Original article

Caregiver Burden: Prevalence and Effect on Productivity among Adult Informal Caregivers of the Elderly in Klang Valley, Malaysia

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Abstract

Background: Caregiver burden refers to the physical, financial and psychosocial hardships of caring for a loved one. Informal caregivers, typically adult children who look after their elderly parents, shoulder an unspoken degree of stress from this filial responsibility. They report having to make major life changes and personal sacrifices. High degree of caregiver burden among working adults potentially affects their productivity at work. This study aimed to identify the prevalence of caregiver burden among adult family caregivers of elderly in Klang Valley, Malaysia and to determine the effect on work productivity. **Methods:** This cross-sectional study was performed on 281 adult family caregivers using a self-administered questionnaire. A short version of Zarit Burden Interview (ZBI-12) was employed to measure caregiver burden. Work Productivity and Activity Impairment as adapted for caregiving (WPAI: CG) was used to measure work productivity as well as regular activities. **Results:** Adult caregivers in Klang Valley reported experiencing moderate level of burden (ZBI-12 score =15.30) in providing care to their elderly. Employed caregivers reported an overall work productivity loss of 57.2% due to caregiver burden. The study subjects experienced 35.2% loss of regular activity productivity

and it significantly correlated with the degree of caregiving burden ($r = 0.499$, $p < 0.05$). Factors affecting caregiving burden include ethnicity of caregivers ($p<0.05$) and care recipients ($p < 0.05$), education level of caregivers ($p = 0.003$), overall health status of caregivers ($p = 0.006$) and care recipients ($p = 0.047$), family relationship of caregivers with the elderly ($p = 0.002$) and living arrangement of the elderly ($p = 0.005$). **Conclusion:** Informal adult caregivers of the elderly in Klang Valley experienced moderate level of caregiver burden and it significantly affected their work productivity.

Keywords: caregiver burden, stress, elderly, work productivity.

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Introduction

According to the Fifth Malaysian Population and Family survey, 95.3% of community-dwelling elderly receive care support from their family[1]. Family members are often the primary caregivers providing informal care to their elderly parents on a voluntary basis[2]. They are not formally trained nor have contract responsibility as in the case of housemaid and nurses. They perform a wide range of care tasks without time limit, including personal care, household chores and emotional support. With these filial duties, informal caregivers are very likely to encounter hardships in elderly caregiving and be subjected to stress. The duty of elderly caregiving is much more difficult for adult

caregivers who are employed as they are forced to juggle multiple roles at the same time.

Caregiver burden is described as an 'illness' for informal caregivers with imbalance of emotional, physical and financial demands [3]. The concept of caregiver burden is multi-dimensional and can be characterised as subjective and objective[4]. Subjective burden deals with the ways the caregivers perceive the care, which is related to their physical and psychological well-beings[4]. Zarit Burden Interview (ZBI) is the most frequently used instrument to measure subjective burden among informal caregivers of the elderly [5]. The 12-items short version ZBI (ZBI-12) was developed by Bédard et al.[6] with improved internal consistency compared to the original version.

A recent study by Ciccarelli and Van Soest[7] noted that caregiving negatively affected the employment status and work performance of caregivers. Longacre et al.[8] reported 39.8% of unemployed caregivers of older adults quit or retired early from their workforce and 52.4% employed caregivers experienced work interference due to caregiving responsibility. The study subjects also reported higher levels of emotional stress. Work productivity can be quantitatively described in terms of 'presenteeism' and 'absenteeism' [9]. Absenteeism refers to the time missed from work due to certain contributing factors. Meanwhile, presenteeism is the estimation of 'productive output' of an individual under the same exposure of those factors [9]. Work Productivity and Activity Impairment adapted for caregiving (WPAI: CG) is the first validated instrument to study the impacts of caregiving on work productivity and regular activity. It is duly validated among informal caregivers of chronically ill older adults.

This study aimed to identify the prevalence of caregiver burden among adult informal caregivers of the elderly in Klang Valley, Malaysia as well as to study the effect on both work productivity

and regular activities. We also analysed the association between caregiver burden and socio-demographics of informal caregivers, care recipients as well as characteristics of informal care situation respectively.

Materials and Methods

Study Design: This is a cross-sectional study using self-administered questionnaire. The inclusion criteria are adult informal caregivers aged between 18 to 64 years old, staying in Klang Valley, Malaysia and provided informal care to at least one elderly in their family on voluntary basis. This study excluded paid caregivers, including housemaids and nurses (i.e. formal caregivers). If the study respondents had more than one care-recipients, only one elderly they cared for the most was considered in this study.

