

# Burden among caregivers of geriatric people in Kavrepalanchok district, Nepal

Manandhar N,<sup>1</sup> Shrestha S,<sup>2</sup> Risal A,<sup>3</sup> Kunwar D,<sup>4</sup> Manandhar K<sup>5</sup>

<sup>1</sup>Nirmala Manandhar, Assistant Professor; <sup>2</sup>Sophiya Shrestha, Nursing Officer, Scheer Memorial Adventist Hospital Medical Institute, College of Nursing, Banepa, Kavrepalanchok, Nepal; <sup>3</sup>Ajay Risal, Professor; <sup>4</sup>Dipak Kunwar, Associate Professor, Department of Psychiatry; <sup>5</sup>Kedar Manandhar, Lecturer, Department of Community Medicine, Kathmandu University School of Medical Sciences, Dhulikhel, Kavrepalanchok, Nepal.

## Abstract

**Background:** Ageing is the natural phenomenal encompassing physical, psychological, and social changes. Today, people are living longer than ever before due to advances in education, technology, medicine, food distribution, and public health. Longevity has also resulted in a care giving burden in the family living together.

**Objectives:** To assess the caregiver's burden among family of geriatric people in Kavrepalanchok.

**Methods:** Analytical cross-sectional study was done to assess the caregivers' burden among family members of geriatric people in Kavrepalanchok. Total sample of 439 was selected using multistage random sampling technique. Among them 21 respondents did not respond. Data were collected from January and February 2019 using validated Nepali version of the Zarit Burden Inventory-22. Descriptive and inferential statistic (t-test and ANOVA) were applied using Statistical Package for Social Sciences 20 version. The scoring  $\geq 21$  on ZBI-22 were considered as burden.

**Results:** The study showed that more than half respondents 256 (58.3%) had no or minimal burden, 183 (41.7%) experienced mild to severe burden while caring the older people at home. There was significant association between caregiver's burden with age, education status, marital status, and occupation respectively.

**Conclusion:** Care giving to elderly is stressful task which affects physical, mental, social, and psychological state of caregivers. Therefore, it would be helpful, if community health organisations could conduct the educational programme for caregivers caring the older family members at home.

**Key words:** Burden; Caregiver; Family; Geriatric.

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## Address for correspondence

Nirmala Manandhar  
Assistant Professor,  
Scheer Memorial Adventist Hospital Medical Institute,  
College of Nursing, Banepa, Kavrepalanchok, Nepal.  
E-mail: [nirmalamanandhar781@gmail.com](mailto:nirmalamanandhar781@gmail.com)

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## INTRODUCTION

Caregiver burden is a "multidimensional biophysical reaction resulting from imbalance of care demands relative to caregiver's personal time, social roles, physical and emotional states, financial, and formal care resources. Worldwide  $\geq 60$  years population is growing faster due to both longer life expectancy and declining fertility. It is expected to grow to two billion by 2050.<sup>1</sup>

International surveys conducted over past few decades have confirmed that caregivers who provide in-home care, experience great deal of stress. However, effective methods for reducing such stress have not necessarily been established.<sup>2</sup> Physical frailty is prevalent syndrome in older adults that increases vulnerability for a range of adverse outcomes including increased dependency and death. Caregivers of older adults experience significant physical, emotional, and financial burden, associated with poor physical and mental health. Additionally, caregivers of frail elderly experience financial and emotional strain

associated with diminished health-related quality of life and life satisfaction.<sup>3</sup>

Many countries are experiencing aging population, and with these changing demographics, there will likely be older people with health and functional decline. While older adults are living longer, burden of chronic disease and functional decline has also grown.<sup>4</sup> Hence, this study was done to assess the caregiver's burden among family of geriatric people.

## METHODOLOGY

An analytical cross-sectional study was conducted from January to February 2019 after taking the ethical clearance from the Institutional Review Committee of Kathmandu University School of Medical Sciences (IRCKUSMS, Ref. 140/80) Dhulikhel Hospital, Kavrepalanchok, Nepal.

Sample size of 439 was calculated by using the formula  $Z^2pq/d^2$  and adding 20% non-response rate 76.<sup>5</sup> Multistage random sampling technique was used to recruit eligible participants.

