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Caregiver burden from caring for dependent elderly in Yangon, The Republic of the Union of Myanmar

May Zun Naing
Department of Community Health Nursing, University of Nursing, Yangon 11131, Myanmar,
mayzunnaing@gmail.com

Sein Yaw May
Department of Community Health Nursing, University of Nursing, Yangon 11131, Myanmar,
syawmay@gmail.com

Min Htike Aung
Department of Community Health Nursing, University of Nursing, Yangon 11131, Myanmar,
umehnha@gmail.com

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May Zun Naing[*], Sein Yaw May, Min Htike Aung

Department of Community Health Nursing, University of Nursing, Yangon 11131, Myanmar

[*]E-mail: mayzunnaing@gmail.com

Abstract

Background: Elderly population and well-being of those are emerging as major challenges for families and communities. This study aimed to identify caregiving burden among caregivers who care for dependent elderly. **Methods**: A cross sectional descriptive study was conducted in Tharkayta Township, Yangon, Myanmar. Total 200 caregivers were selected applying multi-stage sampling method and structured questionnaires were used to collect data. Dependent score of elderly was assessed by using Barthel Index of activities of daily living (ADL) and assessment of caregiver burden through Zarit Burden Interview. **Results**: The results showed that over one fifth of caregivers 21.5% had experienced severe burden, 39.5% had experienced moderate burden, 32.5% had experienced mild burden and only 6.5% had experienced no/little burden. Among elderly population, 11.5% were fully dependent, 40.0% were highly dependent, 46.0% were semi dependent, and only 2.5% were almost independent. Burden of caregivers and dependent score of elderly were negatively correlated (ß = −0.247, p = 0.000) and statistically significant association between age group and burden level (X^2 = 17.335, p = 0.008). **Conclusion**: This study highlighted that community health nurses should emphasize on health education activities regarding caregivers training and home visit program for elderly and their caregivers.

Keywords: caregivers, cross-sectional study, burden, elderly, Myanmar

Introduction

Aging process is natural, and people have to experience the sequence of changes in the passing of the life time. Globally, elderly population occupied 841 million of people in 2013 and it is estimated to increase more than double which is about 2 billion in 2050.[1] Nearly 8 in 10 of the world's elderly population will live in the less developed regions by 2050.[2] Being a developing country, Myanmar is also facing the emerging issue of a growing number of elderly people. Elderly population is about 9.1% of total population (51.48 million) in 2014 with a growth rate of 0.89% over preceding year.[3] The population aged 60 years and above will out-number children under age 15 years in 2035, and in 2050 this group of the population will comprise a quarter of the total population.[4]

In Myanmar, elderly people are supported mainly by families because extended family system has been practiced for many years.[5] Family is an integral part of everyone's life. Thus, elderly care has been the responsibilities of family's members but in these modern societies caregivers have burden from caring for elderly people at home. The main reason for this includes decreasing family size, two-career family and increased life expectancy.[6] Geographical mobility, limited economic capacity and change in attitude about family obligations influence on family support.[7] Meanwhile, there is decline in physical and cognitive functioning in old age.[8]

Caregiver burden comes out when the caregiver perceives a negative experience in home care situation because caregivers are typically not trained.[9] Therefore, caring is a serious challenge for them. Caregivers' burden is a social issue in many countries. Globally caregivers' burden will grow as the world population ages and confronts age-related health conditions, such as chronic diseases.[10]

Caregiver works for many hours in a role, mainly with activities related to bodily care, feeding, elimination, environmental sanitation, health control and other situations, which leads caregivers to experience stressful situations and burdens.[11] The difficulties experienced by caregivers often are considered only after the signs of burnout are apparent.[12] In addition, any financial support cannot be covered for old age security.[13] Moreover, the lack of state-funded infrastructure for the care of elder people may place a greater burden of care on families.[14] In developed countries, government plays a significant role in supporting elder persons whereas in developing countries, the families are the main provider

of care to elder persons.[15] In Myanmar, most of elderly people are totally relied on family caregivers support. In spite of these facts, a limited number of studies was found to explore caregiver burden in Myanmar. Therefore, this study intended to determine the relationship among caregivers' characteristics, dependent elderly and caregiver burden because health care providers including nurses to fulfill the necessary care upon elderly people and their caregivers.

