n = 62)	51.61	0.382	67.74	0.722
	Female (n = 45)	60.00		64.52	
Caregiver Relationship	Spouse (n = 31)	51.61	0.749	58.06	0.215
	Child (n= 16)	62.50		43.75	
	Parent (n = 28)	60.71		50.00	
	Other (n = 32)	50.00		71.87	
Monthly Income (INR)	≤15,000 (n = 39)	71.79	0.046*	74.36	0.054
	15,001–30,000 (n = 28)	42.86		57.14	
	>30,000 (n = 9)	33.33		55.56	
	Unemployed/Nil (n = 31)	51.61		41.94	

Note: *: $p < 0.05$ is statistically significant.

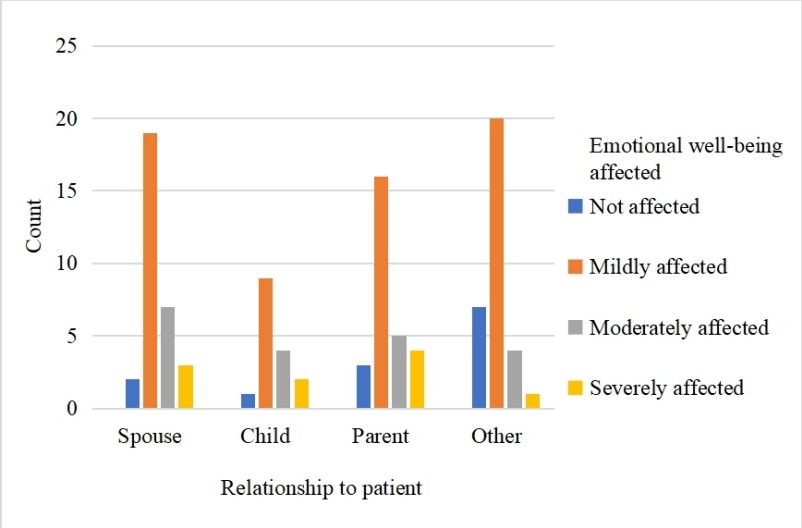

Figure 3. Likert score of emotional well-being affected in caregivers in relation to the relationship between patient and caregiver.

Responses to the open-ended questions provided additional context regarding caregivers' experiences. The most frequently reported challenges were financial

problems or "monetary issues" (mentioned by 55 caregivers, 51.4%), followed by emotional stress or mental health concerns (18 caregivers, 16.8%); a smaller number referred to time pressure or difficulty balancing responsibilities (5 caregivers, 4.7%), while five caregivers (4.7%) explicitly stated that they faced no major challenges. When asked about supportive resources, caregivers most commonly cited family members, friends or relatives as their main source of help (28 caregivers, 26.4%), followed by social or support groups (12 caregivers, 11.3%), and less frequently, healthcare professionals or services (11 caregivers, 10.4%); 14 caregivers (13.2%) indicated that they had little or no effective support. These qualitative findings complement the quantitative burden measures by indicating the central role of financial strain and informal social support in caregivers' narratives.

To further illustrate these themes, caregivers' narratives highlighted both financial hardship and reliance on informal support. One caregiver described that "the cost of treatment and medications is very high, and it is very challenging to move from one place to another for further care. The family has to leave their work to take care of the patient, and it becomes financially challenging," highlighting the cumulative economic burden of prolonged illness. Another caregiver emphasised the importance of interpersonal networks, noting that "support groups and family and friends are helpful for the same," which reflects the central role of informal social support in coping with caregiving demands in this setting.

4. Discussion

Caregiver burden has been documented across a range of chronic and life-limiting conditions, including cancer (Bizuayehu et al., 2024), stroke (Kumar et al., 2022; Mandowara et al., 2020), cardiovascular disease (Jeemon et al., 2026), and end-stage renal disease (Ramasamy et al., 2025). Studies from India and other low- and middle-income settings report that caregivers frequently experience moderate to severe burden, emotional distress, sleep disturbance and disruption of employment and daily activities, particularly when patients have high symptom burden, functional dependence or neuropsychiatric symptoms (Menon et al., 2022; Mishra et al., 2021; Suresh et al., 2025). These findings are broadly consistent with the present study, which found that many caregivers in a general tertiary-care setting reported emotional distress, physical strain, social restriction and financial challenges, even though this study did not focus on any single disease group.