Out of total 13 municipalities of Kavrepalanchok district, six are urban and seven are rural. During the first stage of multistage random sampling, two out of six (Panchkhal and Banepa) and two out of seven (Chaurani Deurali and Bethanchok) were selected by simple random sampling technique. Second stage, from each selected rural and urban municipality, at least 50% of total wards were selected by lottery method. From the urban municipalities in Panchkhal the wards selected were Ward numbers: 2, 3, 4, 5, 6, 7, and 10 and in Banepa the selected wards were Ward numbers: 5, 6, 7, 8, 9, 10, and 13. Similarly, from rural municipalities in Chaurani Deurali the selected wards were Ward numbers: 2, 3, 6, 8, and 9 and in Bethanchok the selected wards were Ward numbers 2, 3, and 4. Construction of social map and numbering of households having elderly was done with the help of female community health volunteer (FCHV). Then the households were selected using systematic random sampling technique. At last, one elderly and family caregiver of selected elderly were selected randomly. If there were more than one elderly and family caregivers at selected household, only one was selected by using lottery method. Of the potential 460 selected elderly individuals, 13 declined to participate, six had impaired hearing, and two were unavailable. Finally, 439 participated in this study. Thus, the proportion of participation was 95.4%. Data were collected using three different tools. Part one consisted of personal and demographic characteristics. Part two consisted of questions that map the elderly person's comorbidity with

regards to chronic physical health problems. Part three consisted of questions from Zarit Burden Inventory-22-item (ZBI-22) which is a standard tool validated in Nepali. A score of 0 - 20 is considered as little or no burden, 21 - 40 as mild to moderate burden, 41 - 60 as moderate to severe burden, and 61 - 88 as severe burden.

All the participants were informed about the nature, purpose, procedures of study and were free to withdraw from the research at any time. An informed written consent was taken from those participants who could read and write, while fingerprints were collected from those who were illiterate. Data collection was done from January and February 2019 using face to face interview technique. The inclusion criteria included the individual family caregiver of older people, who were involved in the care of older people. If there were two or more caregivers in the family, one of them was selected randomly using lottery method. The participants should live in the Kavrepalanchok district and should be able to speak Nepali. Moreover, caregiver and elderly people who had lost the ability to speak or had major hearing loss or unable to give correct answers to at least two of the three following questions were excluded from the study.

## RESULTS

The study was carried out in 439 family caregivers of older people living in Kavrepalanchok district. Mean age was  $40.59 \pm 12.38$  years. Of the 439 participants, 130 (29.6%) were males. More than half of respondents (282, 64.2%) were literate, and majority (386, 87.9%) were married and living with their spouse. Among them, 83 (18.9%) had hypertension, and 66 (15%) had diabetes mellitus.

The major findings of the study showed that more than half respondents (256, 58.3%) had no or minimal burden, 183 (41.7%) experienced mild to severe burden while caring the older people at home (Table 2).

The association between caregivers' burden with age, marital status, occupation respectively which were found to be statistically significant ( $p$ -value  $< 0.001$ , Table 3). There was significance association between caregivers' burden in relation to education status, the highest mean score was found to be in master level ( $28.60 \pm 18.27$ ) and the least caregiver burden score found in bachelor level ( $13.58 \pm 6.15$ ).

The mean  $\pm$  SD score of family caregiver's burden of older people with hypertension present and absent is  $21.57 \pm 10.92$  and  $91.87 \pm 10.78$  respectively (Table 4). The t-test for variable testing at 5% significance, the

p-value obtained in caregivers burden score was 0.930 which was greater than tabulated value 0.05 which was statistically insignificant in relation to their comorbidities

**Table 1: Socio-demographic characteristics of the caregiver, (N = 439)**

Variables	Frequency (%)
<b>Age group ( in years)</b>	
18-35 (young Adult)	342 (77.9)
36-59 (middle Adult)	53 (12.1)
≥60 (old Adult)	44 (10.0)
<b>Sex</b>	
Male	130 (29.6)
Female	309 (70.4)
<b>Residence</b>	
Urban	217 (49.4)
Rural	222 (50.6)
<b>Marital status</b>	
Single	53 (12.1)
Married living with spouse	386 (87.9)
<b>Education level</b>	
Illiterate	157 (35.8)
Literate	282 (64.2)
<b>Occupation</b>	
Employed	173 (39.4)
Housework	229 (52.2)
Unemployed	36 (8.2)
Retired	1 (0.2)
<b>Relationship with elderly</b>	
Father/mother	161 (36.7)
Father-in-law/Mother-in-law	188 (42.8)
Brother/sister	7 (1.6)
Husband/wife	69 (15.7)
Grandfather/grandmother	13 (3.0)
Fupu/Fupaju	1 (0.2)

