ORIGINAL ARTICLE

Caring for you is straining me! -Strain among the informal caregivers of the elderly attending Health Centres of a Coastal City in Karnataka

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Abstract | Introduction | Methodology | Results | Conclusion | References | Citation | Tables / Figures

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Abstract

Background: Census 2011 estimated 104 million elderly in India. Unprecedented demand for informal caregivers of elderly has resulted in physical, emotional and economic difficulties called caregiver strain. **Aim & Objective:** To determine the association between levels of strain among informal caregivers and the dependency levels of the elderly. **Material & Methods:** A cross-sectional study during January -March 2018 was conducted in the health centres attached to field practice areas of a tertiary care hospital. Data collection was done using a pre-tested, semi-structured questionnaire after informed consent from elderly and informal caregivers meeting the inclusion criteria. **Statistical Analysis**: Data was entered in MS Excel and analysed using SPSS version 20. Percentages and proportions of Activities of daily living (ADL) and informal caregiver strain of Modified Caregivers Strain Index (MSCI) and their scores were expressed in median and interquartile range. Spearman's Rho was used to determine the association of ADL and MCSI scores. **Results**: 47.5% of informal caregivers experienced mild stress; 70 % of the 200 elderly were fully functional. Strain level of the informal caregivers showed a negative correlation (0.557) with the dependency level of the elderly. **Conclusion**: With increasing dependency level of elderly, informal caregiver strain should be assessed.

Keywords

Caregiving; Activities of Daily Living; Aged; Burden

Introduction

According to Census 2011, the elderly population in India is around 104 million (1) of which more than 70% of them live in rural areas. (1) 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 65 years of age are estimated to have at least one chronic ailment.(2)

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.(3) In India,

caregiving is more often by a family member and is often resorted to, at all stages of illnesses (4) with the responsibility of providing care to dependent older adults.(5)

Caregivers are prone to fatigue, depression, grief, change in their social relationships and financial hardships (6) as it requires hard work and effort. With more preference towards nuclear families, there has been an unprecedented demand on informal caregivers (4) resulting in physical, emotional and economic difficulties referred to as caregiver stress/ burden. Very few studies in India have evaluated the association of informal caregiver strain in the dependent elderly.

Aims & Objectives

1. To assess the strain among the caregivers of the elderly using the Modified Caregiver Strain Index (MSCI).
2. To assess the dependency level among the elderly using Activities of daily living (ADL).
3. To correlate the caregiver's stress and dependence of the elderly.

Material & Methods

A cross-sectional study on 200 elderly (aged more than 60 years) persons and their accompanying caregivers attending the health centres attached to the field practice areas of a tertiary care hospital was conducted between January -March 2018. A sample size of 194 caregivers was calculated using nMaster software v 2.0 developed by CMC Vellore, based on a study conducted by Sabzwari *et al*. (7) in 2016, that found 50.3% of the caregivers had stress, at a relative precision of 14%. The data from the informal caregivers and accompanying elderly who provided informed written consent. The data collected using a pre-tested semi-structured questionnaire consisting of 3 parts. Part A- which contained questions pertaining to the socio-demographic characteristics of both the elderly and the informal caregivers, Part B- which contained the assessment of Activities of Daily Living of Elderly (ADL) of the accompanying elderly and Part C- which contained the assessment of caregiver strain using the Modified Caregiver Strain Index (MCSI) of the informal caregiver. The scales of Activities of daily living of elderly (ADL) and Modified caregiver strain index (MCSI) were translated to the local language, Kannada and was used to collect the data. The Activities of Daily Living commonly known as Katz's Index, assesses the level of dependence. (8) The Modified Caregiver Strain Index (MCSI) is a tool designed by Onega L, (6) measures strain experienced by individuals involved in care provision using a 13-item checklist. The inclusion criteria for the caregivers was any person aged more than or equal to 18 years accompanying the elderly to the health centres deemed to be informal caregivers. An operational definition for informal caregivers was used to recruit all persons, i.e. who did not receive any remuneration in cash or kind) for the caretaking activities like feeding, providing food, clothing, and residence to the elderly for more than 12 hours a day. Ascertainment of the caregivers accompanying is actual providers of care to the elderly were taken. All consenting elderly patients with the reported age of more than 60 years attending the health centres during the study period were recruited for the study. The study protocol was placed before the Institutional Ethical Committee from the concerned institution for ethical approval, and the study was carried out for two months between January to March 2018. The interns posted in the health centres in the field practice areas of a tertiary care hospital collected data after briefing them regarding the questionnaire and discussing the methodology of the study to ensure uniformity in the recruitment of study participants and collection of data. The collected data was entered in MS Excel and analysed using SPSS software version 20. Qualitative variables like the socio-demographic characteristics like sex of the caregivers & elders, marital status, level of dependence as per activities of daily living (ADL), level of stress as per Modified Caregivers Strain Index (MSCI) were expressed in terms of frequency and percentages. Quantitative variables such as the age of caregivers and elders, the number of years of chronic diseases in the elderly were expressed in terms of mean and standard deviation or median and interquartile range after conducting Shapiro- Wilk test for normality. 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 scores 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) (8). Modified caregiver strain index scores were classified as 16- 26 (Extreme strain), 9-15 scores as moderate strain, 1-8 scores as a mild strain and a score of zero was no strain (6). Spearman's Rho was done to determine the