Methods

Study Design. This was an analytical research carried out to determine correlation between burden of caregivers and dependency of elderly. It was done between May 2017 and September 2017 in Yangon, Myanmar.

Participants. Participants who cared for dependent elderly for a minimum of six months, aged between 18 and 59 years, who were willing to participate in this study and who could read and write in Myanmar language were recruited. Participants with mentally ill were excluded. The minimum sample size needed for this study was calculated by using Dainel, 2013.[16] According to previous study, $p = 0.639$, 95% confidence level and absolute precision (d) = 0.07 was assumed.[17] In order to prevent drop outs and refusal rate, 10% was added. Therefore, a total of 200 participants were recruited in this study.

Sampling Method. Multi-stage sampling method was used. First, Tharkayta Township was chosen from Yangon Region by lottery method. Then, four wards were selected out of 19 wards in Tharkayta Township using simple random sampling method. Third, odd number of streets from each ward were chosen as systematic sampling method. Sample was taken by snowball sampling method and 50 caregivers in chosen streets from each selected ward were recruited to reach the required sample size.

Procedures. Approval was obtained from the Research and Ethical Committee, University of Nursing, Yangon in Myanmar and permission was obtained from the authorized person of Tharkayta Township. All potential participants were approached and if they refused to participate and did not meet inclusive criteria, another subject was selected. The researcher explained information sheet and received informed consent form. It took 30–45 mins for each participant to complete the interview.

Demographic Questionnaire. It was developed by the researcher comprising gender, age, occupational status, family financial adequacy, highest education attainment, race, religion, marital status, nature of the relationship with care-recipients and duration of care giving per year or month.

Barthel Index. It was developed by another study[18] and it was last modified in 2009.[19] It evaluated mobility and self-care activities, and its reliability had been validated in various patient populations and societies. The original instrument's Cronbach's alpha coefficient was 0.95 and 0.96. It was consisted of 10 items and 5-point increments was used in scoring, with a maximal score of 100 indicating that a patient was fully independent in physical functioning, and a lowest score of 0 representing a totally dependent. For each item, participants were asked to report on the ability of care recipients to perform the task without help, rated as follows: 0 = unable or dependent, 1=with some help, and 2 = independent. The score was ranged from 0 to 100, where 0–20 points indicated a fully dependent, 21–61 highly dependent, 62–90 semi-dependent, 91–99 almost independent and 100 points a fully independent patient. The original English version was translated to Myanmar version. Then, contents validity tested by five expert nurses and Cronbach's Alpha coefficient was 0.93.

Zarit Burden Interview. It was developed by previous research that consists of 22-items for measuring the caregiver's perceived burden from providing family care.[20] The original reliability was Cronbach's alpha between 0.83 and 0.89. It was assessed on a 5-point Likert scale, ranging from 0="never" to 4="nearly always". Item scores added up to give a total score ranging from 0 to 88, with higher scores indicating greater perceived burden. Cut off points were used to diagnose burden: scores between 61 and 88 were considered to describe severe burden; scores between 41 and 60 expressed moderate burden; scores between 21 and 40 were considered to express mild burden; and scores below 21 points characterized no/little of burden. The questionnaire was translated into Myanmar version and was validated by five expert nurses and Cronbach's Alpha coefficient was 0.83.

Ethical considerations. This study had been approved by Ethical and Research Committee of University of Nursing, Yangon. The researcher explained the objectives, expected risk and benefits of the study and the informed consent form was obtained from each participant before data collection. Participants can withdraw from the study any time without any impact on care. All data was kept confidential and presented in terms of overall outcomes.

Data Analysis. Statistical package for the Social Science (SPSS) version 22.0 was used for data analysis. Descriptive statistics was used to describe frequency, percentage, mean, and standard deviation. Chi squared test was used to find the association between socio-demographic characteristics and caregiver burden. Correlation between dependency of elderly and burden

of caregiver was assessed by linear regression. The significance of results was at 5% level of significance.