Study Instrument

The survey instrument comprised of two parts, the validated ZBI-12 and WPAI:CG questionnaires. Scores on the ZBI-12 were used to classify the degree of burden by quartiles: no burden (scores between 0 to 3), mild burden (scores between 4 to 9), moderate burden (scores between 10 to 16) and high burden (score of 17 or above, up to 48) [6].

WPAI:CG instrument was used to measure four aspects of productivity (i.e. absenteeism, presenteeism, overall work productivity loss and regular activity productivity loss) [10]. Employed caregivers, including those who were self-employed, recalled the number of hours they missed from work for the past seven days due to caregiving and other reasons such as sick day. They also rated how caregiving affected their productivity on a scale of '0' to '10', with '0' referring to caregiving had no effect on work, and '10' referring to caregiving completely prevented them from working. The regular activity productivity loss of respondents was also scored on a scale of '0' to '10', with '0' referring to caregiving had no effect on regular activities, and '10'

referring to caregiving completely prevented them from performing regular activities [10]. The unemployed caregivers were asked whether they had to quit or retire from their job due to caregiving.

The questionnaire was designed in three major languages, e.g. Malay, Chinese and English to increase response rate and reduce potential reporting bias in data collection.

Sampling Method and Setting

Based on the Cochran's formula, the estimated sample size was 270 subjects with 90% confidence interval.

Random cluster sampling was employed to collect samples from ten municipalities of Klang Valley, i.e. Kuala Lumpur, Putrajaya, Shah Alam, Klang, Petaling Jaya, Subang Jaya, Ampang Jaya, Kajang, Sepang and Selayang. Subjects were approached in public places such as shopping malls, open markets, recreational parks and office areas. The questionnaires were then distributed if they consented to take part in the study. Nearly equal number of samples were collected from each cluster to ascertain fair representation of the population.

A total of two hundred and eighty-one subjects were included from August 2018 to September 2018.

Data Validity and Reliability

All three versions of ZBI-12 and WPAI: CG have officially been validated and approved to be used in this study. The English version of ZBI-12 is available from the published article by Bédard et al.[6]. The validated Malay version of ZBI was obtained from the original author with permission [11]. The validated Chinese version of ZBI-12 was adopted from the published article by Ko et al.[12]. WPAI-CG instrument adapted in this study was originally developed by Giovannetti et al.[10] in English. Chinese and Malay version of WPAI: CG were adopted from their official versions of WPAI: GH (General Health) [13,14].

A pilot study consisting of 30 randomly chosen respondents was conducted prior to the index study that yielded a Cronbach's alpha value of 0.782. The reliability test conducted on a sample size of 270 respondents achieved a good internal consistency with a Cronbach's alpha value of 0.885 [15].

Statistical Analysis.

Standard descriptive analysis was performed to summarise the demographic profile of study respondents and care-recipients. The prevalence of caregiver burden was computed as mean total ZBI-12 score. Presenteeism, absenteeism, overall work productivity loss and regular activity productivity loss of the respondents were calculated based on the formulae adopted from Giovannetti et al.[10]. Overall work productivity loss of employed caregivers was calculated from absenteeism, presenteeism and percentage of hours actually worked in seven days preceding study participation [10].

Spearman rank-order correlation analysis was conducted to determine the associations between total ZBI-12 score and absenteeism, presenteeism, overall work productivity loss and regular activity productivity loss of study respondents. This analysis was also applied to determine the relationship between total ZBI-12 score and socio-demographics of caregivers (i.e. age, overall health rating), overall health rating of care-recipients, duration of care and intensity of care. Mann-Whitney and Kruskal-Wallis tests were performed to compare the total ZBI-12 score across various characteristics of caregivers (i.e. gender, employment status, types of employment, nationality, ethnicity, highest education level, marital status), care-recipients (i.e. gender, ethnicity, relationship with caregivers) and living arrangement of care-recipients.

All statistical analyses were performed using Statistical Package for Social Sciences (SPSS) Version 22.0. For all analyses, a P

value of less than 0.05 was considered to indicate statistical significance.

Ethics Approval

This study was approved by the SEGi University Ethics Committee (Approval Code: SEGi/RIMC/FOP/18/2018). Written informed consent was obtained from all study participants prior to survey enrolment.

