

Caregiving Burden of Family Caregivers of Older Adults and Perceived Social Support

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ABSTRACT

Introduction: As family is the backbone of providing long-term care for their older adults in Nepal. Prolong caring responsibilities put the family caregivers in a state of exhaustion. One of the elements of that has potential of reducing the effect of stressors among family caregivers is social support. This study aimed to assess the caregiving burden of family caregivers of older adults and their social support status in Toka Municipality of Kathmandu district.

Methods: A descriptive cross-sectional study was conducted for assessing caregiving burden of family caregivers and their social support status after completion of translation English version of six-item cognitive impairment test (6-CIT) questionnaires and social support rating scale (SSRS) into Nepalese language. Non-probability, convenience sampling technique was used while selecting 60 family caregivers of older adults. Data was collected using a structured interview schedule at participants' residences between September and October 2021.

Results: This study depicted that 23.3% of family caregivers of older adults had reported caregiving burden. The content validity index of Nepalese version of 6-CIT and SSRS were 0.90 and 0.75, as measured after consulting with 5 experts' scoring in average. Likewise, 80% of family caregivers perceived moderate level of social support and its calculated Cronbach alpha value was 0.794.

Conclusion: Nearly one-fourth of family caregivers have caregiving burden and nearly four fifth of them perceive moderate level of social support. The Nepalese version of the 6-CIT and SSRS have the acceptable content validity index as well as SSRS has high Cronbach Alpha value. These findings directed the researcher for conducting the main study on factors associated caregiving burden of family caregivers in Nepal.

Keywords: Caregiving burden, family caregivers, older adults, elderly people, social support

INTRODUCTION

Ageing is a global phenomenon which is emerging issues of public health concern.¹ It is well proved that as people get older, they mostly experience an increasing chance of chronic diseases with multimorbidity. High prevalence

of chronic diseases and the increase of physical, intellectual, mental, and sensory limitations among older adults are indications of high demand of long-term care.² Like other countries, Nepal also has high annual growth of older people age 75 and more is 3.8%.³ Nearly two-thirds of older adults have multi-morbidity worldwide

utilizing advanced healthcare services, and 90% have at least one chronic disease.^{4, 5, 6} Likewise, a study reported that the people with chronic diseases are occupying 80% of outpatient services in health care facilities; ultimately increasing the demand of homebased care in Nepal.⁷ Family caregivers urge to engage in long-term homebased care, rising difficulty because of limited healthcare facilities and formal support.^{8, 9} The family members assist their older family members in assisting for activities of daily living and instrumental activities of daily living as well as in health care activities. High demand and continuous heavy load of caregiving for older people may face challenging issues for family caregivers in assisting with activities of daily living and handling symptoms of chronic illnesses.^{7, 10} As limited health care facilities and insufficient formal support, family caregivers often face an extremely taxing challenge in physical and psychological health, or economic condition while providing long-term home-based care for their older family members with a disability.¹¹ While providing care for sick family members over a long period, the family members may feel burden.¹³ Caring responsibility of family caregivers may influence their employment, educational opportunities, finances, and social life.¹⁴

Perceived support means the assessment of the availability of support when it requires that quality of support can be measured by an individual, whereas received support means the nature and frequency of specific support transactions.¹⁵ Caregiving for family members is an excellent opportunity to analyze the status of social support in relation to psychological outcomes¹⁷; as caring for a relative may be a stressful condition that may result negative effects on health and wellbeing of caregivers.¹⁸ Social support includes the moral and material aid offered to individuals from the parents, family members, relatives, friends and neighbors.¹⁹ Social support and collaborative decision making through family meetings are important for health outcomes in family caregivers and older adults.²⁰ It positively influences mental health by relieving negative feelings and increasing psychological well-being

through receiving and perceiving external help.²¹ The perceived social support may be a good predictor of subjective burden. The perception of social support as adequate may be related to appraising a situation as less stressful.²² Social support serves to diminish psychological stress, alleviate emotions, and strengthen resilience.^{23, 24}

Limited studies have been carried out in Nepal which depicted high level caregiving burden among family members of patients with mental illness,^{25, 26, 27, 28} hemodialysis,^{29, 30} spinal cord injuries³¹, and autism spectrum disorders.³² However, the study of family caregivers of the older adults with disabilities³³ was very few. In the context of the Kathmandu valley, specifically Tokha Municipality, older adults with disabilities depend mainly on family members for daily living activities.³⁴ Therefore, the researchers conducted this study to identify the status of caregiving burden of family caregivers of older adults with disability and social support status in Tokha Municipality, Kathmandu.