**Table 2: Caregiver burden level of respondents according to Zarit Burden Inventory (N = 439)**

Variable	Frequency (%)
No or minimal burden	256 (58.3)
Mild to moderate burden	159 (36.2)
Moderate to severe burden	22 (5.0)
Severe burden	2 (0.5)

**Table 3: Association between caregiver's burdens with different socio demographic variables (N = 439)**

Variable	Mean ± SD	p-value ANOVA Test
<b>Age</b>		
18-35 years	18.95 ± 9.39	
36-59 years		<0.001
≥60 years		
<b>Marital Status</b>		
Unmarried	14.46 ± 6.43	
Married with Spouse	20.32 ± 10.68	<0.001
Separated	28.00 ± 18.33	
Divorced	43.00 ± 0.00	
Widowed	32.00 ± 12.67	
<b>Occupation</b>		
Government	16.50 ± 6.89	
Nongovernment	18.58 ± 9.12	0.002
Self-employ	17.68 ± 8.11	
House work	21.58 ± 11.67	
Unemployed	22.30 ± 3.37	
Retired	3.00 ± 0.00	
<b>Education status</b>		
No formal education	23.27 ± 1.96	
Primary level	22.08 ± 11.04	0.001
Secondary level	17.01 ± 8.53	
Higher secondary level	16.05 ± 6.64	
Bachelor level	13.58 ± 6.15	
Master level	28.60 ± 18.27	
<b>Gender</b>		
Male	19.78 ± 10.36	0.144
Female	20.36 ± 11.01	

**Table 4: Association between caregivers' burdens with disease related variables (N = 439)**

Variable	Mean ± SD	p- value (t-test)
<b>Comorbidity</b>		
Diabetic present	19.98 ± 10.61	0.335
Diabetic absent	20.22 ± 10.86	
<b>Cardiac disease</b>		
Cardiac disease present	21.12 ± 10.36	0.810
Cardiac disease absent	20.13 ± 10.85	
<b>Asthma</b>		
Asthma present	20.06 ± 9.40	0.175
Asthma absent	20.22 ± 11.17	
<b>Gastritis</b>		
Gastritis present	19.11 ± 9.63	0.573
Gastritis absent	20.32 ± 10.88	

Gout present	17.61 ± 6.52	0.373
Gout absent	20.32 ± 10.90	
Hypertension present	21.57 ± 10.92	0.930
Hypertension absent	91.87 ± 10.78	

## DISCUSSION

Care for caregivers should be considered from the first consultations with patients and provided whenever needed, in parallel with the patient's evolution. The approach should be multidisciplinary, with the participation of all the health professionals involved in patient care.<sup>6</sup>

The findings show that more than half of respondents (256, 58.3%) had no or minimal burden, 183 (41.7%) experienced mild to severe burden while caring for the older people at home. This study is consistent with the study done in Malaysia (2015) which showed 78.3% of caregivers of older people with chronic illness had low and 21.7% had high level of burden.<sup>7</sup> The current study showed the mean age of the respondents was 40.59 ± 12.38 years which was significantly associated with the caregivers' burden ( $p < 0.001$ ). This finding is found to be consistent with the findings of the cross-sectional study done in rural lower Egypt (2012) that showed the mean score had significant association with caregivers' burden with the age ( $p = 0.001$ ).<sup>8</sup>

Caregivers' role and responsibility leads to a decline in their physical and mental health, and also it can affect their employment, education, and social life. Lacking in knowledge regarding age related changes such as physiological, psychological, cognitive, and chronic disease conditions might be contributing factors for increased burden level of caregivers. While providing care and treatment, the entire focus is given to the patient and the needs and demands of these family members and primary caregivers are often overlooked and neglected. The vital role played by such family caregivers is well recognised but burden on them is poorly understood. Caregivers' burden is considered a "multidimensional biophysical reaction resulting from an imbalance of care demands relative to caregiver's personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other roles they fulfill."<sup>9</sup>

