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# Factors influencing caregiver burden and its prevalence level amongst family caregivers of patients with palliative care needs and serious illnesses

Amritha Suresh<sup>1\*</sup>, Guruprasad T S<sup>1</sup> and Sreejini Jaya<sup>1</sup>

## Abstract

**Background** The support of family caregivers is vital in home-based palliative care, ensuring quality care for patients with palliative care needs. In their commitment to prioritising the well-being of their loved ones, caregivers often neglect their own physical and emotional health, leading to varying degrees of caregiving burden. This study aims to estimate the prevalence of caregiver burden and identify the key factors associated with it among family caregivers of patients receiving services from a palliative care institution in Thiruvananthapuram district, Kerala.

**Methods** This cross-sectional study included 270 family caregivers aged 18 years and above, providing care for three months to less than a year to patients registered at the selected palliative care institution between September 2023 and August 2024. Data was collected telephonically using a structured interview schedule and the burden level was assessed using the Achutha Menon Centre-Caregiver Burden Inventory. The distribution of burden levels was analysed and associations with study variables were examined using Chi-square test. Binary logistic regression was performed to identify significant predictors of moderate-to-high caregiver burden. A 95% confidence interval was used and a p value of  $\leq 0.05$  was considered to be statistically significant.

**Results** Findings revealed that 54.8% of caregivers experienced moderate levels of burden. Factors associated with moderate to high burden included being employed, spending full time with the patient, experiencing a career break and perceiving that caregiving impacted their family's future plans. Caregivers who faced difficulty in seeking help, struggled to balance work and home responsibilities, had existing diseases or experienced emotional and physical challenges in the past four weeks were more likely to report moderate-high burden. Lack of breaks, limited support, poor social connections outside home, insufficient time for self-care, deteriorating health post-caregiving and inadequate sleep also contributed to higher burden.

**Conclusion** Findings emphasise the multifaceted challenges caregivers face, reinforcing the need for the implementation of comprehensive support mechanisms including emotional and psychosocial support, accessible respite care services and flexible workplace policies to reduce burden and enhance caregiver well-being.

\*Correspondence:

Amritha Suresh  
amritha.suresh@palliumindia.org

Full list of author information is available at the end of the article



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**Keywords** Family caregiver, Palliative care, Caregiver burden, Palliative care institution

## Background

According to the World Health Organization (WHO), Palliative Care (PC) aims to improve the quality of life of patients and their families' facing problems associated with life-threatening, debilitating illnesses. Generally, when we speak about providing health care, the prominent people who come to our minds are doctors and nurses. But the case is different when we consider chronic illnesses, disability or advanced cancer, which requires continual long-term care from family members. Family caregivers (FC) are the pillars of PC by undertaking practical tasks, providing emotional support and easing pain and other symptoms, as well as cooperating with health services, all with the determination of improving the quality of life of someone close to them [1]. FC is someone close to the patient, i.e. a partner, family member or friend who plays a vital role in providing care and various forms of assistance to the patient [2]. However, caring for a family member at home is challenging and demanding, as older patients with PC needs and serious illnesses or approaching end-of-life often have intricate symptoms and healthcare needs that worsen as their disease progresses and death approaches [3]. Therefore, FCs play an integral role in care provision and their support is a crucial aspect of caring for family members at home.

It is known that caregivers support other people's social or health needs, which can be either through paid caregivers or unpaid close family members imparting care. But when this care is given within the family, their roles and responsibilities are contemplated as 'routine' [4]. However, the physical and emotional burden of caregiving is often extensive [5]. Most of the time, the FCs are neglected or missed out and the entire care focus will be patient centric. The range of activities carried out by FCs includes providing nursing care and helping with daily living activities. Time and again, these informal FCs are often burdened with the responsibility as they are unprepared and untrained to address the patient's health care needs. They often don't get support from close family members or others to face such situations. Furthermore, this kind of informal caregiving remains hidden in the significant trajectory of healthcare provision, leading to serious health consequences for caregivers if not addressed. They also experience various health conditions ranging from physical and emotional distress to depression. Apart from providing care to the near ones, most often they may have to stop their employment and are not even addressed by any government system such as providing them with any kind of support or allowance for their work [6, 7].