Results

The total sample of the study was 200 caregivers, and the vast the majority of caregivers were women 87.5%. The age characteristics of the caregivers where 44.5% were between the age of 46 and 59 years. About 39% were between the age of 32 to 45 years and 16.5% were between the ages of 18 to 31 years. Half of them, 50%, had completed primary and secondary school, 38.5% were high school level and only 12.5% had received a university education. Sixty seven percent of caregivers reported financial inadequacy. Just over 40% of caregivers were unemployed and students. Moreover, most of caregivers over 80% were Burma and Buddhist and just over one fifth were single. Most of caregivers 62.0% were their heir and second cousins were just over a quarter. Overall, the mean duration of caregiving was 5.61±4.87 years Table 1. Nearly half of the elderly 46% were reported that they were semi dependent, 40% were highly dependent, 11.5% were fully dependent and only 2.5% were almost independent Table 2. The mean (±SD) of the burden level was 45.75±16.79 Table 2.

Table 1. Socio-demographic characteristic of the caregivers (N = 200)

| Variables	Number	Percent (%)
Gender		
Female	175	87.5
Male	25	12.5
Age (Years)		
46–59	89	44.5
32–45	78	39.0
18–31	33	16.5
Occupational status		
Unemployed/ Student	82	41.0
Own business/ Seller/ Actor/ Tailor	64	32.0
Government/ Company staff/ NGO/ Daily wages	54	27.0
Financial status		
Not adequate	134	67.0
Adequate	66	33.0
Education status		
Primary / Secondary school level	100	50.0
High school level	77	38.5
University / Master Degree	23	12.5
Race		
Burma	165	82.5
Others	35	17.5
Religion		
Buddhist	170	85.0
Others	30	15.0
Marital status		
Married / Divorced / Widow	157	78.5
Single	43	21.5
Relation to care recipient		
Daughter / Son	124	62.0
Niece / Granddaughter / Grandson / Daughter in law / Son in law	53	26.5
Wife / Husband	23	11.5
Duration of caregiving (years)		
≤ 5 years	125	62.5
> 5 years	75	37.5

Table 2. The dependency level of elderly and the burden levels of caregivers (N = 200)

Dependent level	Number	Percent (%)
Fully dependent (0 to 20)	23	11.5
Highly dependent (21 to 61)	80	40.0
Semi dependent (62 to 90)	92	46.0
Almost independent (91 to 99)	5	2.5
Burden level		
No/Little (0 to 20)	13	6.5
Mild (21 to 40)	65	32.5
Moderate (41 to 60)	79	39.5
Severe (61 to 88)	43	21.5

Table 3 . Association between socio-demographic characteristics and burden of caregivers (N = 200)

Variables	Level of burden (N, %)				Total	p
	No	Mild	Moderate	Severe		
Gender						
Female	12 (6.8)	57 (32.6)	73 (41.7)	33 (18.9)	175	
Male	1 (4.0)	8 (32.0)	6 (24.0)	10 (40.0)	25	0.087
Age Group						
46–59	4 (4.5)	21 (23.6)	35 (39.3)	29 (32.6)	89	
32–45	8 (10.3)	28 (35.9)	31 (39.7)	11 (14.1)	78	0.008*
18–31	1 (3.0)	16 (48.5)	13 (39.4)	3 (9.1)	33	
Occupation						
Unemployed/Student	5 (6.1)	23 (28.0)	36 (43.9)	18 (22.0)	82	
Own business/Seller/Actor/Tailor	6 (9.4)	26 (40.6)	17 (26.6)	15 (23.4)	64	0.246
Government/Company staff/NGO/ Daily wages	2 (3.7)	16 (29.6)	26 (48.2)	10 (18.5)	54	
Financial						
Not adequate	6 (4.5)	40 (29.9)	57 (42.5)	31 (23.1)	134	
Adequate	7 (10.6)	25 (37.9)	22 (33.3)	12 (18.2)	66	0.180
Education						
Primary/Secondary school level	4 (4.0)	29 (29.0)	41 (41.0)	26 (26.0)	100	
High school level	7 (9.1)	27 (35.1)	30 (39.0)	13 (16.9)	77	0.563
University/Master	2 (8.7)	9 (39.1)	8 (34.8)	4 (17.4)	23	
Race						
Burma	12 (7.3)	58 (35.2)	63 (38.2)	32 (19.3)	165	0.153
Others	1 (2.9)	7 (20.0)	16 (45.7)	11 (31.4)	35	
Religion						
Buddhist	12 (7.1)	60 (35.3)	64 (37.6)	34 (20.0)	170	0.142
Others	1 (3.3)	5 (16.7)	15 (50.0)	9 (30.0)	30	
Marital Status						
Married/Divorced/Widow	11 (7.0)	50 (31.8)	61 (38.9)	35 (22.3)	157	0.879
Single	2 (4.7)	15 (34.9)	18 (41.9)	8 (18.5)	43	
Duration of Caregiving						
≤5 years	6 (4.8)	44 (35.2)	51 (40.8)	24 (19.2)	125	0.363
>5 years	7 (9.3)	21 (28.0)	28 (37.3)	19 (25.3)	75	