METHODS

A descriptive, cross-sectional study was conducted among family caregivers of older adults with disability to identify caregiving burden and social support in Tokha Municipality of Kathmandu District. The population aged ≥ 60 years was 9, 688 residing in this municipality.³⁴ Sixty family caregivers of older adults with at least one activities of daily living (ADLs)³⁵ and four or more instrumental activities of daily living (IADLs)³⁶ for 3 months or more were included for this study. This study followed a non-probability convenience sampling technique. The researcher herself identified and recruited eligible respondents using the community leaders and female health volunteers. Family caregivers who could not communicate clearly or obtained score ≥ 11 were excluded.^{37, 38}

A structured Nepalese version of interview schedule was used to collect data. It consisted of five parts. Part I consisted of questions related to sociodemographic characteristics of both family caregivers and their older adults. Part II consisted of the Nepalese version of six-

item cognitive impairment test (6-CIT) Scale developed by Katzman, et al.³⁷ for selecting the family caregivers. It contains a range from 0 to 28; a score of 0-10 indicates intact memory, but a score of ≥ 11 indicates cognitive impairment³⁸. Part III included a checklist to assess impairment in ADLs and IADLs using tools developed by Lawton & Brody. The internal consistency reliability of Nepalese version of ADL scale and the IADL scale were 0.87 and 0.88, respectively.³⁹ Part IV consisted of SSRS developed by Xiao⁴⁰ to assess perceived social support among family caregivers. This scale comprises 10 items and produces a total score ranging from 12 to 66, categorized as low (≤ 22), moderate (23–44), or high (≥ 45) levels of support. The content validity index of Nepalese version of SSR was obtained 0.75 through expert reviewed. Part V consisted of the Nepalese version of the Zarit Burden Interview (ZBI) questionnaire.⁴¹ The internal consistency reliability of 22-item Nepalese version of Zarit Burden Interview Questionnaire was 0.77.³³ This tool consists of 22 items rated on a 5-point Likert scale. Based on established cutoff scores: (1) caregivers with ZBI scores ≥ 21 was classified as having caregiving burden; (2) caregivers with scores ≤ 20 was classified as not having burden.⁴²

Instrument Translation, Content Validity Index of the SSRS and 6-CIT:

First, the English version of SSRS and 6-CIT by following 5 sequential steps, which were forward translation; forward translation synthesis; back translation; harmonization; and calculation of content validity index. For forward translation; two native Nepalese language experts in both English and Nepalese language translated SSRS and 6-CIT by instructing them individually as use short, clear and simplified sentences; use the active voice; use nouns repeatedly; can use additional phrases to ensure understanding of item content; avoid item content that includes possessive forms of words; be specific; not use vague words; familiarize the translator with item content, and avoid more than one verb. With collecting combined work of two translators, the researcher, including both translators, collectively synthesis the contents of both instruments in Nepalese

language. After that another two translators assigned the Nepalese version of SSRS and 6-CIT for back translation into English language. With the collective decisions of the four translators including the researcher herself completed the task of harmonization. Then, the content validity index was conducted by a panel of five nursing experts (one lecturer from Psychiatric Nursing, two associate professors from Adult Health Nursing, one retired professor, and one research expert). The panel independently evaluated the contents of the Nepalese version of 6-CIT and SSRS. The content validity index of 6-CIT and SSRS was found 0.90 and 0.75, respectively.

