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# Caregiver's Burden: A Study on The Level of Burden Among The Caregivers of The Elderly in The Rural Areas of A Medical College Hospital in Mangaluru

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## Abstract

**Introduction:** The census 2021 has revealed that the elderly population in India is 138 million with most of the elderly living in the rural areas. Physiological changes along with their morbid conditions make them vulnerable for the need of support & caregivers most of the time.

## Aims & objectives

- to assess the strain among the caregivers of the elderly using the Modified caregivers strain index (MCSI).
- to assess the dependency level among the elderly using the Katz index of Activities of daily living (ADL).

3. to correlate the caregivers stress & the dependency of the elderly.

Material and Methods: A proforma based study was conducted from 24/05/23 to 23/08 /23 in the field practice areas of the Department of community medicine of Father muller medical college. Data collection was done using digital response questionnaire after informed consent was taken from the elderly & informal caregivers meeting the inclusion criteria. A sample size of 155 was chosen after calculation from prevalence of previous studies.

**Statistical analysis:** Data was entered in MS excel & analysed using SPSS version 23. Percentages & proportions of Activities of daily living (ADL) & informal caregivers strain by using the Modified

caregivers strain index (MCSI) was calculated. Spearman Pearson's coefficient was used to determine the association between ADL & MCSI scores.

**Results:** 37.4 % of informal caregivers experienced mild strain. 79.4% of the 155 elderly were fully functional. Strain level of the informal caregivers showed a negative correlation (- 0.267) with the dependency level of the elderly.

**Conclusion:** With increasing dependency level of elderly, informal caregivers strain was also proportionately increasing showing an association between activities of daily living (ADL) & Modified caregivers strain index (MCSI).

**Keywords:** Caregiving, elderly, burden, activities of daily living, strain.

#### Introduction

The census 2021 has revealed that the elderly population in India is 138 million with most of the elderly living in the rural areas.

Physical and mental disability is prevalent among the elderly which increases with age. Consequently older people usually need more assistance with daily activities when they are older.

Physiological changes along with their morbid conditions make them vulnerable for the need of support/caregivers most of the time.

Nearly 80% of the elderly, more than 60 years of age are estimated to have atleast one chronic ailment.

An informal caregiver is a family member or a natural person who aids and supervises the daily cares, contributing to the caretaking responsibilities of a person who is disabled or weak.

In India caregiving is more often by a family member and is often resorted to at all stages of illnesses with the responsibility of providing care to dependant older adults.

Burden of care was defined by Zarit, an American Gerontologist as the discomfort experienced by the principal caregiver of an older family member including the caregiver's health, psychological well-being, finances, and social life.

Caregivers are prone to fatigue, depression, grief, change in their social relationships, and financial hardships as it requires hard work and effort.

Very few studies in India have evaluated the association of informal caregiver strain in the dependent elderly. Therefore there is a need to identify the severity of caregiver burden and later plan to develop the strategies or interventions that could support them

# **Objectives**

- To assess the strain among the caregivers of the elderly using the Modified caregiver strain index(MCSI).
- 2. To assess the dependency level among the elderly using Katz index of Activities of daily living(ADL).
- 3. To correlate the caregiver's stress and dependency of the elderly.

# **Materials and Methods**

A questionnaire-based study was conducted from 24/05/23 to 23/08/23 for a period of 3 months in the field practice areas of the Department of Community Medicine of a medical college hospital in Mangaluru.

Ethical clearance was obtained from the Institutional ethics committee Vide Ref No. FMIEC/CCM/671/2023.

A sample size of 155 was chosen by calculations from prevalence (P = 50.3 %) of previous studies using the formula n =  $(Z \text{ alpha})^2 P(1-P) / e^2$ .

Data collection was done using a digital response questionnaire after informed consent was taken from the elderly and informal caregivers meeting the inclusion criteria.

The inclusion criteria for the caregivers was any person aged more than or equal to 18 years who is taking care of the elderly and deemed to be an informal caregiver. All consenting elderly with a reported age of more than 60 years during the study period were recruited for the study.

The questionnaire consists of 3 parts. Part A- consists of questions about the socio-demographic characteristics of both the elderly and the informal caregivers. Part B- consists of an assessment of activities of daily living of the elderly and Part C- consists of the assessment of caregiver strain using the modified caregiver strain index(MCSI) of the informal caregiver Activities of daily living(ADL) score based on the ability of the elderly to perform the activities were given one point. The total scores on the six items of the activities of daily living were added to assess the degree of dependence as fully functional (score of 6), moderate impairment (score of 4-5), and severe impairment (score of <3). Modified caregiver strain index scores were classified as 16-26(extreme strain), 9-15 scores as moderate strain, 1-8 scores as mild strain, and a score of 0 no strain.

Spearman's correlation coefficient was used to determine the association between the dependency level of the elderly(ADL) scores and caregiver strain(MCSI) scores. Statistical Analysis was done by entering the data in the MS Excel sheet and analyzed using SPSS version 23. Percentages and proportions of activities of daily living and informal caregiver strain by using the modified caregiver strain index was calculated.

