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Original Research Article

Caregiver burden of the elderly in a selected urban community, Chittoor district, Andhra Pradesh

Chandana N.[1], Marteena James[1], Kokilavani C.[1], Padmasree P.[1], Soniya N.[1], Jayanthi Tarugu[2]*, Udayasree K.[2], Kiranmayi Koni[3]

[1]Department of Nursing, The Apollo College of Nursing, Chittoor, Andhra Pradesh, India
[2]Department of Medical and Surgical Nursing, The Apollo College of Nursing, Chittoor, Andhra Pradesh, India
[3]Department of Psychiatric Nursing, All India Institute of Medical Sciences, Raebareli, Uttar Pradesh, India

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***Correspondence:**
Dr. Jayanthi Tarugu,
E-mail: jayanthibhargav23@gamil.com

ABSTRACT

Background: In India, families are the primary source of support in caring for the elderly, whereas the potential group of family caregivers is shrinking. Caregivers need greater recognition and support to help them care for the elderly and to maintain their own health and well-being. Assessment of the perceived burden of caregivers helps identify those in need of support.
Methods: A cross-sectional questionnaire-based study was conducted to estimate the perceived level of caregiver burden in families of elderly and to identify the association between selected socio-demographic characteristics of the caregivers and the level of caregiver burden. The caregivers of 50 elderly people categorized as mild and moderate dependents as per the Katz index of Independence were included in the study. The Zarith caregiver burden scale was used to evaluate their perceived level of caregiver burden.
Results: Thirty-two (64%) caregivers were found to experience a mild to moderate perceived level of caregiver burden. An ordinal regression analysis between other burdens/responsibilities (predictor) of the caregiver and the perceived level of caregiver burden showed a significant association (χ^2; p=0.009) between the two. An odds ratio of 6.7 (95% CI, 2.22 to 22.7; p=0.00115) showed that as the predictor increased, the event (caregiver burden) increased as well.
Conclusions: The majority of the caregivers suffer from a mild to moderate perceived level of caregiver burden. They experience more burden when they hold additional responsibility of caring for the elderly.

Keywords: Caretaker, Caregiver burden, Elderly, Late adulthood, Old age

INTRODUCTION

The demographic transition in the ageing of the population is a global phenomenon. The World Health Organization (WHO) predicts that by 2050 the world population aged 60 years or more will double, whilst those aged 80 years or more will number up to 400 million persons. India is ageing much faster than previously thought and is expected to have nearly 20% of the aged population of the world.[1-3] India with 1.31 billion population, the second largest population globally, comprises 17% of the world's total aged population. The proportion of the "oldest old" adults aged 80 and older has doubled over the past 65 years, from 0.4% to 0.9%.

In India, families are the primary source of support in caring for the elderly and assumes a central place as the mode of old age security in India.[4] Elderly refers to anyone of chronological age of 65 years or older.[1] In India, it is very common to find multi-generational co-residence of elderly with children and grandchildren where family

members are expected to act as primary caregivers to elderly dependents.[5] This poses a challenge for the children as they need to make right choices regarding their elderly parents; also, the role of caregiver is increasingly a complex and demanding one.

Though the need for care giving is rapidly increasing, the potential group of family caregivers is shrinking. Now families are small, having few children and sometimes they may live far from their parents. Earlier, women in the family-wives, daughters, daughters-in-law, were not employed, hence they took care of the elderly dependents; while today they are employed and therefore have limited time to spare for care-giving and other responsibilities.[6]

The caregivers are burdened with multiple roles that it is important to acknowledge the sacrifice they make and extend a helping hand by supporting them to maintain their health and well-being, financial security, etc. If the prolonged distress of the caregivers is not recognized in time this will lead to burnout. Assessing early and supporting appropriately in time will improve the quality of life of the caregivers. This study was planned to identify the perceived level of caregiver burden and its association with selected socio-demographic characteristics.

METHODS

Study design and setting

A cross-sectional observational study conducted in the Urban community (Murakambattu, Chavatapalli, G.D. Nellore, Greamspet), Chittoor district, Andhra Pradesh, India for total 8 months from February 2021 to October 2021. The study approval was obtained from the institutional ethics committee. Individual written consent was obtained from the caregivers prior to enrolling them in the study. The study was explained to the participants and confidentiality of data was ensured.

Sample

Caregivers of elderly residents aged 60 years and above are the sample under study. Care givers are the family members of the elderly, who volunteer their time, without pay, to help with the care needs of the elderly.

The study includes the primary care givers taking care of elderly people with moderate or severe functional disability, assessed by the 'Katz Index of Independence in activities of daily living' for the past 3 months and excludes families with recently impaired elderly (below 3 months of impairment) and the care giver family member who have not attend the care needs of the elderly for the past 3 months.