association of the dependency level of the elderly (ADL scores) and caregiver's strain (MSCI scores).

Results

Of the 200-elderly attending the health centres during the study period, most of the elderly 139(69.15%) were between age groups of 60-70 years of age, and the mean and standard deviation of the age of the elderly participants was 69.45±7.0 years. About 107(53.5%) of the elderly were female. Most of the elderly were educated up to primary school, i.e. 1-4th standard and 126(63.0%) of the elderly were married. Of the 200 caregivers, 195(97.5%) of the caregivers were relatives of the elderly, of which 112(56.0%) were the children of the elderly followed by the spouse 51(25.5%). The most common comorbidity was hypertension in 134(67.0%) of the elderly followed by type II diabetes mellitus in 57(28.5%) and stroke in 17(8.5%) of the elderly. The median duration of hypertension among the elderly with hypertension and Type II diabetes was 10 [5-15] years. The median family size of the study population was 4[3.25-5.0]. Of the 200 caregivers interviewed, the 13 questions of the Modified Caregiver Strain Index showed that the strain faced regularly was due to the behaviour of the elderly being upsetting, feeling of overwhelming in 19(9.5%) and financial strain in 18(9.0%). The most common strain in caregivers faced regularly was related to strain on finances in 61(30.5%) overwhelming feeling & making work-related adjustments in 59(29.5%). [Table1] gives a detailed description of the caregiver's strain as per Modified Caregivers Strain Index (MCSI).

The scores of the caregiver strain index ranged from 0(no strain) to 19 (higher level of strain) on a scale of 26, and the levels of strain experienced by the caregivers are depicted in [Figure 1].

The median scores of the caregivers as per modified caregiver strain index was 3[0-7].

The [Table 2] shows the findings of the ADL of the elderly based on the sex of the elderly

There were no statistically significant differences in the ADL activities and the age group and sex of the elderly. The most common problems faced in both males and female elderly was the need for dressing, i.e. 45(22.5%), followed by for toileting in 17(18.3%) in elderly males and bathing 23(21.0%) for females. [Figure 2] depicts the level of dependency level of the elderly.

Most of the elderly were functionally independent 140(70.0%), and severe dependency level was seen only among 33(16.5%) of the elderly whereas the rest of the elderly 27(13.5%) were moderately dependent and this was not found to differ statistically among the age groups or sex of the elderly.

The summary of the scores of the Activities of Daily Living(ADL) of the Elderly were correlated with the scores of the Modified Caregivers Strain Index(MCSI) using Spearman's Correlation and was found to have a highly significant (P value- <0.001) negative correlation of (-0.557) is summarized in [Table 3]. This study showed that lower the scores of Activities of Daily Living of the Elderly (i.e., more dependency) higher was the caregiver strain.