#### Results

Of the 155 elderly interviewed during the study period, most of the elderly 116(74.8%) were between the age group of 60-69 years of age.

About 86(55.5%) of the elderly were female. Most of the elderly 87(56.1%) were illiterate and 136(87.7%) of the elderly were married. Of the 155 caregivers, 51(32.9%) were the sons of the elderly and 41(26.5%) were the daughters of the elderly. The most common co-morbidity in the elderly was diabetes 40(36%).

Most of the families of the elderly have a family size of 3-5 members 71(45.8%). Of the 155 caregivers interviewed, the 13 questions of the Modified Caregiver Strain Index showed that the strain faced regularly was due to the disturbance of sleep 24(15.5%), followed by feeling overwhelmed 22(14.2%) and financial strain 14(9%). Table 1 gives a detailed description of the caregiver's strain as per Modified Caregiver's Strain Index(MSCI).

The scores of the Caregiver's Strain Index ranged from 0(no strain) to 26(highest level of strain) on a scale of 26 and the levels of strain experienced by the caregivers are depicted in Figure 1.

The median score of the caregiver's stress as per the MCSI was 1(0-6).

Table 2 shows the findings of the ADL of the elderly based on the sex of the elderly.

Among the activities of daily living the most common problem faced by the males was for dressing 11(15.9%) followed by transferring 9(13%) and among the females it was for transferring and continence 8(9.3%) and 8(9.3) respectively. Figure 2 depicts the level of dependency of the elderly. Most of the elderly were fully functional 123(79.4%), and 14(9%) were severely impaired, whereas 18(11.6%) were moderately impaired.

The summary of the scores of the Activities of Daily Living of the elderly was correlated with the scores of the Modified Caregiver Strain Index(MCSI) using Spearman's correlation coefficient & was found to have

a highly negative correlation of -0.267 and is summarized in Table 3. This study showed that the lower the scores of ADL (i.e. more dependency) higher the caregiver strain.

Table 1: Modified Caregiver Strain Index in Caregivers of Elderly(N=155)

Caregivers experiences as per MCSI	Yes, regularly	Yes, sometimes N (%)	No
	N (%)		N (%)
My sleep is disturbed	24 (15.5)	26 ( 16.8 )	105 (67.7)
Caregiving is inconvenient	13 ( 8.4 )	18 ( 11.6 )	124 ( 80 )
Caregiving is a physical strain	12 ( 7.7 )	22 ( 14.2 )	121( 78.1)
Caregiving is confining	9 ( 8.5 )	30 ( 19.4 )	116 ( 74.8 )
There have been family adjustments	119 ( 7.1 )	35 ( 22.6 )	109 ( 70.3 )
There have been changes in personal plans	12 ( 7.7 )	28 ( 18.1 )	115 ( 74.2 )
There have been other demands on my time	9 (5.8)	31 (20)	115 ( 74.2 )
There have been emotional adjustments	10 ( 6.5 )	27 ( 17. 4 )	118 ( 76.1 )
Some behaviour is upsetting	11 (7.1)	17 ( 11 )	127 ( 81.9 )
It is upsetting to find the person I care for has changed so much from his /her former self	9 (5.8)	17 (11)	129 ( 83.2 )
There have been work adjustments	13 ( 8.4 )	26 (16.8	116 ( 74.8 )
Caregiving is a financial strain	14 (9)	31 ( 20 )	110 ( 71 )
I feel completely overwhelmed	22 ( 14.2 )	29 (18.7 )	104 ( 67.1 )

Table 2: Activities of Daily Living (ADL) of The Elderly in The Study Population (N= 155)

Activities of daily living	Independent elderly n ( % )		Dependent elderly n (%)	
	Male	Female	Male	Female
Bathing	64 ( 92.8 )	81 (94.2 )	5 ( 7.2 )	5 ( 5.8 )
Dressing	58 (84.1 )	80 ( 93 )	11 (15.9)	6(7)
Toileting	63 ( 91.3 )	81 ( 94.2 )	6 (8.7 )	5 (5.8)
Transfering	60 ( 87 )	78 (90.7)	9 ( 13 )	8 ( 9.3 )

Continence	63 (91.3)	78 (90.7)	6 (8.7)	8 (9.3)
Feeding	63 ( 93.1)	81(94.2)	6 (8.7)	5 ( 5.8 )

Table 3: Correlation of The Modified Caregivers Strain Index (MCSI) & Activities of Daily Living (ADL) Score

	Spearman Pearson correlation coefficient	P	
ADL vs Caregiversstrain	- 0.267	0.001	significant

Figure 1: Strain Levels in Caregivers of Elderly (AS PER MCSI)