Sampling technique: purposive sampling technique

The caregivers of the elderly residents whose dependency was categorized as mild to severely dependent as per the Katz index of independence in activities of daily living (Katz ADL) were included in the study.

Sample size

Sample size was calculated using the $n = Z^2 p (1–p)/d^2$ formula assuming 'p' as 0.15, 'd' as 0.2 at a 95 % confidence level. The estimated sample size was 50.

Data collection

Families with elderly people were identified with the help of volunteers working at Sachivalayam (local government facilities set up in the Indian state of Andhra Pradesh, also called as secretariats). A door to door survey was conducted to assess the level of dependence (by applying the Katz Index of Independence in activities of daily living scale) of an elderly population after taking their informed written consent.

Caregivers of elderly with moderate to severe dependence were recruited into the study after taking their consent and the data from them was collected using a semi-structured questionnaire consisting of the investigator-made proforma for socio-demographic variables and the Zarit burden interview scale. The latter consisted of 22 items with rating on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always) with the total sum of scores ranging between 0-88. Higher scores indicated an increased perceived level of burden.[7] Interpretation of scores with level of burden of Zarit burden interview scale are as follow: 61-88 was intense burden, 41-60 was moderate to severe burden, 21-40 was mild to moderate burden and below 21 was no burden.

Data analysis

EZR software was used for statistical computations. Data was described by summary statistics using frequency, percentage or mean and standard deviation where ever applicable. Inferential statistics were applied to test the association between the level of burden of caregivers with their demographic variables.

RESULTS

Majority of the elderly (n=18, 36%) were women (n=31, 62%) aged 70 years and above (Table 1).

Most (n=34, 68%) of the care givers were also women, few of them were suffering from hypertension (n=3, 6%), diabetes mellitus (n=1, 2%). Most of them (n=31, 62%) were facing financial stress while some of them experienced emotional burden (n=15, 30%) (Table 2).

Level of dependence of elderly

Among the elderly, 17 (34%) were moderately dependent, 23 (46%) were severely dependent, and the rest of them were (n=10, 20%) profoundly dependent (Figure 1).

Table 1: Distribution of demographic variables of elderly (n=50).

Demographic variable	Frequency (%)
Age group of elderly (years)	
60-65	7 (14)
66-70	10 (20)
71-74	15 (30)
76-100	18 (36)
Sex of elderly	
Male	19 (38)
Female	31 (62)
Education of elderly	
Nil	16 (38)
Primary school	9 (18)
Secondary school	2 (4)
Diploma/degree	1 (2)
Bachelor/higher	0(0)
Occupation of elderly	
House wife	4 (8)
Coolie	19 (38)
Farmer	18 (36)
Nil	3 (6)
Line inspector	1 (2)
Sales manager	1 (2)
Weaver	1 (2)
Lorry driver	1 (2)
Cleaner	1 (2)
Police	
Elderly income per month	
>78,603	1 (2)
39,033-78,062	0 (0)
29,200-39,032	1 (2)
39,516-29,199	0 (0)
11,708-19,515	3 (6)
3908-11,707	3 (6)
<3907	42 (84)
Source of income for elderly	
Nil	2 (4)
Pension	46 (92)
From son	2 (4)
History of chronic illness of elderly	
Diabetes mellitus	18 (36)
Hypertension	21 (42)
Paralysis	3 (6)
HTN, DM	1 (2)
Asthma	1 (2)
Nil	4 (8)
CVA	1 (2)
DM, paralysis	0 (0)
HTN, fracture	1 (2)
Marital status of elderly	
Single	0 (0)
Married	33 (66)
Separated	1 (2)
Divorced	0 (0)

Continued.

Demographic variable	Frequency (%)
Widow	16 (32)
Relationship of the elderly with care	
Mother	16 (32)
Father	4 (8)
Mother –in-law	9 (18)
Father-in-law	2 (4)
Daughter-in-law	2 (4)
Grandmother	1 (2)
wife	6 (12)
Son	2 (4)
Cousin	1 (2)
Husband	4 (8)
Grand daughter-in-law	1 (2)

Table 2: Distribution of demographic characteristics of care giver (n=50).