The work and responsibility in a single family usually comprises of married couple and/or their children. When one of the older adult in a nuclear family falls sick with a disease like cancer, the entire responsibility including

domestic household chores, child-rearing, concomitant professional strains, managing finances coupled with the mammoth task of caregiving falls on the otherwise healthy caregiver. On the other hand, the structure of joint family is such that roles are defined for each member of the family. During a catastrophic period, when a member develops a chronic/terminal illness and is unable to take care of him/her or is in need of assistance, joint family acts as a buffer and the burden is shared by other members. Since, there are more than one member to take care of the patient, therefore, the brunt of care giving does not fall on a single person but is shared by all. These factors might have led to a lower burden among caregivers residing in joint families rather than older people living with only spouse in this study and also that 386 (87.9%) of respondents were married living with spouse and 9 (2.1%) were widow which is significantly associated with the caregiver burden level ( $p < 0.001$ ). This finding is consistent with the study done in family caregivers' burden at cancer hospitals in National Capital Territory of Delhi (2010)<sup>9</sup> that showed there is significant association between marital status and caregiver burden level ( $p = 0.03$ ). This might be similar socio-cultural settings in which the study was conducted. In this study, divorced family caregivers were in the highest burden category, with mean score of 43.00 ± 0.00, than the unmarried caregivers, with the mean score of 14.46 ± 6.43. The higher caregiver burden among divorce caregivers in this study could probably be attributed to the fact that they are expected to assume more self responsibility in terms of taking care of the older people in the family. Unmarried members on the other hand, though relatively free, do not feel obligated to take an equivalent responsibility and consequently may have had a lower burden.<sup>9</sup>

The result of the present study showed that there was significant association between education level and caregiver burden level ( $p = 0.001$ ), which is consistent with the study done by De Sa Neves, (2013) that showed there was association between educational level and caregiver burden level ( $p = 0.04$ ).<sup>5</sup>

The findings of this study were not associated with gender and caregivers' burden level ( $p = 0.144$ ) which is similar to the findings of study done in family of Iranian elderly psychiatric patient which also showed no significant association of gender with the caregiver burden ( $p = 0.18$ ).<sup>10</sup>

The caregivers' burden is higher in caring with older people and increased co morbidities, behavioural and psychological symptoms, level of functional and

autonomy and stage of cognitive disease.<sup>11-13</sup> But the findings of this study showed no significance association with the caregivers' burden level ( $p > 0.05$ ) with comorbidities: 83 (18.9%) had hypertension, 66 (15%) had diabetes mellitus, which is in contrast with the finding of study done in burden and associated factors for caregivers of the elderly in a developing country at local community of Karachi, Pakistan (2016) which showed that 48.4% had hypertension and 30.1% diabetes.<sup>11</sup> This indicates that there are higher cases of hypertension and diabetes. The findings also show insignificant association between comorbidity of elderly and caregiver burden level ( $p = 0.08$ ).<sup>11</sup> In Nepal, there is social obligation to care of older people. Most of the elderly individuals wish to be taken care by their own children. It is because of this concept already set up in their minds which make caregivers feel more responsible towards taking care of their older family members even when the old family members have chronic diseases. This might be reasons of negative association with disease condition in the study.

The very high participation rate (439 out of 460, 95.4%) within the randomly drawn sample, involving random selection of the rural and urban clusters reduced the chances of participation bias. The careful face-to-face interviews ensured hardly any missing data. Support of the FCHVs during the household survey ensured acceptance in the community. The selected sample was found to be more or less representative of the population of Kavrepalanchok district, which again is fairly representative of the nation as a whole. Standardised and validated instrument for Nepal was used as tool.

Limitation of this study was not including physical status of the elderly people. The authors wanted to measure the level of caregivers' burden with this cross-sectional study. The study could not establish causal of burden and its level after certain period. The presence of physical health problems was based on self reports in front of family so that it may be over or under reporting.

## CONCLUSION

The study can conclude that there was significant association between caregivers' burden in age, marital status, education, occupational status of respondents. Care giving to elderly is a stressful task which affects physical, mental, social, and psychological state of caregivers. So, bringing out the educational intervention to the caregiver of older adult is recommended. This study provides a baseline data for further related study on caregiver burden of chronic illness of older people.

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