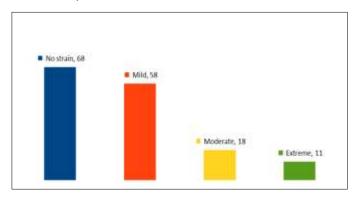
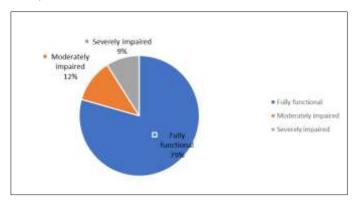


Figure 2: Dependency Levels of Elderly (Based On ADL)



## Discussion

The mean ADL score in our study was found to be 5.48 +/- 1.25. However in a study conducted by Teja Pristavec (1) the mean ADL score was 1.34 +/- 1.19, which was lesser than our values. In a study conducted by Ran etal (6) in China ,the mean ADL score was found to be 5.2 which was lesser than in our study.

Functional dependency level for ADL was calculated. In our study we found that 123 elders (79.4%) were fully functional without any dependency. In a study done by

Chen etal only 3 elders (1%) were fully functional without any dependency. This was found to be lesser than in our study. A study conducted by Sharma etal (7) showed that 78.2% of elders were fully functional & independent which was lesser than in our study. In a study done by Patil K et al (8) showed that 67% of the elderly were fully functional without any dependency & this was lesser than in our study. Also, a study done by Bhaskar A. et al showed a fully functional level of 66.4% among the elderly, which was also lesser than in our study. 18(11.6%) of elders were moderately impaired in our study. Whereas in the study done by Chen et al 49(16.2%) of the elders were moderately impaired (6) which was higher than in our study.14(9%) of the elders were severely impaired in our study which was lesser than in the study done by Chen etal (6) wherein there were 56(18.5%) of the elders who were severely impaired.

In our study we found that the maximum dependency level among males was for dressing, 11(15.9%), whereas for females it was for transfer 8(9.3%) & also for continence 8(9.3%).

In a study done by Ankeeta Menona Jacob it was found that the maximum dependency level among males as well as for females was for dressing, 18(19.4%) & 27(25.2%) respectively. In a study done by Veerapuetal (10) maximum dependency level for ADL among the elders was for toileting.

In our study among the 155 caregivers, 58(37.4%) of them experienced mild strain, whereas 18(11.6%) of them experienced moderate strain & extreme strain was seen in 11(7.1%) of the elderly caregivers. 68(43.9%) of the caregivers did not have any strain at all (no strain).

In a study done by Manju Dhandapani etal (4) it was seen that 45 (64%) of the elderly caregivers had mild strain & 22(31%) of them experienced moderate strain while 3(5%) experienced severe strain. All these strain levels were higher than the strain levels seen in our study. The mean of the caregivers strain in our study was 4.35(S.D=6.55) & the median was 1 (interquartile range = 0-6).

In a study done by Bhavin Mandowaraetal (5) it was seen that the mean was 6.93 (S.D = 2.94) & the median was 7 (interquartile range = 5-9), which were all higher values than that seen in our study. In a study done by Hsu etal (11) the median caregivers strain index was 2 (interquartile range = 0-13) which was more than in our study.

Modified caregivers strain index scores in our study revealed that the caregivers experienced maximum strain due to disturbed sleep 24 (15.5%) which was on a regular basis during their caregiving.

The study done by Manju Dhandapani etal (4) showed that the maximum strain was the financial strain 29 (41%) which was higher than seen in our study ,as the financial strain in our study was seen among 14 (9 %) of caregivers.

In our study we found out that the caregivers strain was inversely proportional to the Activities of daily living (ADL) score. When the ADL score was less, there was an increased caregivers strain & vice versa. In our study ,when ADL vs caregivers strain was calculated there was an inversely proportional relationship between the ADL

& caregivers strain & the Spearman Pearson's correlation coefficient was – 0.267 which was significant ( P=0.001 ).In a study done by Manju Dhandapani etal (4) it was found that the ADL ( activities of daily living ) was inversely related with MCSI (modified caregivers strain index ) & the Spearman Pearson's correlation coefficient was – 0.18 which was lesser than in our study, & P=0.22 which was not significant.

Also, in a study conducted by Mehta K K (12) showed that the modified caregivers strain index (MCSI) was inversely proportional to the ADL scores (-0.348) which was statistically significant & was higher than in our study.

#### **Conclusions**

The most common domain of dependence in the activities of daily living among the elderly was for dressing. Disturbance of sleep was the most common domain affecting the informal caregivers of the elderly as per the Modified Caregiver's Strain Index(MCSI). The caregiver strain of the informal caregivers of the elderly had a significant negative correlation with the level of dependency of the elderly. The higher the dependence of the elderly, the greater the necessity for evaluation of caregiver strain to ensure the continuum of care for the elderly & the strain increased proportionately with increase in dependency level.

### Recommendation

There is a need for evaluation of caregiver strain among informal caregivers of the elderly and appropriate support should be ensured & extended to the informal caregivers. Schemes to ensure financial support to the informal caregivers of the elderly should be provided.

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