Discussion

To the best of our knowledge, this is the first study conducted in India to evaluate the possible relationship between the caregiver strain and the dependency level of the elderly using the ADL. The median ADL score in the present study was 4.98±1.8 which was lesser in comparison to the mean ADL score in study conducted by Ran *et al*, in China (9) which was found to be 5.2 and that the scores varied significantly among the age groups, however no such variation in ADL scores were seen in the present study. A study conducted by Sharma *et al*,(10) showed that the functional dependence for Activities of Daily Living was found to be 21.8%. Whereas in the present study the functional dependency level estimated was found to be higher 30.0% which was comparable to the study conducted by Patil K *et al*,(11) where the dependency level was 33.3% and also the study conducted by Bhaskar A *et al*,(12) where the dependency level was 33.6%. The maximum dependency level seen in the Activities of Daily Living in the present study was for dressing 45(22.5%) which in contrast to the study conducted by Sharma *et al*,(10) where dependence was highest for Bathing, i.e. 21.8%, and also in study conducted by Veerapu *et al*,(13) where the maximum dependence for toileting (12.7%) was seen. The study also explored the differences in the Activities of Daily Living (ADL) in male and female elderly but did not find any statistically significant difference. However, a study conducted by Sharma *et al*,(10) and Bhaskar A *et al*,(12) found the dependence levels to be higher among elderly females whereas Milla n-Calenti J *et al*,(14) found males to be more

dependent as per the Activities of Daily Living (ADL). The present study showed that caregivers experienced mild caregiver strain index a median of 3[0-7] when compared to the study done by Hsu T *et al*. (15) where the median caregiver strain was found to be 2[0-13] in caregivers of elderly cancer patients. The cut off of the high level of Caregiver strain index as per the module was said to be a score of 7 or more (16). High levels of caregiver strain were seen in 47(23.5%) of the present study population which was comparable to study conducted by Chow OE (17) which reported 22.9% of them experiencing strain and higher compared to the study done by Hsu T *et al*,(15) 15% which was seen among caregivers of elderly cancer patients. In the study conducted by Dhandapani *et al*,(18) where caregivers of patients of intracranial tumours were interviewed, and the maximum strain was found to be for financial strain 29(41%). However, in our study, though the maximum strain was for financial strain, it was found to be lower in our study 19(9.5%) when compared to the study conducted by Dhandapani *et al*,(18) which probably occurred due to different types of population in the studies. The study conducted by Mehta K (19) in Singapore showed that the modified caregivers strain index (MCSI)was inversely proportional to the ADL scores (-0.348) and was found to be statistically significant, which is comparable to our study which also showed similar results.

Conclusion

The most common domain of dependence in the Activities of Daily Living (ADL) among the elderly attending the health centres was for dressing. Financial strain was the most common domain affected among the informal caregivers of the elderly as per the Modified Caregivers Strain Index (MCSI). The caregiver strain of the informal caregivers of elderly had a significant negative correlation with the level of dependency level of the elderly attending the health centres. Higher the dependence of the elderly, greater is the necessity for evaluation of caregiver strain to ensure the continuum of care for the elderly.

Recommendation

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

Limitation of the study

The limitations of the study were that it evaluated the relation of informal caregiver strain and dependency level in elderly of only who were attending the health centres. The informal caregiver strain may not be the complete estimate of the informal caregiver strain as the informal caregivers of severely dependent elderly cannot visit the health care centres alone without ensuring someone to take care of them. There could have been more than one informal caregiver of the elderly, but we evaluated the caregiver strain of only the informal caregiver who attended the health centre was evaluated for caregiver strain which could have diluted the caregiver strain.

The relevance of the study

This study is probably the first published study in India which explores the relationship of caregiver strain and dependency level of the elderly in India. This study has given insights into the strain experienced by informal caregivers in the context of elderly attending health centres.

Authors Contribution

AMJ: contributed in all the process of the study, RK: contributed in all the process of the study except being the guarantor, KR: Involved in data acquisition and data analysis.

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Tables

TABLE 1 MODIFIED CAREGIVER STRAIN INDEX IN CAREGIVERS OF ELDERLY (N=200)