Demographic variable	Frequency (%)
Age group of caregivers	
<18	0 (0)
19-25	0 (0)
26-35	14 (28)
>35	36 (72)
Gender of caregiver	
Male	16 (32)
Female	34 (68)
Education of caregiver	
Nil	14 (28)
Primary school	10 (20)
Secondary school	19 (38)
Diploma/degree	7 (14)
Bachelor/higher	0 (0)
Occupation of caregiver	
Nil	3 (6)
Painter	5 (10)
Coolie	7 (14)
Farmer	2 (4)
Shopkeeper	1 (2)
Housewife	23 (46)
Teacher	1 (2)
Business	4 (8)
Yan worker	1 (2)
Working in garage	2 (4)
Masen	1 (2)
Caregiver income per month	
>78,603	0 (0)
39,033-78,062	1 (2)
29,200-39,032	0 (0)
39,516-29,199	2 (4)
11,708-19,515	3 (6)
3908-11,707	14 (28)
<3907	30 (60)
Present health status of caregiver	
Healthy	40 (80)
Diabetes mellitus	3 (6)

Continued.

Demographic variable	Frequency (%)
Hypertension	5 (10)
Joint and back pain	1 (2)
PCOD	1 (2)
Marital status of caregiver	
Single	2 (4)
Married	46 (92)
Separated	1 (2)
Divorced	0 (0)
Widow	1 (2)
Other burden/responsibilities of caregiver	
Emotional burden	15 (30)
Financial stress	31 (62)
Anger/depression	4 (8)
Duration of caregiver role	
<1Month	0 (0)
1-3Month	1 (2)
3-6Month	4 (8)
>6Month	45 (90)
History of loss of job out of caregiver role	
Yes	2 (4)
No	48 (96)

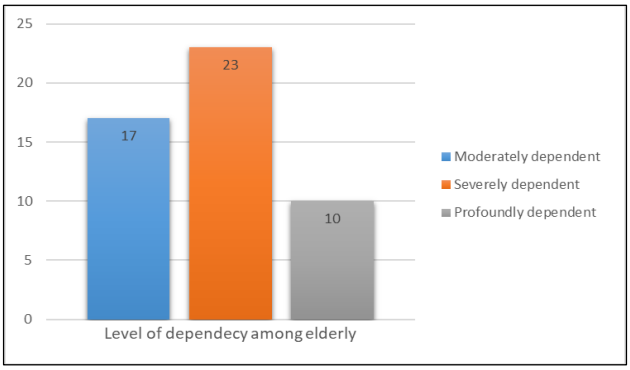

Figure 1: Distribution of sample based on the level of dependency (n=50).

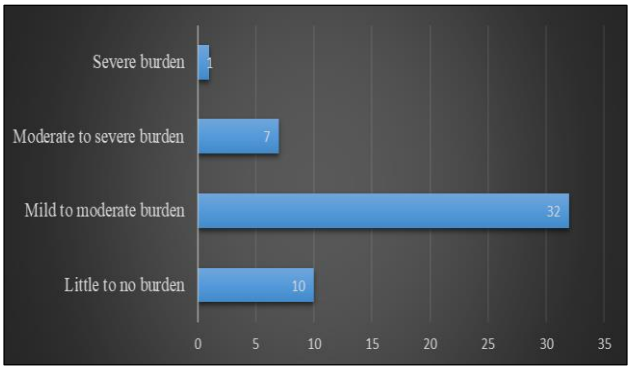

Figure 2: Level of caregiver burden in the caregivers of elderly residents.

Table 3: Association between the socio-demographic characteristics of caregivers and level of caregiver burden perceived by caregiver.

Variables		Level of burden over			
		N (%)	χ2	df	P value
Age group (years) of caregiver	26-35	14 (28)	4.0816	3	0.31
	>35	36 (72)			
Gender of caregiver	Male	16 (32)	3.1742	3	0.38
	Female	34 (68)			
Education of caregiver	Nil	14 (28)	9.4018	9	0.25
	Primary school	10 (20)			
	Secondary school	19 (38)			
	Diploma/degree	7 (14)			
Occupation of caregiver	Nil	3 (6)	27.855	30	0.36
	Painter	5 (10)			
	Coolie	7 (14)			
	Farmer	2 (4)			

Continued.