The Institutional Review Board of Xiangya School of Nursing, Central South University, China, and the Nepal Health Research Council, Nepal, granted Ethical Approval No. 455-202-PhD, on 2nd September 2021 for this study. The formal administrative approval was also granted from Tokha Municipality. With the help of community leaders and female health volunteers, the researcher identified the family caregivers of older adults. Written informed consent was obtained after each respondent was told of the study's aims. The duration of interview was roughly 45 to 50 minutes. Confidentiality was guaranteed by withholding individuals' identity and conducting interviews apart from the older adults by preserving privacy. Respondents got freedom for declining, withdrawing, or rejecting to answer any question at any moment; participation in this research was completely volunteer. Data was collected between September and October 2021. Data was checked daily, coded, and entered in Statistical Package for the Social Sciences (SPSS) version 25.0. Descriptive statistics, including frequency, percentage, mean, and standard deviation, were used for analysis. Cronbach Alpha value of SSR also calculated.

RESULTS

Family caregivers' and older adults' characteristics

Table 1: Information related to Family Caregivers (n = 60)

Family caregivers' related variables	Number	Percent
Relationships with the older adult		
Spouse	5	8.3
Son/daughter in law/grandson	45	75.0
Daughter or son-in-law	7	11.7
Other blood relative	3	5.0
Age (in years)		
18-39	25	41.7
40-59	27	45.0
≥ 60	8	13.3
Gender		
Male	15	25.0
Female	45	75.0
Types of residencies		
Own house	48	80.0
Rented house	12	20.0
Current occupation		
Unpaid work	45	75.0
Paid work	15	25.0
Economic status		
Insufficient for 1 year	34	56.7
Sufficient for 1 year	26	43.3
Types of family		
Joint	54	90.0
Extended	4	6.7
Single	2	3.3
Family members		
2-5 members	38	63.3
≥6 members	22	36.7
Feeling of extra stress: Present	4	6.7
Health problem		
No health problem	44	73.3
Present of health problem	16	26.7
Duration of care		
3months-60 months	40	66.7
61-120 months	13	21.7
≥121 months	7	11.6

Daily caring hours		
1-2 hours	22	36.7
3-7 hours	30	50.0
≥8 hours	8	13.3
Mean caring time per week: 27.13 ±25.03hours		
Duration of sleep		
1-5 hours	11	18.3
≥6 hours	49	81.7
Duration of rest at daytime		
Have rest time 1-2 hours	37	61.7
No rest time	23	38.3

Table 1 depicts 75.0% of family caregivers belonged to own family members with age group of 18-39 years (41.7%) 40-59 years (45.0%) with a mean age of 45.92±14.05 years. Similarly, 75.0% were female and 82.3% lived in their own house. Likewise, 75.0% were involved in unpaid work and 43.3% had sufficient income for 1 year. Almost all (90.0%) belonged to a joint family and composed of 2-5 members (63.7%). Few (7.6%) reported additional stress, two thirds had been caring for 3-60 months, half of them involved in caring for 3-7 hours daily, majority (81.7%) could sleep well and still 38.3% were unable to take rest at daytime.

Table 2: Information related to Older Adults with Disability (n = 60)

Older adults' related variables	Numbre	Percent
Age (in years)		
60 – 69	4	6.7
70 -79	20	33.3
Mean age: 82.58±8.34 years ≥80	36	60.0
Gender		
Male	22	36.7
Female	38	63.3
Marital status		
Unmarried/Single	20	33.3
Married and living with a couple	40	66.7
Status of ADL impairment		
1-2 activities impairment	30	50.0
3-5 activities impairment	23	38.3
Complete impairment	7	11.7
IADLs impairment		
Partial impairment	40	66.7
Complete Impairment	20	33.3
Governmental financial support: Yes	53	88.3
Status of health problems		
One or two problems	33	55.0

Three or more problems	27	45.0
Psychological status		
Memory intact	55	91.7
Memory impaired	5	8.3

Table 2 shows that 60.0% of older adults belonged to age group of 80 or more years and more, 63.3% and 65.0% were females and singlehood respectively. Half of them had ADLs impairment in 1-2 activities, 38.3% and 11.7% had 3-5 activities and complete impairment respectively. Regarding IADLs impairment, 33.3% had complete impairment. Majority (88.3%) of them received senior citizen allowances. More than half (55.0%) of them had one or two health problems, and only 8.3% had memory deficit.