Caregiving for a patient with serious mental illness or neurodegenerative disease involves immense, chronic psychological stress very different from physical caregiving. The psychological burden in such a case is much less concerned with medical issues but related to managing behavior and coping with ambiguous grief for the lost self of the patient. In advanced Parkinson's disease (stages IV–V of the Hoehn and Yahr rating system), caregiving is correlated with a decline in functional independence of the patient and dependence in Instrumental Activities of Daily Living (IADL).

Clinical observations and prior research suggest that neuropsychiatric symptoms (e.g., impulsivity, behavioural problems, psychosis) can have a particularly strong impact on caregivers' emotional well-being, sometimes even more than motor

symptoms.

Thus, informal care over the long term is never easy, even if it feels natural. In India, families are expected to take on this role because of cultural and social values, but limited government and institutional support make it harder. Young caregivers, especially for chronic illness patients, often face emotional stress and financial strain that affect their own life choices (Das, 2023).

In this survey, sociodemographic characteristics of the 107 participants outline fundamental trends in the adoption of informal caregiver roles in India. Most of the patients included were relatively young adults, with 44.85% falling under the category of being 30 years old or younger and 32.71% representing the 31–50 age group. Moreover, the number of men accounted for a majority, amounting to 69.16%. The caregiver population featured analogous yet slightly older youth, where the highest share (47.66%) belonged to the 31–50 age group, while 38.32% of participants had not exceeded the age of 30. The average caregiver age amounted to 35.95 ± 11.50 years. It should be noted that this age is significantly smaller compared to the mean caregiver age reported in parallel neurological research from Western China, which is 49.9 ± 12.6 years. The difference may be explained by the higher dependence on younger age groups in the studied sample, especially those in the prime of their education and working years (Cao et al., 2022). Unlike in national literature, the prevalence of female participation in the care process does not prevail in the current study, since men constitute an absolute majority among the caregivers (57.94%). Survey results showed that there was no statistically significant association between gender and emotional or financial burden.

In developing countries like India, it is often not practical or affordable to keep patients in healthcare facilities for long-term rehabilitation and supportive care. Instead, caregivers usually take on this responsibility at home. The Indian tradition of joint families is especially helpful in this regard, as the care of a patient can be shared among several members, which reduces the burden on any one individual (Baishya, 2024). Results also showed that caregivers were patients' spouses (31), son/daughter (17), mother/father (30), brother/sister (18) and other (11). Chi-square test results did not show any statistically significant correlation between the type of relationship and the level of emotional/financial strain imposed ($p = 0.749$ and $p = 0.215$, respectively). This is an important clinical implication because it suggests that the very nature of the care duties outweighs the importance of any interpersonal relationship in causing stress.

The primary diagnosis of 107 varied across a wide spectrum of medical, surgical and psychiatric conditions. This can broadly be divided into two sub-categories: Acute conditions like fractures and infections (e.g., dengue, cellulitis, appendicitis) and chronic issues like chronic kidney disease (CKD), liver cirrhosis and various cancers. A noteworthy portion of cases were related to obstetrics and gynaecology, including pregnancies and post-natal care. There were cases involving serious conditions that required intensive care, like septic shock and viral encephalitis. This diversity suggests that caregiver burden is not limited to a single category.

The psychological strain associated with extended periods of caregiving can manifest in multiple ways, including chronic anxiety, anticipatory grief and clinically

significant depressive symptoms. In this study, 66.35% of respondents felt anxious or worried, 34.58% suffered from frequent occurrences of sadness, depression or feelings of helplessness, whereas 19.62% complained about constant stress or frustration. These cross-sectional data do not allow causal inferences, but they highlight the close relationship between intensive caregiving roles and poorer psychological well-being.