In India, the population of patients requiring PC is rising and FCs are an integral part of the care team. Approximately one in nine Indians will develop cancer during their life, and one in seven will pass away [8]. Many times, cancer is often diagnosed at a very late stage and the chronic nature of cancer demands the involvement of caregivers as a part of the care [2]. In India, families play a significant role in caregiving. Often, informal caregiving to patients may frequently fall upon the family due to tradition, lack of formal care or financial limitations. There are marked inequities in access to palliative care across India, as professional services and institutional facilities are unevenly distributed. As a result, certain population groups are able to access care, while many others remain underserved. While FCs are integral members of the family, they often pay the cost of caregiving by neglecting their own needs. This may manifest as physical strain, emotional and psychological stress and difficulties in balancing both work and household responsibilities along with caregiving. Although numerous studies have examined the burden of caregiving among informal caregivers, research exploring caregiver burden of patients enrolled in a PC setting is often found limited. This study aims to estimate the prevalence level of caregiver burden and to identify factors influencing caregiver burden among FCs of patients receiving services from a PC institution in Thiruvananthapuram district of Kerala.

## Methods

### Study design and study setting

The study employed a mixed-methods design incorporating both quantitative and qualitative components. This paper showcases the quantitative findings of caregiver burden and its associated factors using a cross-sectional study design and data collected from FCs of patients enrolled with the institution between September 2023 and August 2024. Participants included consenting individuals aged 18 years and above who were providing care for a duration of at least three months but not exceeding one year.

### Sampling and data collection

Sampling was carried out using the patient entry register of the PC centre to identify patients who were enrolled and their corresponding FCs were later contacted for participation. Participant selection was done based on the inclusion criteria and data collection was done through telephone interviews. Caregiver burden prevalence of 19.7% as reported in a previous study by Unnikrishnan et al. [9] was used to estimate the required sample size for the study. With a 95% confidence level, 5% precision and

an anticipated 10% non-response rate, the final sample size was calculated to be 269, which was rounded to 270. Data were collected using a structured questionnaire that captured the sociodemographic details, caregiving challenges and the caregivers' personal and health related challenges. Caregiver burden was assessed using a nine-item tool-the Achutha Menon Centre-Caregiver Burden Inventory [10]. This tool was developed specifically for the Kerala setting. It comprises of two subscales: consequences of caregiving (five items) and lack of financial security (four items). It demonstrates good psychometric properties, with a content validity index of 0.77, a Cronbach's alpha of 0.82 and high test-retest reliability ( $\rho = 0.87, p < 0.001$ ). Respondents rate each item on a four-point Likert scale (Strongly disagree, Disagree, Agree, Strongly agree). The total burden score is obtained by summing the two subscale scores [10].

### Statistical analysis

The data were entered directly into Excel sheet and analysis was done using IBM Statistical Package for Social Sciences (SPSS) Version 20 for Windows. Univariate analysis was conducted to summarise the distribution of the study variables. To explore for associations between caregiving burden and independent variables, bivariate analysis was performed using Chi-square and binary

logistic regression was used to estimate odds ratio and 95% confidence intervals. A p-value of less than 0.05 was considered to be statistically significant.

### Ethical considerations

The Institutional Ethics Committee of Trivandrum Institute of Palliative Sciences, Thiruvananthapuram, Kerala had reviewed the study and gave clearance to conduct the study (TIPS/IEC-4/2024Frw). Participation in the study was completely voluntary and participants were given the option to withdraw their participation at any point. Study objectives, possible benefits and risks were thoroughly explained to the participants. Telephonic informed consent was obtained from all the participants before the start of the study. Participant's identity and personal information were kept confidential.

### Results

#### General characteristics of study participants

Majority of the participants (75.6%) were females. The mean age of the participants was  $47.3 \pm 12.54$  years. The highest attained education level by the participants was attaining matriculation (27.8%); around 71% of participants belonged to the Hindu community; 92.2% of the participants were married and 41.5% were unemployed, while around 56% of participants were unemployed at the time of data collection. Table 1 depicts the sociodemographic characteristics of the study participants.

