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Original Research Article

Informal caregiver burden among carers of bedridden elderly: a cross sectional study in North Kerala

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ABSTRACT

Background: In the cultural context of India, informal caregiving stands as the foremost form of support to the elderly. This study investigates the status of caregiver burden and it's psychological impact on informal caregivers of bedridden elderly in rural north Kerala, India. The study also delves into the socio-demographic factors associated with caregiver burden as well as psychological distress among family caregivers.
Methods: A cross-sectional descriptive study. The data was collected from (n=120) caregivers using the burden assessment scale and psychological distress assessment scale. Descriptive statistics and inferential statistical tests were employed in this study.
Results: The study results reveal that female informal caregivers experience a higher caregiver burden compared to the male counterpart. Most caregivers experience mild to moderate levels of burden and significant levels of stress anxiety and depression. Caregiver burden has a significant difference with the type of relationship with the care recipient and duration of care.
Conclusions: This study implies that there is a need for multifaceted interventions to alleviate the caregiver burden and address the psychological manifestations among caregivers.

Keywords: Informal caregiver, Burden, Bedridden elderly, Stress, Anxiety, Depression, North Kerala

INTRODUCTION

Old age includes ages surpassing the average lifespan of a human being. According to WHO, in 2019, the number of people aged 60 years and older was 1 billion. It is anticipated that this number will increase to 1.4 billion by 2030 and 2.1 billion by 2050.[1] While increasing trends in population aging are observed in all Indian states, the pace and extent are not uniform. The demographically advanced south Indian state Kerala has 20% of its population falling into the above 60 age range the old age dependency ratio is highest in Kerala (30) and majority of this population resides in rural areas.[2] The increase in the number of older adults may cause significant social and economic demands which necessitates careful policy decisions related to the provision of health services for the elderly.

In India, after the age of eighty, the proportion of bedridden or immobile citizens rises by 27 percent.[3] Multi-generational co-residence is widely prevalent and is the norm in India. As an Asian country based heavily on cultural values such as family cohesion, familism and filial piety the majority of individuals prefer to receive informal care from children or get home assistance services.[4] Therefore, the family remains as the primary source of care for the elderly and a mode of old age security

Informal caregiving is substantial in the long-term care for a bed bound elderly. With the unique context that India

presents and the lack of adequate formal infrastructure and systems for elder care, it is pertinent to look into how an emotionally painstaking job of caregiving can influence an informal caregiver.

Informal caregiving is providing ongoing assistance with Activity of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL) for individuals affected by chronic illness or disabilities without pay.[5] Kerala has 22.7% of the elderly age 60 and above reported to having at least one Activity of Daily Living (ADL) limitation.[2] The degree and quality of the family relationship, the emotional bond, sense of duty, personal sense of obligation and the rearrangement of working hours for caregiving or level of caregiver's employment are some of the factors influencing the decision of providing care.[5-9]

Studies have been conducted on the positive aspects of caregiving.[10,11] But the effects of caregiving are highly individualized and have a wide range of impacts and are differing according to kinship, cultural context and geography.[12,13] The profession, wealth, relationships, physical and mental health, and general well-being of a caregiver can all be impacted by providing care. The caregiver's perception of the care recipient's suffering is also an influencing factor.[14]

Earlier researches noted health hazards associated with providing care as well as reported substantial decline in care provider's quality of life due to caregiving.[15,16,17] It causes distress to the caregiver and negatively affects their physical health and causes psychological problems.[16,18] Consistently assisting an old or disabled person is reported to trigger a caregiver's chronic stress.[19] Older caregivers and spousal caregivers had worse physical health effects due to caregiving.[20] Psychological distress may disrupt healthy eating patterns and sleeplessness which can cause negative impact on physical and mental health in caregivers.[21]

The strain or stress experienced by individuals caring for chronically ill or disabled persons is referred to as caregiver burden.[22] Both caregiver and care recipient characteristics play a significant role in influencing caregiver burden.[23] Several studies have highlighted an elevated risk of poor health and depression, clinically significant anxiety.[18,24] High levels of clinically significant anxiety have been linked to caregiver burden and detrimentally effect on physical and psychological health and often lead to negative changes, including reduced provision of care.[25,26]

Indian women take the role of being the primary caregiver, as a result of the existing gender regime wives are culturally expected to take care of their older husbands.[27] To meet the demands of the expanding older adult population, it will be vital to sustain the health of informal care providers. Global research on informal caregivers and the associated burden they face has highlighted psychological impacts, yet there is a notable gap in understanding the caregiving experiences of those attending to bedridden patients, particularly the elderly.[10,11,18,23,28,29] The responsibilities shouldered by informal caregivers over time can weigh heavily on them, but investigations into how this burden varies based on the caregiver's gender or relationship to the care recipient remain limited. The effects of caregiving endure long after the elderly person's passing, with caregivers often experiencing ongoing mental health challenges due to the demands placed upon them. Moreover, while existing studies have explored the influence of culture on caregiving experiences, there is a significant dearth of research into how India's cultural nuances impact the caregivers of bedridden older adults.