Interpreting the current findings through Pearlin's Stress Process Model, the high levels of emotional distress, physical strain and financial challenges reported by caregivers can be viewed as the combined effect of primary stressors (directly related to the patient's condition and care demands) and secondary stressors (role strain, occupational disruption, and financial toxicity) (Pearlin et al., 1990). These interconnected stressors appear to translate into poorer psychological and social outcomes in this study, which highlights the need for multidimensional support that addresses both care tasks and broader role demands.

In this case, local data correlate with those at a national level. Thus, a nationwide study of caregivers for stroke patients in rural India demonstrated a direct link between caregiving responsibilities and the emergence of clinical anxiety ($r = 0.84$) and depression ($r = 0.56$) (Mandowara et al., 2020). Emotional problems are likely exacerbated by the observation of the gradual but irreparable deterioration of mental or physical functions of their patients. This is particularly hard for caregivers because it involves grieving over the loss while maintaining a sane face for the sake of providing necessary support to the patient.

The physical requirements involved in providing care, such as moving patients, handling complicated mobility problems, delivering complex medications, dealing with feeding tubes, as well as maintaining cleanliness of the patient, lead to negative physical outcomes on the part of caregivers. Among the sample population, it was found that 44.86% of the caregivers experienced physical pain or physical health problems arising from caregiving.

One particular problem is the fact that health care professionals tend to disregard their own health needs when taking care of the patients. For instance, it was found that 59.81% of the caregivers had sometimes neglected themselves regarding their own medical needs, whereas 7.47% of them had regularly neglected themselves. This type of negligence is further aggravated by the problem of acute sleep deprivation. Studies show that physical health issues arising from caregiving are often connected with the fact that caregivers lack sufficient sleep. Furthermore, studies confirm that women caregivers as well as parents have more chances to suffer from various fatigue syndromes. Thus, the fact that Indian culture expects women to keep all their stress inside themselves while attending to both the patient and the housework shows the real "cost of compassion" (Goyal-Honavar et al., 2025).

It is important to note that ongoing temporal constraints associated with caregiving significantly limit the opportunities of caregivers to engage in social relations and maintain productive occupational performance. According to the study findings, a majority of participants (60.74%) completely ceased to engage in leisure activities. Some (24.30%) had sporadic disruptions at work. The remaining respondents (34.58%) had definite occupational limitations that affected their professional lives.

Role confinement results in deep social isolation. Due to various constraints like inadequate time and physical energy, caregivers tend to avoid leaving their homes and thus become isolated from others. This isolation forms a vicious circle because the fewer social resources one has, the higher is his or her psychological strain. Consequently, the absence of a decent system of relief leads caregivers to isolation from the surrounding world, lowering the quality of their lives (Bongelli et al., 2024).

The impacts on economic factors have been twofold: firstly, there has been a drastic rise in household expenses as a result of incurred medical costs, and secondly, the flow of income into the family has been restricted due to decreased employment among caretakers. According to the results of the study, 38.31% of participants faced economic problems; specifically, 11.21% had to quit their job, whereas 25.23% were limited to working part-time. As per the qualitative data collected within the course of the questionnaire, the majority of the respondents referred to terms like "monetary problems," "economic burden," and "very high expenses for treatment."

It should be noted that the monthly income group has a statistically significant impact on the degree of emotional burden ($p = 0.046$). Specifically, 71.79% of those with monthly earnings not exceeding 15,000 INR felt emotionally overloaded compared to 33.33% with monthly earnings exceeding 30,000 INR. It is essential to highlight that financial toxicity is closely associated with psychological distress and persistent worry about the financial future of the family, particularly among caregivers with lower household income.

The economic value of caregiving and its effect on the well-being of family caregivers, especially in rural areas, is still not well studied. Such type of research is required in India. Only a limited number of quantitative studies have assessed factors such as the financial costs of caregiving, the intensity of care provided, and the amount of time spent by caregivers looking after older adults (Lalani et al., 2025).