#### Caregiving details of study participants

Out of the 270 participants, nearly 95% reported themselves as the patient's primary caregiver. Among those who were not the primary caregiver (5.2%), the prime responsibility of caregiving most commonly lay with the patient's mother, followed by daughters, sisters and wives; indicating profound female participation in this role (75.6% were females). FCs cared for a wide range of health conditions, including both cancer and non-cancer and nearly 55% of patients were diagnosed with cancer. The duration of these disease conditions ranged from 3 months to 22 years, with a mean value of  $1.51 \pm 2.31$  years, which also indicates the duration of caregiving. When the FCs were grouped based on the mean score, 20.4% participants had been living with the diagnosis for more than one year. Slightly more than half (50.7%) of the participants reported providing care to bedridden patients and the mean duration of caregiving was  $6.54 \pm 3.35$  months. For majority of the participants (89.3%), it was their first caregiving experience. Among those with prior caregiving experience, the duration ranged from 1.5 months to 9 years, with 8.6% having provided care for more than one year. Only a small proportion of participants (3%) received any form of caregiving training and only 1.9% were trained by a PC nurse. Among the caregivers, 78.5%

**Table 1** Sociodemographic characteristics of the participants

Variables	Categories	N (%)
Age group	< 47.3 years	147 (54.4)
	$\geq 47.3$ years	123 (45.6)
Gender	Male	66 (24.4)
	Female	204 (75.6)
Education level	Illiterate	1 (0.4)
	Primary level (1st –4th grade)	6 (2.2)
	Upper primary (5th –7th grade)	12 (4.4)
	High school (8th –9th grade)	36 (13.3)
	Matriculation (10th grade)	75 (27.8)
	Higher secondary (11-12th grade)	67 (24.8)
	Graduation	61 (22.6)
Religion	Post graduation and above	12 (4.4)
	Hindu	191 (70.7)
	Christian	35 (13.0)
	Muslim	44 (16.3)
Marital Status	Unmarried	16 (5.9)
	Married	249 (92.2)
	Divorced/Separated	3 (1.1)
	Others	2 (0.7)
Occupation	Retired	6 (2.2)
	Government employee	8 (3.0)
	Private sector employee	59 (21.9)
	Unemployed	112 (41.5)
	Others	85 (31.5)
Current employment status	Employed	119 (44.1)
	Unemployed	151 (55.9)

of caregivers spent their entire day with the patient and 23% of the study participants did not have any break from their caregiving schedules. Of the 77.8% who received help in caregiving, 39.3% were supported exclusively by a female family member, indicating a strong traditional gendered role.

### Challenges in patient caregiving

Among the caregivers, 38.5% were competent enough to care the patient; around 69% had to assist with the patient's immobility and 36.3% of FCs lacked knowledge or required assistance for nursing care. Although a significant number (90.7%) of participants felt that caregiving did not affect their family life, among those who reported an impact, the most common concerns were financial

strain, feelings of loneliness, emotional disturbances and disruptions to their children's education. Impact of caregiving on job discontinuity was observed at 50.4% and on family future planning was at 29.3%.

A significant majority (84.8%) were unaware of or did not have access to community or social support services in their area and around 39% of FCs found it difficult to seek help from others. Respite care support was non-existent with 98.5% never having been offered such services. Willingness to avail respite care for their family member was found negligible at 1.1% and majority of FCs (85.2%) felt it was pointless, believing they could handle the responsibility themselves, while the remaining participants cited financial constraints as a major barrier to approach these centres. Table 2 depicts the challenges faced by the caregivers.