Variables		Level of burden over			
		N (%)	χ2	df	P value
	Shopkeeper	1 (2)			
	Housewife	23 (46)			
	Teacher	1 (2)			
	Business	4 (8)			
	Yan worker	1 (2)			
	Working in garage	2 (4)			
	Masen	1 (2)			
Caregiver income per month	9,033-78,062	1(2)	4.9991	12	0.93
	29,200-39,032	0(0)			
	39,516-29,199	2(4)			
	1,708-19,515	3(6)			
	3908-11,707	14(28)			
	<3907	30(60)			
Present health status of caregiver	Healthy	40(80)	27.685	15	0.08
	Diabetes mellitus	3(6)			
	Hypertension	5(10)			
	Joint and pain	1 (2)			
	PCOD	1 (2)			
Marital status of caregivers	Single	2 (4)	5.2484	9	0.41
	Married	46(92)			
	Separated	1(2)			
	Divorced	0(0)			
	Widow	1(2)			
Other burden and responsibilities of caregiver	Emotional burden	15(30)	21.637	6	0.009*
	Financial stress	31(62)			
	Anger/depression	4(8)			
Duration of caregiver (months)	<1	0 (0)	6.9353	6	0.43
	1-3	1(2)			
	3-6	4(8)			
	>6	45(90)			
History of loss of job of caregiver	Yes	2 (4)	1.1719	3	1
	No	48 (96)			

*Statistically significant association (p≤0.05).

Level of burden among care givers

Majority of the caregivers 32 (64%) experienced mild to moderate burden, few of them experienced little to no burden (n=10, 20%) and moderate to severe burden (n=7, 14%), while one caregiver has had severe burden (n=1, 2%) (Figure 2). There was no association between the level of dependency of the elderly and the level of burden perceived by the caregiver. An ordinal regression analysis between other burdens/responsibilities of the care giver and level of care giver burden was significantly associated (p=0.009)) and has shown an increase in level of caregiver burden with an increase in other burdens/responsibilities of care giver with an odds ratio of 6.7 (95% CI, 2.22 to 22.7; p=0.001) (Table 3).

DISCUSSION

The majority of the elderly in the study were found to be severely dependent. Dependency in elderly can usually be attributed to factors such as age, illness, disability etc.[8,9] In this study the dependency can majorly be attributed to the co-morbidities like diabetes and hypertension which majority elders are found to be suffering from. The process of aging of the human body leads to impairment of energy, homeostasis and abnormalities in carbohydrate metabolism leading to hyperglycemia. Blood pressure also increases with age as the blood vessels naturally thicken and stiffen over time.[10,11]

Most of the caregivers in the present study were women. This is in line with global findings where an estimated 66 percent of caregivers as women, even though the proportion of men taking up the caregiver's role is steadily increasing.[12] A greater sense of responsibility toward family members is always demonstrated by women compared to men. Women are well connected with the emotional well-being of people whom they provide care. The caregivers in the study reported facing financial stress, while some of them experienced emotional burdens too, which might be because they tend to withdraw from paid work hours or leave the job to care for an older adult,

leading to loss of income, which in turn result in reduced social security and other retirement benefits. They may also incur significant out-of-pocket expenses to pay for help and other care-giving expenses.[13-15] In contrast, nearly one fourth of the caregivers expressed that they have no burden out of caregiver roles because most of them were young, healthy and they were housewives. Hence, they were able to spare their time and attention to the needs of the elderly. It was also observed that in Murakambattu community, most of the families run petty shops like vegetables, fancy stores and other groceries which are attached to their own houses, thus giving the male and female caregivers adequate time to the care of their elderly dependents, which must have reduced the caregiver role burden while managing their source of income unaffected.

The majority of the caregivers were experiencing mild to moderate burden, while a single caregiver reported intense burden. A similar finding was found in another cross-sectional study where the family burden in caregivers of elderly with cognitive impairment residing in rural and tribal population of a district in Western India showed results indicating the majority of caregivers suffer from a mild-to-moderate burden.[13]

There was a significant increase in the level of caregiver burden with an increase in other burdens/responsibilities of care giver. Insufficient financial resources, economic restraint is an important factor associated with caregiver burden and, sometimes, despite the government providing financial assistance to patients with chronic illnesses to help the caregivers reduce the burden.[8,9] Hence, targeted steps may be taken to conduct caregiver training programs in taking care of dependent elderly and alleviate their suffering, especially during the times of admission of the elderly in hospital, training sessions can be planned for care givers.[14,16,17]

CONCLUSION

The majority of the caregivers were suffering from mild to moderate level of perceived caregiver burden. The study findings helped us to understand that the caregivers are at risk of developing a caregiver burden. So targeted steps may be taken to conduct training programs to take care of dependent elderly and alleviate their suffering, especially during the times of admission of the elderly in hospital, training sessions can be planned for caregivers. Additionally, one can also identify alternative care services and get help and support. Systematic and meaningful approaches to supporting family caregivers by helping them to identify the appropriate resources must be done. Performance standards to guide the family caregivers could be developed.

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Ethical approval: The study was approved by the Institutional Ethics Committee of the Apollo Institute of Medical Sciences and Research (AIMSR), Murukambattu, Chittoor, Andhra Pradesh (IEC approval number: SR001/IEC/AIMSR/2021)

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