The primary aim of this research is to evaluate the extent of caregiver burden and its psychological impact on informal caregivers of bedridden elderly individuals in rural North Kerala, India. The specific objectives are: (a) to analyze the caregiving burden faced by family caregivers, (b) to assess the levels of anxiety, stress, and depression among informal caregivers, (c) to examine the correlation between caregiver burden and the stress, anxiety, and depression experienced by these caregivers, and (d) to explore how other socio-demographic factors are associated with caregiver burden.

METHODS

It is a descriptive cross-sectional study using a random sampling technique, among primary informal caregivers of bedridden elderly patients. Study was conducted in two districts of Kerala, in three taluks, from Wayanad district-Mananthavady taluk and from Kannur district - Iritty and Thalassery taluk where selected using simple random sampling and through ASHA (Accredited Social Health Activist) worker's potential participants were identified and proportional random sampling technique was used for identifying informal caregivers for study from potential participants. The study included caregivers aged twenty-one and above who had a close relationship (spouse, children, son/daughter-in-law, sibling) with the care recipient. The total number of participants was 120, comprising 30 males and 90 females (n=120, M=30, F=90). The study included caregivers aged twenty-one and above who had a close relationship (spouse, children, son/daughter-in-law, sibling) with the care recipient. The total number of participants was 120, comprising 30 males and 90 females (n=120, M=30, F=90). Informed consent was individually obtained from each caregiver before data collection.

The data were collected through an interview-schedule using a 51-items tool, where the instrument used in the study consists of three parts. Socio-demographic details of the caregiver (name, age, gender, education level, income status, occupation and status of employment, marital status, duration of care, and relationship to care recipient) and the care recipient (age, gender, major health issue) was captured in the first part. The second part of the

questionnaire is Zarit Burden Interview (ZBI-22) having good psychometric properties Cronbach's α 0.92, consisting of 22-items and covered various dimensions including dependency of patients, consequences of caregiving, the uncertainty of care and exhaustion, personal strain and role strain occurred, self-criticism or guilt and frustration or embarrassment faced by caregiver.[30] The final part includes the Depression, anxiety and stress scale (DASS-21) developed by Lovibond and Lovibond, which is widely used for research purposes and screening at community health settings to examine the symptoms of depression, anxiety and stress.[31] The data were collected from caregivers who provided informed consent and data analysis done using the software JAMOVI (version 2.2.5). Descriptive statistics and inferential statistical tests like Mann-Whitney U test, Independent-t-test, One -way variance and Spearman's rank correlation were used in the study. Results were presented using mean±standard deviation, number and percentage of responses and tables of inferential statistical tests and interpretations.

RESULT

The mean age of informal caregivers is 49.17±12.01; the mean duration of care 38.3±38.1 months. Most of the informal caregivers were married (95%) and among the total participants, 75% were women. Most of the family caregivers were either a son/daughter-in-law (44.17%) or an adult child or a grandchild (35.83%) of care recipients and only (20.83%) of spousal caregivers were the study participants. Among the total participants, 28.33% had a college/higher education; the rest (72.67%), only had a school-level education. The majority of caregivers (80.84%) were employed in the unorganized sector, including roles such as housewives, MGNREGA (Mahatma Gandhi National Rural Employment Guarantee Act, 2005) workers, contract workers, and daily wage laborers, whereas 19.16% were engaged in organized sector jobs such as nursing or teaching. Notably, 33.3% of participants had left their jobs to care for their bedridden family members.

The mean age of care recipients is 79.3±10.9; female (56.66%). They were mainly diagnosed with generalized weakness (30.83%), degenerative diseases or cerebrovascular (35.83%), cancer (12.5%) and orthopedic problems (20.83%).