Results

Demographic of Respondents, Care Recipients and Informal Care Situation

A total of 281 subjects were included in the study. Majority of respondents were female (58.4%), Malaysian (99.3%) and of Bumiputera ethnicity (52.7%). Of the 179 employed respondents (63.7%), 48% were working full-time (N=135), 12.1% self-employed (N=34) and 3.6% were employed part-time (N=10). Among 102 respondents who were not working, 11.8% quit or retired early from their previous job due to caregiving. The study respondents rated their own health status with an average of 7.9 (SD = 1.68) on a scale of ten.

The demographics of the elderly receiving care was vastly skewed towards female (67.3%) of Bumiputera background (53.0%). At the time of the survey, the respondents rated the health status of their elderly (i.e. parents, grandparents, spouse, other relationships) a low score of 4.53 on a scale of ten.

The study respondents reported to have spent an average of 59 months (SD=78.65) rendering informal care to their elderly, clocking in about 7.7 hours per day (SD=6.31) for caregiving.

Table 1: Demographic of respondents, care recipients and informal care situation.

Characteristics	N	Percentage (%)	Mean ± SD	Median (IqR)

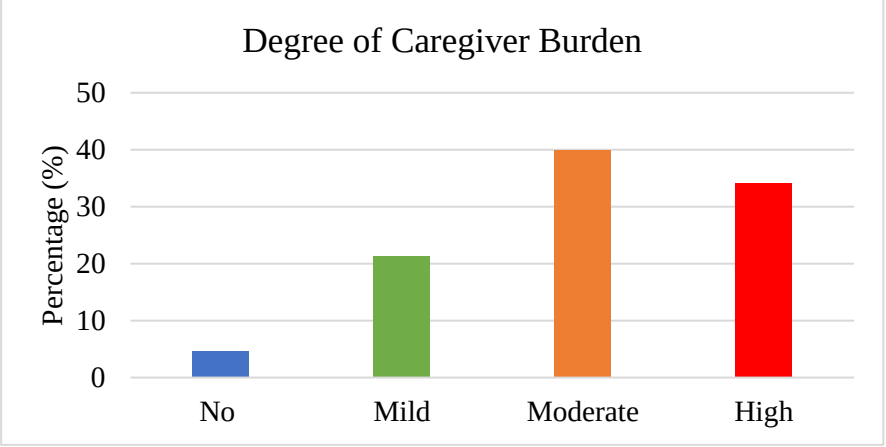
Caregiver gender				
Male	117	41.6	NA	NA
Female	164	58.4		
Caregiver age	281	NA	35.5 ±12.05	34 (19)
Caregiver ethnicity				
Bumiputera	148	52.7		
Chinese	96	34.2	NA	NA
Indian	35	12.5		
Others	2	0.7		
Caregiver nationality				
Malaysian	279	99.3	NA	NA
Non-Malaysian	2	0.7		
Caregiver educational level				
Primary school	16	5.7		
Secondary school	109	38.8		
Pre-university education	57	20.3	NA	NA
Undergraduate education	80	28.5		
Postgraduate education	17	6.0		
Others	2	0.7		
Caregiver marital status				
Never married	115	40.9		
Married	160	56.9	NA	NA
Others	6	2.1		
Caregiver current employment status				
Working	179	63.7	NA	NA
Not working	102	36.3		
Types of employment status				

Employed, full time	135	48.0		
Employed, part time	10	3.6		
Self-employed	34	12.1	NA	NA
Unemployed	38	13.5		
Student	54	19.2		
Retired	8	2.8		
Others	2	0.7		
Quit or retire early due to caregiving				
Yes	12	11.8	NA	NA
No	90	88.2		
Overall health rating of caregiver	281	NA	7.9 ± 1.68	8 (3)
Care recipient gender				
Male	92	32.7	NA	NA
Female	189	67.3		
Care recipient ethnicity				
Bumiputera	149	53.0		
Chinese	94	33.5	NA	NA
Indian	36	12.8		
Others	2	0.7		
Family relationship of caregivers with care recipients				
Parents	154	54.8		
Spouse	5	1.8	NA	NA
Grandparents	112	39.9		
Others	10	3.6		
Overall health rating of care recipient	281	NA	4.5 ± 2.25	5.0 (3.0)
Living arrangement of elderly				
Live along with caregiver	167	59.4	NA	NA
Live apart from caregiver	114	40.6		

Duration of care (months)	281	NA	59.0 ± 78.65	24.0 (66.0)
Intensity of care (hours per day)	281	NA	7.7 ± 6.31	5.0 (6.5)

Note. N = Frequency. SD = Standard deviation. IqR = Interquartile range. NA = Not applicable.

Graph 1: Degree of caregiver burden



Caregiver Burden

The mean ZBI-12 score recorded among our study subjects was 15.3. This corresponds a caregiver burden of moderate intensity. Figure 1 shows the distribution of burden perceived by the study respondents.