**Table 2** Challenges in patient caregiving

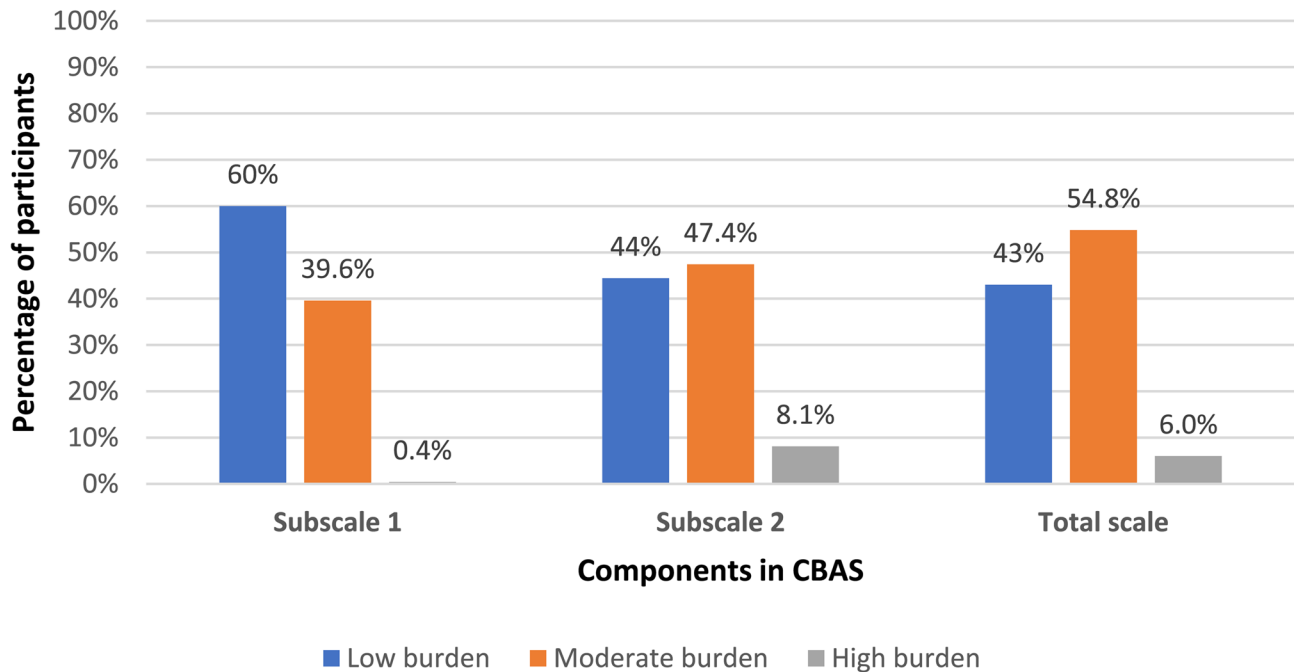
Challenges in patient caregiving	Total n (%)
Fully aware of how to take care of the patient	
No/Somewhat	166 (61.5)
Yes	105 (38.5)
Need to assist the patient with immobility	
No	84 (31.1)
Yes	186 (68.9)
Able to manage the medications of the patient	
No/Need assistance from others	11 (4.1)
Yes	259 (95.9)
Aware of the nursing care to be provided to the patient	
No/Need assistance from others	98 (36.3)
Yes	172 (63.7)
Patient caregiving affected your family life	
No	245 (90.7)
Yes	25 (9.3)
Experience a break in your career/job due to caregiving	
No	134 (49.6)
Yes	136 (50.4)
Caregiving affects the family's future planning in any way	
No	191 (70.7)
Yes	79 (29.3)
Have community/social support in your locality to help you	
No/Don't know	229 (84.8)
Yes	41 (15.2)
Face difficulty in asking for help from someone	
No	165 (61.1)
Yes	105 (38.9)
Offered respite care services for the patient from any institutions/people	
No	266 (98.5)
Yes	4 (1.5)
Know about any respite care services offered in your vicinity	
No/Don't know	260 (96.3)
Yes	10 (3.7)
Willing to send the patient for respite care if available	
No	267 (98.9)
Yes	3 (1.1)

### Personal and health related challenges

Among the participants, 15.2% reported not having enough time to care for their own well-being. Nearly one third (32.6%) had to care additionally for an elderly parent/child at home apart from the routine caregiving role. Nearly all (99.6%) commented that their health remained the same or had worsened compared to the time before the initiation of their caregiving role and around 49.3% reported suffering from multiple co-morbidities. Getting adequate sleep was a major concern and only 25.6% reported getting adequate sleep. More than half (61.9%) found great difficulty in performing physically demanding caregiving tasks like lifting or helping the patient move. Around 35.2% reported acute health-related episodes, while 62.2% experienced emotional distress such as being depressed or anxious. Additionally, 18.9% experienced occasional difficulty in staying socially connected.