Table 3: Status of Social Support by the Family Caregivers (n=60)

Social support status	Number (%)	Mean±SD	Range
Low (0 – 22)	11 (18.3)	26.88±5.71	18-45
Moderate (23 – 44)	48 (80.0)		
High (≥45)	1 (1.7)		
Total	60 (100.0)		

Cronbach Alpha value 0.794, possible score: 12-66

Table 3 shows that majority (80.0%) of family caregivers perceived a moderate level, nearly one fifth (18.3%) perceived low and only 1.7% had perceived high social support. The Cronbach’s Alpha value of Nepalese version of SSRS was 0.794.

Table 4: Status of Caregiving Burden of Family Caregivers

Burden Status	Score	Number	Percentage
No or mild burden	0 – 20	46	76.7
Moderate to severe burden	21-88	14	23.3
Total		60	100.0

Table 4 shows that more than three-fourths (76.7%) of family caregivers of older adults with disability had no burden, and 23.3% of them had a burden.

Table 5: Association of Care Burden with Family Caregivers’ Related Factors (n=60)

Family caregivers’ related variables	Burden (n=14) No. (%)	No Burden (n=46) No. (%)	p-value*
Relationships with the older adult			
Own family members	12(22.6)	41 (77.4)	0.727
In-law and others	2 (28.6)	5 (71.4)	
Age (in years)			
18-39	7 (28.0)	18 (72.0)	0.654
40-59	6 (22.2)	21 (77.8)	
≥ 60	1 (12.5)	7 (87.5)	
Gender			
Male	2 (13.3)	13 (86.7)	0.290
Female	12 (26.7)	33 (73.3)	

Types of residencies			
Own house	11(22.9)	37 (77.1)	0.879
Rented house	3 (25.0)	9 (75.0)	
Current occupation			
Unpaid work	12 (26.7)	33 (73.3)	0.290
Paid work	2 (13.3)	13 (86.7)	
Economic status			
Insufficient for 1 year	2 (66.7)	1 (33.3)	0.069
Sufficient for 1 year	12 (21.1)	45 (78.9)	
Types of family			
Joined	12 (22.2)	42 (77.8)	
Extended	1 (25.0)	3 (75.0)	0.658
Single	1 (50.0)	1 (50.0)	
Family members			
2-5 members	9 (23.7)	29 (76.3)	
≥6 members	5 (22.7)	17 (77.3)	0.933
Feeling of extra stress			
No stress	12 (21.4)	44 (78.6)	
Having stress	2 (50.0)	2 (50.0)	0.192
Health status			
No health problem	7 (15.9)	37 (84.1)	
Having health problem	7 (43.8)	9 (56.3)	0.038*
Duration of care			
3months-60 months	11 (27.5)	29 (72.5)	
61 or more	3 (15.0)	17 (85.0)	0.281
Daily caring hours			
1-2 hours	1 (4.5)	21 (95.5)	
3-7 hours	10 (33.3)	20 (66.7)	0.031*
≥8 hours	3 (37.5)	5 (62.5)	
Duration of sleep			
1-5 hours	5 (45.5)	6 (54.5)	
≥6 hours	9 (18.4)	40 (81.6)	0.055
Duration of rest at daytime			
Have resting time	6 (16.2)	31 (83.6)	
No rest time	8 (34.8)	15 (65.2)	0.098

*p-value significant <0.05

Table 5 shows caregiving burden of family caregivers was significantly associated with daily care providing hours (p-value 0.031) and health status of family members (p=0.038). Whereas, caregiving burden was not significantly associated with relationship with older adults, age

and gender of family members, type of residency, current occupation, economic status, types of family, numbers of family members, feeling of extra stress, duration of care, duration of sleep and availability of daytime (p-value <0.05).