Work Productivity and Activity Impairment

Employed caregivers of the elderly reported to experience various degree of work interference due to their filial duties, specifically 27.5% of absenteeism and 34% of presenteeism. This translates

to a substantial work productivity loss of 57.2% and an overall loss of regular activity productivity of 35.2%.

As shown in Table 2, spearman correlation tests showed positive correlation between ZBI-12 score and presenteeism ($r = 0.447$, $p < 0.05$), overall work productivity loss ($r = 0.335$, $p = 0.001$) as well as regular activity productivity ($r = 0.499$, $p < 0.05$).

Associations between Caregiver Burden and Characteristics of Caregivers, Care Recipients and Care Situation

Caregiver burden was inversely associated with the health status of the adult caregivers ($r = -0.148$, $p = 0.006$) and the elderly they were rendering care for ($r = -0.1$, $p = 0.047$). Caregivers with Chinese background reported the highest burden (ZBI-12 score = 17.00) and it was significantly different from those of Bumiputera caregivers (ZBI-12 score = 11.00, $p < 0.05$). Kruskal-Wallis test showed there were significant difference in caregiver burden sustained by caregivers of different educational backgrounds ($p < 0.003$).

Caregivers who were spouses of the elderly reported to experience statistically significant burden (ZBI-12 score = 34) compared to other family relationships. Respondents who were the children or grandchildren taking care of their elderly reported significantly lower burden ($p = 0.012$ and $p = 0.025$ respectively), compared to those who had other family ties with the care recipients (e.g. relatives).

Table 2: Spearman correlation between total ZBI-12 score and work productivity as well as regular activity productivity.

	r	*p*
Absenteeism	0.023	0.415
Presenteeism	0.447	<0.05

Overall Work Productivity Loss	0.335	0.001
Regular Activity Productivity Loss	0.499	<0.05

Note. r = correlation coefficient. *p* = significance

Table 3: Association between caregiver burden with socio-demographics of caregivers, care recipients and care situation.

	r	M	*p*
Overall health rating of caregiver	-0.148	NA	0.006
Caregiver ethnicity			<0.05
Bumiputera	NA	11.00	
Chinese		17.00	
Indian		12.00	
Others		7.00	
Caregiver highest education level			0.003
Primary education	NA	20.00	
Secondary education		11.00	
Pre-university education		12.00	
Undergraduate education		16.00	
Postgraduate education		13.00	
Others		21.50	
Overall health rating of elderly	-0.100	NA	0.047
Care recipient ethnicity			<0.05
Bumiputera	NA	11.00	
Chinese		17.00	
Indian		11.50	
Others		12.00	
Family relationship of caregiver to care recipient			0.002
Parent	NA	12.00	
Spouse		34.00	
Grandparent		13.00	
Others		27.50	

Living arrangement of elderly			0.005
Live along with caregiver	NA	14.00	
Live apart from caregiver		12.00	

Note. r = correlation coefficient. M = Median. *p* = significance. NA - Not applicable.

Discussion

In this cross-sectional community-based survey that directly analysed the prevalence of caregiver burden and its impact on work productivity, we found that the degree of caregiver stress experienced by employed caregivers in the metropolitan city of Klang Valley, Malaysia, was deeply concerning. Based on the self- administered Zarit Burden Interview (ZBI-12) questionnaire, the level of caregiver burden among the 281 study subjects was recorded to be of moderate intensity. Furthermore, this largely underrated stressor was also shown to significantly affect the work productivity of these employed caregivers. These findings concur with works of Longacre et al.[8] and Abu Bakar et al.[16] in their respective studies whereby caregiving was shown to negatively affect work performance of employed subjects leading to work-care conflicts.

As with many Asian societies, filial piety has a deep-rooted cultural significance in Malaysia [17,18]. With intergenerational co-residence being a very common yet integral attribute of Asian families [19], family members naturally shoulder the responsibility of caring for their elders.

Often unprepared and/ or inadequately trained, these informal carers take on a tough and daunting task of looking after their frail parents/ grandparents which could result in undue stress and anxiety. Over time, this could overspill into their work performance and affect their productivity at work.

In our study, the respondents acknowledged to an overall work

productivity loss of 57.2% exclusively due to their responsibilities of providing care to their elderly parents/ spouses in the household. This loss of work productivity was linearly associated with the degree of burden endured by the study respondents. In other words, the greater the burden of caregiving, the higher the loss of productivity at work.