### Factors associated with caregiver burden

The Caregiver Burden Assessment scores (CBAS) derived from the Achutha Menon Centre-Caregiver Burden Inventory were recategorized into Low and Moderate-High burden, given the minimal number of participants in the high-burden category (2.2%), to facilitate further analysis with the study variables. The distribution of components of CBAS is illustrated in Fig. 1. The caregiving burden levels and its association with the study variables are shown in Table 3. FCs who were employed, spent full time with the patient, experienced a career break, felt that caregiving affected their family's future planning, faced difficulty in seeking help, struggled to balance work and home schedules, had existing diseases or experienced emotional and physical challenges in the past four weeks were more likely to report moderate-high burden. Lack of breaks, absence of support, lack of social connections outside home, insufficient time for self-wellbeing,



**Fig. 1** Distribution of components of Caregiver Burden Assessment Scale (CBAS)

worsened health post-caregiving and lack of adequate sleep also contributed to higher burden.

Caregivers who reported getting breaks (Adjusted OR=0.44, 95% CI: 0.207–0.950) and adequate sleep (Adjusted OR=0.44, 95% CI: 0.21–0.91) during caregiving were significantly less likely to experience moderate-high caregiver burden compared to those who do not. Caregivers who felt that caregiving affected their family's future planning were 3.57 times more likely to experience moderate-high caregiver burden than those who do not perceive such an effect (Adjusted OR=3.57, 95% CI: 1.68–7.61) (Table 4).

## Discussion

This study aimed to assess the prevalence level of caregiver burden along with identification of associated factors among FCs of patients with PC needs and serious illnesses receiving services from a PC institution in Thiruvananthapuram district of Kerala. We found that 54.8% of caregivers experienced moderate levels of caregiver burden. Similar trends have been observed in a study conducted in Kerala, where 56% of young caregivers (aged 18 to 59 years) and 56.5% of older caregivers (aged 60 years and above) reported experiencing moderate to high levels of perceived burden [11]. These findings are also consistent with a study among FCs of individuals with chronic kidney disease in a northeastern state of India, which reported that 52% experienced mild to moderate levels of burden [12]. Upon dichotomising the burden scores in our study, results revealed that receiving

breaks and adequate sleep during caregiving episodes were associated with reduced caregiving burden.

Majority of caregivers in our study were women, reflecting the traditionally gendered role of caregiving within the families, a pattern observed in similar studies of caregivers [13–17]. Caregiving is a highly individualised experience, as some gradually assume the role as they begin to recognise a loved one's increasing need for support, while others are thrust into it suddenly due to a crisis such as a life-threatening diagnosis, stroke or other unexpected health events [6]. In our study, majority (89.3%) reported that this was their first experience serving as a caregiver highlighting that most were likely to be unprepared for the responsibilities and challenges associated with caregiving.

Only 3% of the participants had ever received any form of caregiving training and of these, 1.9% were trained by a PC nurse; which is significantly less. This highlights that most caregivers step into this role without any prior knowledge, experience or formal training, which is similar to the findings of Schulz et al. [6]. These results highlight the need for training, related to medical and personal care skills, problem-solving, stress management and emotional resilience. Training should also include hands-on skills related to lifting and mobility, assistance with daily activities, setting goals and other strategies tailored to both the caregiver's and the patient's needs [18]. Our study also highlights the need for symptom management as aligned with the findings from Park et al. [19]

Studies have identified two main categories of caregiver needs: enabling needs, which involve support for