Upon asking about their challenges, caregivers frequently cited financial strain as the most important challenge, using phrases like "financial burden," "monetary issues," and "cost of treatment." In their responses about support, many caregivers reported relying on informal networks, including family, friends, and relatives, as their main source of practical and emotional help, whereas only a few caregivers found support from formal systems like doctors and healthcare facilities (Bongelli et al., 2024). These qualitative observations are based on descriptive grouping of open-ended responses and are intended to complement, rather than replace, the quantitative burden indicators reported in the results.

To combat significant financial distress resulting from chronic diseases, the Government of India introduced comprehensive health insurance schemes, most importantly the Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PM–JAY), offering coverage of up to INR 5 lakh per household for secondary and tertiary hospital care. Even though PM–JAY significantly lowers catastrophic hospitalization expenses, certain critical systemic flaws persist.

Based on empirical evidence, health insurance has significantly decreased catastrophic expenditure amongst heart failure cases from 40.3% to 30.8%, although the mean out-of-pocket expense of INR 70,869 persists for those who hold insurance

(Jeemon et al., 2026). This inconsistency emerges because insurance predominantly covers inpatient treatments. While the regular financial implications linked to chronic diseases include outpatient visits, long-term pharmacological treatment, diagnostic imaging, and non-medical expenses such as transport to tertiary health institutions, personalized diet and lost wages, none of these is usually included in insurance packages.

Another factor impacting access to care in India is the phenomenon known as "the urban paradox." While major cities boast sophisticated, fully equipped tertiary hospitals, caregivers in urban settings have inadequate access to adequate rehabilitation services. Long wait times during commutes in heavy traffic, lack of infrastructure facilitating mobility of people with disabilities, the fragmentary nature of private healthcare systems and lack of a familial network cause problems with both increased costs and social isolation. As a result, treatment discontinuity commonly occurs.

Even with abundant evidence that has proved the existence of caregiver burden, the official healthcare sector has continued to focus exclusively on clinical patients' results. Consequently, caregivers were left to depend on informal social support through friends and family members, who may not always suffice. Nevertheless, clinical research has shown that specific psychosocial interventions may alleviate caregiver burden.

The latest quasi-experimental study done in North India tested a "Comprehensive Caregiver Support" intervention on oncology caregivers. The intervention included education on symptom management, deep breathing, relaxation, and counseling sessions to help caregivers become aware of sources of financial support. There was a statistically significant decrease in burden among those undergoing the intervention compared with the control group, alongside an improvement in the caregivers' self-efficacy and quality of life (Sharma et al., 2026). It is vital to provide caregivers with the skills they need to change their approach to emotional coping into problem-solving. Thus, most support programs are designed for patients, and they overlook caregivers' health, even though research shows that even simple telephone-based interventions can significantly improve caregivers' knowledge and skills (Bank et al., 2006; Goyal-Honavar et al., 2025).

Doctors at busy Indian tertiary care centers typically do not find enough time to conduct adequate training programs for caregivers; in such cases, nurse-managed training programs can be extremely effective and easily replicable. It has been noted in an evaluation study of a Nurse-Led Stroke Rehabilitation Empowerment Program (NLREP) that a structured education program coupled with empathy and follow-up care played a significant role in improving the coping skills and self-confidence of the caregivers (Mangalabarathi et al., 2024).

The systematic understanding of patients' conditions, provision of detailed guidance in the performance of various daily activities (like managing feeding tubes or performing lifts safely to avoid strain injuries among caregivers), as well as the availability of special hotlines for medical emergencies, helps in reducing the uncertainty of caregivers. Even economical methods like telephonic support groups have proved effective in improving health knowledge and resiliency of caregivers (Bank et al., 2006).

The response to the hidden patient problem would require policy changes at the macro level. Firstly, the health insurance schemes of each country need to evolve from mere inpatient coverage to a form that covers expensive catastrophic costs of outpatient visits related to chronic diseases, specifically those incurred in diagnosis and prescription for long-term pharmacotherapy, thus avoiding distress financing. Secondly, it is absolutely necessary that there should be an official setup of respite care, which will help families get rest and recuperation time, without putting the health of their patient relatives at risk. Finally, tele-rehabilitation and other telemedicine facilities could make it possible for people living in rural areas or far-off urban locations to consult their patients' therapists and psychologists remotely, eliminating the problem of physically carrying the patient to hospitals.