Caregiver experiences as per Modified Caregivers Strain (MCSI)	Frequency n (%)		
	Yes, regularly	Yes, sometimes	No
My sleep is disturbed	13(6.5)	46(23.0)	141(70.5)
Caregiving is inconvenient	4(2.0)	47(23.5)	149(74.5)
Caregiving is a physical strain	11(5.5)	47(23.5)	142(71.0)
Caregiving is confining	11(5.5)	45(22.5)	144(72.0)
There have been family adjustments	12(6.0)	43(21.5)	145(72.5)
There have been changes in personal plans	3(1.5)	57(28.5)	140(70.0)
There have been other demands on my time	10(5.0)	47(23.5)	143(71.5)
There have been emotional adjustments	14(7.0)	36(18.0)	150(75.0)
Some behaviour of the elderly is upsetting	19(9.5)	39(19.5)	142(71.0)
It is upsetting to find the person I care for has changed so much from his/her former self	13(6.5)	37(18.5)	150(75.0)
There have been work adjustments	2(1.0)	59(29.5)	139(69.5)
Caregiving is a financial strain	19(9.5)	61(30.5)	120(60.0)
I feel completely overwhelmed	18(9.0)	59(29.5)	123(61.5)

TABLE 2 ACTIVITIES OF DAILY LIVING(ADL) OF THE ELDERLY IN THE STUDY POPULATION (N=200)

Activities	The dependency levels of the elderly population				p-value
	Independent Elderly n (%)		Dependent elderly n (%)		
	Male	Female	Male	Female	
Bathing	76(81.7)	84(78.5)	17(18.3%)	23(21.5)	0.571
Dressing	75(80.6)	80(74.8)	18(19.4)	27(25.2)	0.321
Toileting	76(81.7)	90(84.1)	17(18.3)	17(15.9)	0.653
Transferring	78(83.9)	91(85.0)	15(16.1)	16(15.0)	0.819

Continence	81(87.1)	92(86.0)	12(12.9)	15(14.0)	0.818
Feeding	77(82.8)	93(86.9)	16(17.2)	14(13.1)	0.416
Total	68(48.6)	72(51.4)	25(41.7)	35(32.7)	0.376
Chi- square test, statistical significance at P value- 0.05					

TABLE 3 CORRELATION OF THE MODIFIED CAREGIVER STRAIN INDEX(MCSI) AND ACTIVITIES OF DAILY LIVING(ADL) SCORE

	Modified Caregiver Strain Index	p value
Activities of daily living in elderly	-0.557	<0.001*
Spearman's Rho, *p value <0.001		

Figures

FIGURE 1 STRAIN LEVEL IN CAREGIVERS OF ELDERLY AS PER MODIFIED CAREGIVER STRAIN INDEX

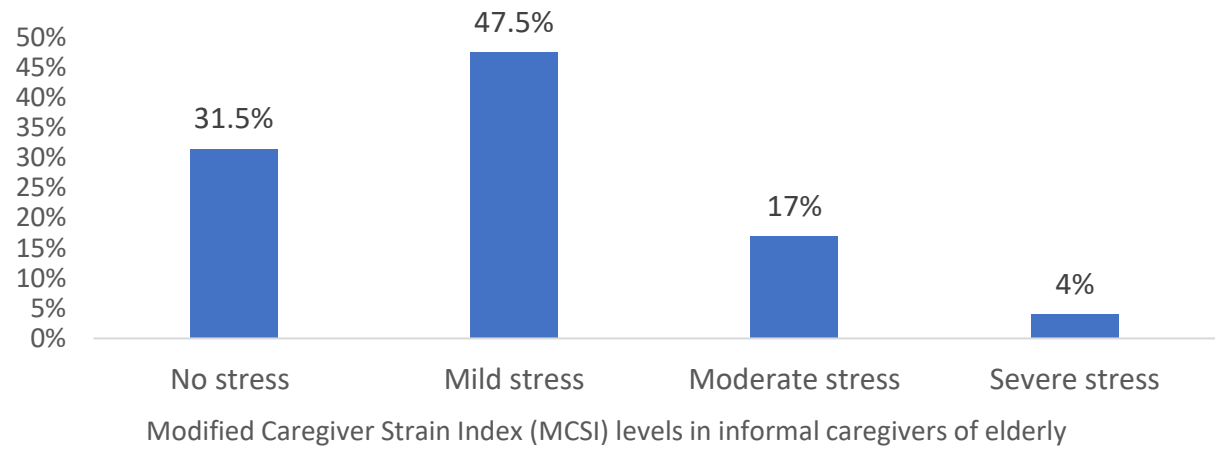

FIGURE 2 DEPENDENCY LEVELS OF THE ELDERLY BASED ON ACTIVITIES OF DAILY LIVING (ADL)SCORES