**Table 3** Distribution of caregiver burden levels by sociodemographic and caregiving variables

Variables	Categories (n, %)	Low burden	Mod-High burden	p value
<b>Occupation</b>	Unemployed/Retired	87 (49.2)	90 (50.8)	0.005
	Employed	29 (68.8)	68 (31.2)	
<b>Spends full time with the patient</b>	No	32 (55.2)	26 (44.8)	0.034
	Yes	84 (39.6)	128 (60.4)	
<b>Breaks in between caregiving</b>	No	18 (29.0)	44 (71.0)	0.012
	Yes (routinely/occasionally)	98 (47.1)	110 (52.9)	
<b>Support/help received with caregiving</b>	No	16 (26.7)	44 (73.3)	0.004
	Yes	100 (47.6)	110 (52.4)	
<b>Experience a break in your career/job due to caregiving</b>	No	68 (50.7)	66 (49.3)	0.010
	Yes	48 (35.3)	88 (64.7)	
<b>Caregiving affected family's future planning</b>	No	102 (53.9)	89 (46.6)	< 0.001
	Yes	14 (17.7)	65 (82.3)	
<b>Face difficulty in asking for help from someone</b>	No	80 (48.5)	85 (51.5)	0.022
	Yes	36 (34.3)	69 (65.7)	
<b>Sufficient time for well being</b>	No/Sometimes	43 (30.7)	97 (69.3)	< 0.001
	Yes	73 (56.2)	57 (43.8)	
<b>Maintain social connections outside of the home</b>	No	54 (37.2)	91 (62.8)	0.041
	Yes	62 (49.6)	63 (50.4)	
<b>Challenging to balance work/home schedules for caregiving</b>	No	52 (59.1)	36 (40.9)	< 0.001
	Yes	64 (35.2)	118 (64.8)	
<b>Health in general before and after caregiving started</b>	Worse	15 (26.8)	41 (73.2)	0.006
	Better/Same	101 (47.2)	113 (52.8)	
<b>Presence of any diseases</b>	No	70 (51.1)	67 (48.9)	0.006
	Yes	46 (34.6)	87 (65.4)	
<b>Gets adequate sleep</b>	No/Sometimes	70 (34.8)	131 (65.2)	< 0.001
	Yes	46 (66.7)	23 (33.3)	
<b>Health-related problems or difficulties in performing daily activities in the past four weeks due to caregiving challenges</b>	No	90 (51.4)	85 (48.6)	< 0.001
	Yes	26 (27.4)	69 (72.6)	
<b>Any emotional issues or feeling depressed or anxious in the past four weeks due to caregiving challenges</b>	No	59 (57.8)	43 (42.2)	< 0.001
	Yes	57 (33.9)	111 (66.1)	

**Table 4** Caregiver characteristics associated with Moderate-High caregiver burden levels

Variables	B*	Adjusted OR** (95% CI***)	p value
Breaks in between caregiving			
No		Ref	
Yes	-0.81	0.44 (0.207-0.950)	0.036
Caregiving affected family's future planning			
No		Ref	
Yes	1.274	3.57 (1.68-7.61)	0.001
Gets adequate sleep			
No		Ref	
Yes	-0.816	0.44 (0.21-0.91)	0.027

\*B: Regression coefficient, \*\* Odds Ratio, \*\*\* Confidence Interval

patient care (like symptom and medication management) and direct support needs, which relate to the caregiver's own well-being. The most frequently expressed needs were help with managing patient symptoms and having personal time for self-care [20]. In our study, 77.8% of caregivers reported to have received help in caregiving,

suggesting that a significant proportion of caregivers had access to enabling support. Another study done among FCs aged 60 years and above reported that 60.2% of caregivers received assistance from other family members in providing care to the patient [21]. However, this also reflects a considerable reliance on external assistance, possibly indicating the complexity of caregiving responsibilities. Caregiving often intersects with multiple life roles, leading to challenges such as financial strain, emotional stress, loneliness and disruptions to family life. While some caregivers in our study accepted their role without perceiving major disruption, others reported significant burdens, consistent with findings from previous studies. Evidence also shows that financial strain and work productivity loss are common among caregivers, further impacting their quality of life. Likewise, 50.4% of caregivers in our study reported to have experienced a career or job interruption due to their caregiving responsibilities. Park et al. reported that among caregivers, 30%

of those who were employed felt that their caregiver role restricted their job performance [19]. Family and work conflict occurs when the time and energy available to an individual is limited leading to competing demands between caregiving responsibilities and job commitments, hence resulting in an interference between the two roles [22]. With respect to respite services availability, majority of the participants in this study were neither offered nor aware of the availability of respite care services in their locality.

While respite services are well established and accessible in many high-income countries, they remain underdeveloped in our settings cultural expectations that is often reflected in the attitudes and behaviour of people, as caregiving is mostly perceived as a familial responsibility, with caregivers prioritising the needs of their loved ones over their own [23]. A multicentric study done in India revealed that caregivers were aware of institutions offering paid caregiving, of which one-fourth of caregivers had utilised these services indicating that the 'cost factor' remains a major barrier to institutional care, often stopping caregivers in taking help from such centres in the absence of a primary caregiver [24]. Reflecting similar concerns, our study found that about 15% of the caregivers were not willing to send patients for respite care due to financial constraints, highlighting the continued challenge of affordability in accessing such services.