This cross-sectional survey provides a snapshot of caregiver burden at a single-center setting, which limits causal inference and generalisability. Hence, it is not possible to map the caregivers' longitudinal journey with evolving burdens because of patient-related clinical variables like disease severity, functional dependence, duration of illness, caregiving intensity, level of disability and the modest sample size reduced statistical power for detecting small effects in subgroup and multivariable analyses, which describes the need for larger, multicenter studies using probability sampling methods to generate more generalizable data and further qualitative research to explore in depth the emotional, physical, and economic burdens experienced by caregivers, as well as strategies to effectively address and mitigate these challenges.

5. Conclusion

The informal caregiver is a key sustaining component of health systems who contributes through unpaid, continuous and often physically strenuous work. Caregivers are often described as "invisible patients" whose well-being is closely intertwined with that of the person they care for. Lower caregiver burden is associated with higher social support and more positive caregiving experiences. The present single-center, exploratory study findings indicate that many caregivers experience emotional fatigue, physical strain, social isolation and financial distress and highlight the need to recognise caregiver burden as a distinct public health concern and to move from an exclusively patient-focused approach toward more comprehensive strategies that also aim to assess, support and protect caregivers' well-being.

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References

Baishya, J. (2024). Caregiver Burden and Stress in Caregivers of Stroke Survivors: Relevant but Neglected. Annals of Indian Academy of Neurology, 27(1), 7–8. https://doi.org/10.4103/aian.aian_390_23

Bank, A. L., Argüelles, S., Rubert, M., et al. (2006). The Value of Telephone Support Groups among Ethnically Diverse Caregivers of Persons with Dementia. The Gerontologist, 46(1), 134–138. https://doi.org/10.1093/geront/46.1.134

Bizuayehu, H. M., Ahmed, K. Y., Kibret, G. D., et al. (2024). Global Disparities of Cancer and Its Projected Burden in 2050. JAMA Network Open, 7(11), e2443198. https://doi.org/10.1001/jamanetworkopen.2024.43198

Bongelli, R., Busilacchi, G., Pacifico, A., et al. (2024). Caregiving burden, social support, and psychological well-being among family caregivers of older Italians: A cross-sectional study. Frontiers in Public Health, 12, 1474967. https://doi.org/10.3389/fpubh.2024.1474967

Cao, L. L., Tang, Y. F., Xia, Y. Q., et al. (2022). A survey of caregiver burden for stroke survivors in non-teaching hospitals in Western China. Medicine, 101(50), e31153. https://doi.org/10.1097/MD.0000000000031153

Goyal-Honavar, A., Singh, G., Chhakchhuakk, L., et al. (2025). The Cost of Compassion: Caregiver Fatigue Associated with Caring for Persons with Disability in a Rural Population in India. Indian Journal of Community Medicine, 50(5), 858–863. https://doi.org/10.4103/ijcm.ijcm_18_24

Jeemon, P., Salim, R., Safvan, K., et al. (2026). Financial Burden, Out-of-Pocket Health Spending, and Household Economic Well-Being in Heart Failure Patients in India: A Multicentre Cross-Sectional Survey. Global Heart, 21(1), 19. https://doi.org/10.5334/gh.1535

Kumar, A., Yadav, A. K., Singh, V. K., et al. (2022). Caregiver burden in caregivers of stroke survivors: A hospital-based study. Annals of Indian Academy of Neurology, 25(6), 1092–1098. https://doi.org/10.4103/aian.aian_318_22

Lalani, N., Osei, E. A., Yang, S., et al. (2025). Financial health and well-being of rural female caregivers of older adults with chronic illnesses. BMC Geriatrics, 25(1), 239. https://doi.org/10.1186/s12877-025-05853-5