Table 6: Association of Careburden with Older Adults' Related Factors (n=60)

Older adults' related variables	Burden (n=14) No. (%)	No burden (n=46) No. (%)	p-value
Age (in years)			
60 – 69	1 (33.3)	2 (66.7)	0.633
70 -79	4 (19.0)	17 (81.0)	
≥80	9 (25.0)	27 (75.0)	
Gender			
Male	6 (27.3)	16 (72.7)	0.583
Female	8 (21.4)	30 (78.3)	
Marital status			
Unmarried /Singlehood	3 (15.0)	17 (85.0)	0.281
Married	11 (27.5)	29 (72.5)	
Stats of ADL impairment			
1-2 activities impairment	3 (10.0)	27 (90.0)	0.002*
3-5 activities impairment	6 (26.1)	17 (73.9)	
Complete impairment	5 (71.4)	2 (28.6)	
IADLs impairment			
Partial impairment	8 (20.0)	32 (80.0)	0.388
Complete Impairment	6 (30.0)	14 (70.0)	
Governmental financial support			
Yes	2 (28.6)	5 (71.4)	0.727
No	12 (22.6)	41 (77.4)	
Status of health problmen			
One or two problems	9 (27.3)	24 (72.7)	0.425
Three or more problems	5 (18.5)	22 (81.5)	
Psychological status			
Memory intact	11 (20.0)	44 (80.0)	0.043*
Memory impaired	3 (60.0)	2 (40.0)	

*Fisher exact

Table 6 shows caregiving burden of family caregivers was significantly associated with older adults' impairment status in activities of daily living and their psychological status (p-value <0.05). Caregiving burden was not associated with older adults' age, gender, marital status, status of impairment in IADLs, financial support from government and status of health problems (p-value >0.05).

DISCUSSION

As this study showed, nearly one fourth of family caregivers had caregiving burden. The family

caregiving burden status in current study is slightly higher than the study conducted by Khanal and Chalise³³ in Nepal might be different because of inclusion criteria and settings different. Studies conducted in Nepal among family caregivers of mental illness,^{25, 26, 27, 28} hemodialysis,^{29, 30} spinal cord injuries³¹, and autism spectrum disorders.³² depicted almost all family members had caregiving burden. This study also depicted as possible factors of caregiving burden were family caregivers' health status and their daily caregiving hours as well as older adults' impairment status in activities of daily living and psychological status

of older adults. The study conducted by Khanal and Chalise³³ also supported that functional limitation in activities of daily living of older adults shown as possible factor of caregiving burden.

In contrast to the findings of the current study as majority family caregivers perceived moderate level of social support, the study done in Saudi Arabia found that nearly majority (59.7%) of family caregivers perceived high level of social support while nearly one third (32.0%) had moderate level of social support. This variation could be cultural and religious different between Nepal and Saudi Arabia.⁴³

Therefore, the local government needs to address caregiving burden of family caregivers of older adults with disability. As social support intervention programs showed effective to prevent or alleviate subjective caregiving burden by creating feeling of connectedness among caregivers. This finding supports the need to social support intervention program to reduce caregiving burden in Nepal. promote social support in caregivers to prevent or alleviate subjective burden, and specifically, to intervene on “feeling connected” more than on “building connections” when preventing or alleviating burden.²²

As this study was a pilot study having small sample size, the findings of this study need to be interpreted in the context of its limitations. Since this study followed descriptive, cross-sectional study design, it limits causal inference. This study followed a convenience sampling technique, which may introduce potential biases; so, findings could not be generalized. Because of using structured interview techniques of data collection, there may be reporting bias or recall bias.

CONCLUSION

Nearly one-fourth of family caregivers have caregiving burden. Possible factors of caregiving burden are caregivers' daily caring hours and their health status as well as older adults' impairment status in activities of daily living and their psychological status. Most of the family caregivers perceived moderate levels of social support. So, activities that can increase perceived

high social support need to be carried out in local level. This study established acceptable value of Nepalese version of the 6-CIT and SSRS through expert reviews and found good Cronbach Alpha value of SSRS is also found good. The findings of this study recommend further studies using analytical study design to identify the factors associated with caregiving burden among family caregivers of older adults with disability.

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