In our study, 15.2% of participants reported that they did not have enough time to care for their own well-being; which is similar to findings reported by Schulz et al., where around 24% of caregivers reported not having self-time [6]. In the present study, 46.3% of FCs reported maintaining some form of social connection outside their homes. Caregivers may benefit from peer support, which can even be from a fellow caregiver. Our study revealed that approximately one-third of caregivers bore the additional responsibility of caring for either an elderly parent or a child, alongside their primary caregiving role. Similarly, findings from the multicentric national level study indicated that one in ten caregivers (9%) were responsible for caring more than one elderly individual, highlighting the burden of multiple caregiving roles faced by many families [24].

### Strengths and limitations

The tool used for estimating the caregiver burden among the study participants was the Achutha Menon Centre-Caregiver Burden Inventory which was developed in Kerala and is considered to be a valid and reliable instrument for measuring the caregiver burden of informal caregivers in Kerala [10]. Our selection criterion of caregiving duration of at least three months but less than one year was to minimise the likelihood of caregivers perceiving their role as a routine part of their life, similar to as reported

by Huang et al. [25] which could have influenced their responses and potentially impacted the outcomes of the study. As a continuation of this study, qualitative component will complement the quantitative findings which will enable a deeper insight into caregivers lived experiences and enable triangulation to strengthen the overall conclusions. A major limitation of our study is the failure to capture the dichotomous aspect of length of caregiving- as shorter or longer, as our study did not capture the length of duration and caregiving burden, since our inclusion criteria were restricted to FCs who had been providing care for at least three months but less than one year. A study by Zainuddin et al. suggests a statistically significant association between caregiving duration and perceived burden, where caregivers with shorter durations of caregiving tend to report higher burden levels, whereas those engaged in caregiving for longer periods often experience comparatively lower levels of burden [26]. However, focusing more on capturing acute episodes of caregiving burden can considerably minimise recall biases. Additionally, the study's geographic scope was limited, as participants were recruited from a single institution, which may constrain the generalisability of the findings.

### Conclusion

Our study provides valuable insights into the factors contributing to moderate to severe caregiver burden of FCs of patients receiving services from a PC institution in Kerala. The findings highlight the complex interplay of personal, emotional and situational challenges faced by caregivers. This calls for the need for implementation of comprehensive support mechanisms including emotional and psychosocial support. To alleviate caregiver stress and enhance overall wellbeing, greater access to respite care and workplace flexibility is needed.

### Abbreviations

CBAS	Caregiver Burden Assessment scores
FC	Family caregivers
LMICs	Low- and middle-income countries
MGNREGA	Mahatma Gandhi National Rural Employment Guarantee Act
PC	Palliative Care
SPSS	Statistical Package for Social Sciences
WHO	World Health Organization
US	United States

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### Authors' contributions

G.T.S seeded the ideology behind the study. S.J. contributed substantially to the study's concept and design. A.S analysed the data, drafted and concluded

the article. S.J. revised the article critically and approved the version to be published. All the authors have reviewed and approved the manuscript.

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#### Data availability

The datasets generated and analysed during the current study are not publicly available due to institutional privacy policies, ethical considerations and confidentiality agreements. Moreover, this study forms part of a larger ongoing study that will further look into the quality of life and lived experiences of caregivers. However, the data may be made available from the corresponding author upon reasonable request, subject to approval from the Trivandrum Institute of Palliative Sciences (TIPS), Pallium India.

#### Declarations

##### Ethics approval and consent to participate

Ethics approval for this study was obtained from the Institutional Ethics Committee of Trivandrum Institute of Palliative Sciences (TIPS), Pallium India, Trivandrum (Approval No: TIPS/IEC-4/2024Frw). Prior to participation, telephonic informed consent was obtained from all the participants after providing them with complete information about the study. This study was conducted in adherence to the ethical principles outlined in the Indian Council of Medical Research (ICMR) National Ethical Guidelines for Biomedical and Health Research involving Human Participants.

##### Consent for publication

Not applicable.

##### Competing interests

The authors declare no competing interests.

##### Author details

<sup>1</sup>Trivandrum Institute of Palliative Sciences, Pallium India, Trivandrum, Kerala, India

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