Lian, L., Zheng, M., He, R., et al. (2022). Analysing the influencing factors on caregivers' burden among amyotrophic lateral sclerosis patients in China: A cross-sectional study based on data mining. BMJ Open, 12(9), e066402. https://doi.org/10.1136/bmjopen-2022-066402

Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. International Journal of Nursing Sciences, 7(4), 438–445. https://doi.org/10.1016/j.ijnss.2020.07.012

Maggio, M. G., Corallo, F., De Francesco, M., et al. (2024). Understanding the family burden and caregiver role in stroke rehabilitation: Insights from a retrospective study. Neurological Sciences, 45(11), 5347–5353. https://doi.org/10.1007/s10072-024-07668-5

Mandowara, B., Patel, A. N., Amin, A. A., et al. (2020). Burden faced by caregivers of stroke patients who attend rural-based medical teaching hospital in western India. Annals of Indian Academy of Neurology, 23(1), 38–43. https://doi.org/10.4103/aian.AIAN_406_18

Mangalabarathi, N., Devi, B., Chinnathambi, K., et al. (2024). Effectiveness of Nurse-Led Stroke Rehabilitation on

Awareness, Activities of Daily Living and Coping in Stroke Patients at a Tertiary Care Hospital in India. Cureus. 16(11), e72843. https://doi.org/10.7759/cureus.72843

Menon, N., Patil, V. M., Ramaswamy, A., et al. (2022). Caregiver burden in older Indian patients with cancer- Experience from a tertiary care center. Journal of Geriatric Oncology, 13(7), 970–977. https://doi.org/10.1016/j.jgo.2022.05.008

Mishra, S., Gulia, A., Satapathy, S., et al. (2021). Caregiver burden and quality of life among family caregivers of cancer patients on chemotherapy: A prospective observational study. Indian Journal of Palliative Care, 27(1), 109–112. https://doi.org/10.4103/IJPC.IJPC_180_20

Pearlin, L. I., Mullan, J. T., Semple, S. J., et al. (1990). Caregiving and the Stress Process: An Overview of Concepts and Their Measures. The Gerontologist, 30(5), 583–594. https://doi.org/10.1093/geront/30.5.583

Ramasamy, S., Rathore, V., Agrawal, V., et al. (2025). Burden level and quality of life of caregivers of hemodialysis patient's in central India: A mixed-method cross-sectional study. BMC Research Notes, 18(1), 291. https://doi.org/10.1186/s13104-025-07374-1

Sharma, D., Kumari, V., Sarin, J., et al. (2026). Impact of Comprehensive Caregiver Support on Self-Efficacy, Quality of Life and Caregiving Burden among Caregivers of Cancer Patients. National Journal of Community Medicine, 17(3), 211–219. https://doi.org/10.55489/njcm.170320266056

Das, S. (2023). Informal caregiving in India is in dire need of a reality check. Available online: https://theestablished.com/community/identity/informal-caregiving-in-india-is-in-dire-need-of-a-reality-check (accessed on 12 April 2026).

Suresh, A., Guruprasad, T. S., & Jaya, S. (2025). Factors influencing caregiver burden and its prevalence level amongst family caregivers of patients with palliative care needs and serious illnesses. BMC Palliative Care, 24(1), 289. https://doi.org/10.1186/s12904-025-01925-w

Syarif, I., Amqam, H., Syamsuddin, S., et al. (2025). Determinant Factors of Stress in Caregivers of Patients with Schizophrenia: Cross-Sectional Study. JMIR Formative Research, 9, e70648. https://doi.org/10.2196/70648

Tang, S., Li, L., Xue, H., et al. (2021). Caregiver burden and associated factors among primary caregivers of patients with ALS in home care: A cross-sectional survey study. BMJ Open, 11(9), e050185. https://doi.org/10.1136/bmjopen-2021-050185

Wagle, S., Yang, S., Osei, E. A., et al. (2024). Caregiving Intensity, Duration, and Subjective Financial Well-Being among Rural Informal Caregivers of Older Adults with Chronic Illnesses or Disabilities. Healthcare, 12(22), 2260. https://doi.org/10.3390/healthcare12222260