The findings indicate that the average burden score among caregivers is 36.4±14.3, with 43.33% experiencing mild to moderate burden and 35.83% facing moderate to severe burden. A minority (15%) reported little or no burden, while 5.83%- predominantly female caregivers-experienced severe burden. Additionally, 11.66% of caregivers reported severe psychological distress in this study. Anxiety was prevalent among informal caregivers, with 86.66% reporting anxiety, predominantly at moderate levels (55%). Notably, 80% of caregivers exhibited moderate to extremely severe levels of anxiety, warranting clinical attention. Stress was reported by 80.83% of caregivers, with the majority experiencing mild stress (53.33%). Depressive symptoms were also prominent, with 77.5% of participants showing signs of depression, of which 34.17% reported mild depression. Furthermore, 43.33% of informal caregivers in this study displayed moderate to extremely severe levels of depression, highlighting the necessity for appropriate intervention measures.

Table 1 presents the results of the independent sample T test, indicating a noteworthy contrast in caregiver burden between male and female caregivers, with females exhibiting a higher burden (38.9±14.3), with a p value of 0.001.

In Table 2, caregiver burden displays significant variance based on the relationship between the caregiver and care recipient. Spousal caregivers (43±12.28, p value: 0.003) exhibit greater burden compared to children/grandchildren and son/daughter-in-law. Regardless of the relationship, caregivers experience mild stress (17.5±6.65), moderate levels of anxiety (14.4±6.13), and depression (14.2±7.98).

Table 1: Caregiver burden in gender of care provider.

Caregiver burden	N	Mean	SD	T value	P value
Female	90	38.9	14.3	3.34	0.001
Male	30	29.5	10.5		

Table 2: Caregiver burden and type of relationship shared with care recipient.

Burden	N	Mean	SD	F	P value
Spousal caregiver	24	43	12.28	6.466	0.003
Child/grandchild	43	31.9	11.72		
Son/daughter in law	53	36.9	16.02		

Note: One-way variance.

Table 3 highlights a significant difference in the experienced stress among caregivers based on their gender, with female caregivers demonstrating higher stress levels (p value: 0.004).

Table 4 demonstrates a significant association between caregiver burden and stress score, indicating a positive correlation between the variables. The Spearman rank correlation coefficient (ρ) is 0.244**, with a p value of 0.004, significance at the 0.01 level. Moreover, there is a notable positive correlation between caregiver burden and the duration of care, with a Spearman rank correlation coefficient (ρ) of 0.168*, a p value of 0.034, and significance at the 0.05 level. Regardless of the cause of illness in the care recipient, caregivers are subject to stress, anxiety, and depression. The results underscore a significant positive correlation between caregiver burden and psychological distress (0.155*), with a p value of 0.045, suggesting that as caregiver burden escalates, so does psychological distress among caregivers.

Table 3: Stress and gender.

Mann- Whitney U	Gender	N	Median	Range	u	P value
Stress score	Female	90	16	30	876	0.004
	Male	30	12	24		

Note: Mann- Whitney U test.

Table 4: Correlation matrix.

Study Variable		Anxiety	Stress	Depression	Duration of care	Psychological distress
Caregiver Burden	Spearman's rho	0.097	0.244	0.088	0.168	0.155
	P value	0.145	0.004	0.171	0.034	0.045

Note: Spearman rank correlation test.

DISCUSSION

The present research investigated the burden experienced by informal caregivers responsible for looking after bedridden elderly individuals. It's clear that those who play a significant role in the care of bedridden older relatives experience a burden, which in turn leads to psychological distress for them. The majority of caregivers in this study (85%) were found to be burdened, with most experiencing mild to moderate levels of burden. Similarly one of the studies focusing on the psychosocial burden among informal caregivers of adult cancer patients attending a tertiary care cancer center in Coastal South India found that one third of the participants had mild to moderate burden.[32] The average burden experienced by the current study participants is 36.4±14.3, which is higher than the burden score of participants in one of the studies carried out in Palmas, Brazil.[33] In a study conducted in the Kaniyambadi block of Vellore district, Tamil Nadu, the mean ZBI total score was 17.9 ±10.6 and the same study also shows that a significant portion reported negative impacts expressed unhappiness, lack of personal time, and feeling a loss of control over their own lives due to their caregiving responsibilities.[27]

Regarding the sample characteristics, it's noteworthy that the majority of participants in this study were women, consistent with the profiles of informal caregivers observed in other studies.[20,32,33] The existing gender dynamics and socio-cultural belief assigns caregiving predominantly to women.[34] This study shows that the caregiving burden among these informal caregivers varies with the gender, the relationship shared with care recipients and the duration of care provided. The female caregivers (38.9±14.3) of bedridden elderly are experiencing significantly higher levels of burden compared to male caregivers. Female caregivers experience higher burden than their male counterparts, and they are expected to be primary caregivers.[35,36] Within the institution of marriage, caregiving is assumed as an obligation of female spousal caregiver.[32] In those women whose wellbeing has declined over time due to long term caregiving, may in turn lead to poor care for the dependent older parent.[36]