*p -value < 0.05
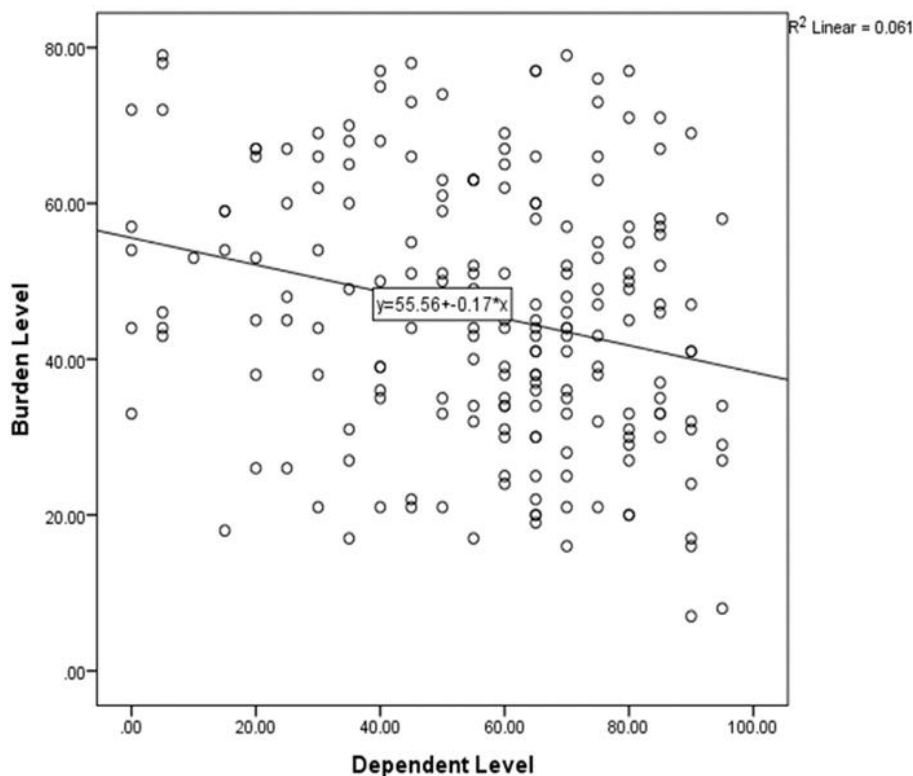
Figure 1. The correlation between burden of caregivers and the dependency of elderly

The caregivers' age (46–59), gender (male), level of education (primary and secondary), caring services more than 5 years, inadequate financial status were feelings of higher caregiving burden in the study group. Age group was statistically significant associated with burden level ($p = 0.008$) Table 3. Figure 1 illustrated that negative correlation was found between burden of caregivers and dependency of elderly (ß = –0.247, $p = 0.000$).

Discussion

The elderly population is increasing not only in Myanmar but also throughout the world. This increasing rate is associated with increases in chronic diseases, the number of dependent elderly and the burden of caregiving.[21] In this study, among the caregivers, (12.5%) were males and (87.5%) were females. Therefore, male to female ratio was 1:7 and there were female predominance than male in this study. Major reason for gender difference might be that caregiving is seen as a feminine duty in Myanmar culture, as is the case for many cultures around the world. Most of the caregivers in our study were women, which is similar to community study was conducted in Egypt, the male and female ratio was 1:6.6.[17] In the Asian Indian context, women are generally more likely to provide care to the elderly and therefore, perception of caregiving is seen women duty likewise in developing country. However,

women are likely to report greater burden than men.[22] In present study, researcher found that women were majority of caregivers, but men perceived themselves as more burdened when faced with the challenge of caring for the elderly. In Myanmar culture, men who are the breadwinners and primarily fulfil responsibilities away from home. In-home caregiving is thus harder for men employed out of the home.