Absenteeism [20,21], crudely defined as habitual absence from scheduled work, due to caregiving was calculated to be 27.5%. Although there was a weak correlation between absenteeism and the degree of caregiver burden, it was not statistically significant. On the other hand, presenteeism, a more complex variant of unproductivity, was recorded at 34%. Not surprisingly, presenteeism was positively associated with the level of caregiver stress in our study.

Presenteeism is characterized by employees not being fully functional in the workplace despite coming to work, due to impaired physical or psychological health issues [22]. In the case of informal caregivers, caring for their loved ones understandably takes a toll on their emotional wellbeing, which in turn could have an adverse impact on their presence of mind and hence, poor efficiency at workplace.

These staggering numbers are a serious cause for concern and acutely reflect an unmet need of our working adults who are clearly overwhelmed juggling between work and rendering care to their elderly. The economic repercussions of these statistics would be an interesting facet to explore to accurately valuate and monetise these intangible costs of informal care provision.

Our results are consistent with the findings by Wolff et al.[23] wherein caregiving had no significant effect on absenteeism but greatly reduced the overall work productivity and performance while at work of those employed caregivers.

Elsewhere, studies have also shown that care provision in a family negatively influences the employment experience and income of employed caregivers with lesser chance of job promotion [16].

Caregivers require time and energy to care for their loved ones. However, when they are at work, they are unable to fulfil their responsibility adequately. As a result, some caregivers are forced to quit or retire early from their job and focus more on caregiving. In our study, 11.8% of the unemployed respondents admitted to leaving their career due to their filial duties. The socioeconomic security of these caregivers as well as the care-recipients remains to be evaluated.

It is interesting to note that there was a significant difference in the caregiver burden perceived by the various ethnic groups in this country, with the Chinese reporting highest level of burden and the Bumiputera carers the lowest. This could in part be explained by the cultural differences between these two societies. Most of the Bumiputera in this country are Muslims and one of the principle teachings in Islam is to be respectful, patient and tolerant when dealing with the elderly [24]. This underpins a strong filial piety whereby they faithfully accept caring for their elderly as a responsibility, and thus see it as less of a burden.

Elsewhere, Ting and Woo[25] had noted that there is an increase in nuclear families among the Chinese which may have weakened the traditional extended family support. Changes in family values between younger and older generations could also contribute to the waning traditional Chinese culture of filial propriety.

The health status of the caregivers as well as the care-recipients had a significant correlation with the perceived burden of care. The poorer the health status of the carers or their recipients, the

greater the burden of care. The finding echoes the premise that the physical and mental health of the caregivers affect their competency in providing the necessary care for their elders [26]. This could serve as a focus area in implementing strategies to alleviate the burden of caring for their elderly.

Similarly, the health condition of the care recipients is also an invariable stressor that compounds the degree of burden borne by the carers [27]. In a study among caregivers of the elderly with chronic illnesses, Ghazali et al.[28] reported that caregiving for elderly with greater functional dependence was seven times more burdensome.

In our study, spousal caregivers experienced the greatest caregiving burden among all because they are considered as the primary caregiver in a family. They tend to perform more care tasks and spend longer time for caregiving without pressuring their children[29]. As observed by Giovannetti et al.[10], co-residing caregivers experienced a greater reduction in work productivity compared to those who lived apart from their care recipients. This is because they are engaged more in the caregiving duties thus affecting their work hours[30].

Elderly caregiver burden could escalate to a serious socioeconomic issue if it is not addressed in a timely manner. Prolonged mental strain endured by these caregivers could lead to chronic stress and eventually burnout. It is therefore imperative that social programmes are put in place to raise awareness about caregiver burden and strategies are individualised to educate the carers on appropriate coping mechanisms.

The strengths of this study include a community-based design with adequate sample size, using validated survey instruments. To our knowledge, this is the maiden study in Malaysia that

directly assessed the prevalence of caregiver stress of the elderly and the impact on productivity at work.

Several limitations need to be acknowledged. The possibility of confounding by unmeasured or unknown factors cannot be excluded. Also, our study may not be generalisable to the entire Malaysian population as it was conducted within Klang Valley.

Conclusion

In conclusion, informal caregivers of elderly in Klang Valley, Malaysia reported to experiencing moderate level of caregiver stress, that was significantly associated with overall work productivity and regular activity productivity loss. The prevalence of absenteeism and presenteeism was recorded at 27.5% and 34%, respectively with the latter having significant correlation with the degree of caregiver burden. The welfare of informal caregivers in this country needs to be addressed via social or individually tailored programmes as to safeguard the socioeconomic health of our nation.

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