In this study the spousal caregivers of older adults have shown significantly higher burden compared to the adult children/ grandchildren or son/daughter-in-law carer; as they have close relationship to the care recipient, they tend to spend longer duration for care, emotionally attachment to the partner.[7] Spousal caregivers are an essential source of informal care, where the spousal caregiver's age is an influencing factor of stressor.[7] Furthermore, research indicates that women devote more time to caregiving and are primarily responsible for performing personal-care tasks compared to men. Studies have consistently demonstrated that women encounter heightened levels of mental and physical strain, experience greater caregiver burden, and endure higher levels of psychological distress while fulfilling caregiving responsibilities.[7,35,36]

Present study results reveal that informal caregivers of bedridden elderly are experiencing significant levels of burden and stress, anxiety, and depression which is aligned with previous study from Tamil Nadu and also many other studies on family caregivers from different parts of the world.[24,25,27,36] High stress levels among caregivers can negatively impact work, family and relationships.[13] This study shows that there is a significant correlation between caregiver burden and psychological distress among caregivers. Similar relation is found in the previous study among informal caregivers of patients with head and neck cancer in the Netherlands.[37] The characteristics of both caregivers and as well as recipients have a significant

influence on experienced burden and the stress, anxiety and depression experienced by a carer.[13] Similar to other studies here the results show that stress among caregivers increases with burden.[38] There exists a potential risk for burden, declining physical and psychological health in informal care givers of chronically ill family members.[18,24,26] This psychological distress may affect the caregiver's efficiency to provide care.

In this study results show that caregiving burden increases with long duration of care; longer the duration, the caregiver experiences more burden and it can cause limitations on the mental health of the caregiver.[22] One of the studies from Indonesia on understanding how length of caring duration increases burden and reduces health status of cancer patients' family caregivers have found the same.[39] Prior research has demonstrated a clear association between psychological impairments and health consequences caused by responsibilities of care specifically with regard to subjective burden and depression; anxiety and depressive symptoms have been found common in caregivers.[5,7] A study conducted in India examining the role of caregiving as a risk factor for both poor health and depression among informal caregivers reveals that caregivers, regardless of their socio-economic status, face a heightened risk of experiencing depression and poor health compared to non-caregivers. Additionally, nearly half of the caregivers who devote more than forty hours per week to caregiving duties exhibit symptoms of depression.[40]

Similar to previous studies, this study also finds a significant association between caregiver burden and stress.[19] But no significant correlation was found between the variables such as depression and anxiety with caregiver burden which contradict the previous studies.[24] Also, certain studies show that depression and caregiver burden can be an independent construct or there is weak correlation.[33] Caregivers are experiencing depressive symptoms even at lower care demand or lower dependency. The leading factors responsible for caregiver depression were understood as lack of social support, additional caregiver responsibilities, strained family relationships, or problems with work-life balance are some both internal and external factors that may contribute to mild depression in caregivers but are not considered in this study.[14]

Major strengths of this study were the standardized tools used and use of interview schedule as the mode of data collection which made the data more reliable. The random sampling method used in this study helped in identifying appropriate samples for the study and use of inferential and descriptive statistics for the analysis. Additionally, the geographical area of this study is also unexplored by any other researchers till the date.

Present study has few limitations. Firstly, the study has considered a very small sample size, and larger scale studies in similar nature can explore more. Unequal number of male and female participants is another limitation, studies need to be done with an equal number of male and female caregivers.

CONCLUSION

This study emphasizes the pivotal role of informal caregivers in attending to bedridden family members, underscoring the substantial burden and psychological distress they endure. These challenges can undermine caregivers' well-being and caregiving efficiency. Despite the government of India's National Program for Health Care of Elderly (NPHCE) promoting active and healthy aging through services such as domiciliary visits and family caregiver training, there remains a deficiency in addressing caregiver burden. Our findings highlight the need for comprehensive interventions to address this burden and the psychological issues faced by caregivers. Encouraging male participation in caregiving is also crucial for fostering shared caregiving responsibilities which needs a behavioral change. Moving forward, this study finding can contribute in designing care economy models as well as public health policies catering to needs of geriatric population and their family caregivers.

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