Age group 45–59 years suffered from the more burden than any other age group was found in this study. Statistically analysis showed that there was significant association between age group and burden level. However, a previous study showed a negative correlation between the age of the informal caregiver and the burden, meaning that burden decreases as the age of the caregiver increases. Concerning the literature, results vary as the variable age of the informal caregiver can be positively correlated to burden or negatively correlated to burden.[23]

Other findings from the current study demonstrated that occupational status of caregivers, (41.0%) were unemployment and more than half of them were financial inadequacy. Family with low income can be financial and emotional burden when faced with providing care for the dependent elderly. Brazilian studies have identified the lack of financial resources as one of the main difficulties in caring for dependent

relatives.[24] Some studies showed that caregivers employed in the work force experience less caregiver burden while other research suggested that employment (especially full-time) among caregivers lead to greater burden. Further research found no significant differences between strain in employed and non-employed family caregivers.[25]

Concerning the educational status, half of the caregivers (50.0%) were primary and secondary school level and only (12%) had received a degree or higher education. Similarly, one study stated that the caregivers (92.1%) were primary and secondary school level and only (7.1%) were university education level.[12] The caregivers' educational level did not indicate a strong association related to burden in a study addressing caregivers of demented elderly individuals.[7] In the same way, result from the current study showed that there was no statistical association between educational status and burden level. Single caregivers had lower ZBI scores as compared to married ones. Single persons may have fewer responsibilities, while married caregivers have to cope with their family's problems in addition to those of their parents. One study found that higher burden among married than single that was reliable with the present study.[26]

Result from the present study sons and daughters were the most common caregivers and it was consistent with a previous study, the elderly live with their daughters or sons especially if their spouse is deceased in developing countries because of the traditional social structure.[27]

According to statistics, there was no statistics association between caregiving duration and burden in this study. However, burden increased with the number of years spent by caregivers in caregiving activities. It is thought that, as the duration of caregiving increases, caregivers start to have more problems in providing care.[23]

Almost all elderly were dependent condition in this study. Among them, 46.0% and 40.0% elderly were semi dependent and highly dependent respectively. Twenty three were fully dependent and only 2.5% were almost independent in this study. With the process of population aging and increasing incidence of non-communicable chronic diseases, the cognitive deficit and the loss of functional capacity, dependence on home care becomes progressive, thus becoming an important public health problem.[28] More than 250 million older people around the world experience moderate to severe disability.[29] There are more than 40 million older people in low- and middle-income countries.[30]

The mean burden score for this sample was 45.75±16.79 with (39.5%) of the respondents suffering from moderate burden, (32.5%) were mild burden and (21.5%) suffering from a severe burden. Only (6.5%) were no/little burden. Most of studies that used the ZBI, reported a mean burden level of 29.9±9.3,[31] suggesting that the caregivers in this study were more burdened than those in a variety of other caregiving studies. A study was conducted to target all impaired elderly and their principal caregivers found that burden among family caregivers was mean burden score 35±14.[17]

Each item of the burden interview scale was analyzed, and higher scores were found in other study question numbers 7, 8, 14, and 20.[32] In current study, caregivers presented the highest proportion of the answer always feel overwhelmed when responding to question numbers 8, 14, 20 and 21 related to feel relative is dependent on you and feel you should be doing more for relative. Therefore, data showed that caregivers felt that they needed to do more that they care for and elderly relied on caregivers.

This study revealed that there was negative correlation between dependent level and caregiver burden. One previous study discovered that care giving activities statistically significant negative correlation between burden score and ADL score.[33] The other study result revealed that the greater the dependence of the elderly individual, the greater the chances of the caregiver being burdened.[11]

The above findings have several implications for the care of dependent elderly and their families. Elderly suffering from chronic diseases and have experienced dependent conditions are more and more expected to be taken care of at their home by family members. Therefore, care giving can be very challenging and can lead to burden with potential negative consequences on both the caregiver and the care receiver.

Conclusion

Although almost all caregivers suffered from burden conditions, this study revealed that there was negative correlation between elderly functional disability and the level of the burden. Further researches are needed to completely understand the entire process of caregivers' burden. In order to maintain their health, elder's families should be trained and educated related to the principle of home caregiving and the healthy lifestyle. Taken as a whole, these finding provide support for emphasizing early community interventions through redesigning in-home services that better meet the social needs of dependent elderly and provide more efficient respite to caregivers.

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Conflict of Interest Statement

There were no conflicts of interest.

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