

RESEARCH ARTICLE

Caregivers' burdens and its' association with activities of daily living performance of individuals with stroke: A cross-sectional study

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Abstract:

Stroke leads to disability and has become the leading cause of dependence in daily life activities. Caring of individuals with stroke requires a lot of energy, time and resources to fulfil the individuals' needs. This situation leads to burdens and strains to the caregivers. There is a limited study on the relationship between Activities of Daily Living (ADL) performance of stroke's individuals with caregivers' burdens in literature. Thus, the aim of this study was to examine the association between ADL performance of individuals with stroke and the caregivers' burdens. A cross-sectional study was conducted with 59 individuals with stroke and their caregivers aged ranged from 20 to 86 years old. It was found that there was no significant correlation between the ADL performance of the individuals with stroke and the caregivers' burdens. However, there was a significant association found between caregivers' burdens and the duration of having the stroke ($p=0.030$). This study suggests that caregivers' burden is not associated with dependency level in ADL of individuals with stroke, but the duration of having the stroke does.

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Keywords: Activities of daily living, caregivers' burden, stroke

1. INTRODUCTION

There was a rise in the incidence and prevalence of stroke in Malaysia between 2010 to 2014 [1]. More than half of stroke survivors have initial mobility deficits and more than 30% of the survivors are unable to ambulate by themselves six months after the stroke [2]. This situation limits the individuals' ability to perform Activity of Daily Living (ADL). Some individuals with stroke require care from family members or professional caregivers [3]. A huge physical, mental, and financial burden for the individuals, their families, and society might be contributed by the long duration of disabilities [4]. A study reported individuals' functional status (ADL) was found to be one the strongest predictors of total burden among Polish populations [5].

Malaysian has a unique culture in terms of value, norms, and customs, which would result in a different finding on caregivers' burdens. The diversity in ethnic and races, which have different religion and beliefs in Malaysia will have an influence on the level of burden among caregivers. A study suggested that non-white caregivers have lower levels of caregiver stress, burden and depression as compared to the white caregiver [6]. Therefore, findings from previous

studies lead to further exploration given the multi-ethnic and culture of the Malaysian population.

Sociodemographic data of caregivers and individuals with stroke also influence the caregivers' burdens. Previous studies indicates that female gender, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver are risk factors for caregivers' burdens [7–10]. Malaysian caregivers would have different results pertaining to caregivers' burdens, especially when culture and racial factor is considered.

Performances in ADL may influence the level of caregivers' burdens. Caregivers who experience high levels of burden were reported to have deteriorations in psychological well-being and overall quality of life [11]. Therefore, it is important to enhance ADL performance of individual with the stroke, which directly can reduce the caregivers' burdens. Occupational therapist needs to play a significant role not only in improving the ADL performance among individuals with stroke, but also to decrease the caregivers' burdens and also improve their quality of life.

A significant amount of time spent, financial resources and energy are the characteristics of caregiving; to extend in which the stroke' individuals or care receiver being dependent on the effort of caregivers to the point where it exceeds the normal care. Due to lack of other available alternatives or due to the strong wish of the caregivers to stays in a home setting, close relatives and spouses were often involved in caregiving over longer periods and they performed it voluntarily. Displeasing activities such as helping an incontinent individuals with bladder management or helping a physically impaired in transferring can be physically exhausting as it was part of caregiving tasks [12]. However, most studies conducted in Malaysia were on the burden of the caregivers and the underlying factors for the burden, and the coping strategies for the caregivers, but there is limited study on the association of dependency level in ADL and caregivers' burdens in taking care individual with stroke.

Therefore, the aim of this study was to identify the relationship between the level of ADL performances of individuals with stroke and the caregivers' burdens in Malaysia. This study also explored the association between sociodemographic characteristics of caregivers with stroke's individual ADL performance and burden.

2. MATERIALS AND METHODS

2.1 Design

A cross-sectional survey was conducted to 59 individuals with stroke and their primary caregivers from January to May 2019. This design was chosen because it allows researchers to investigate associations between contributing factors and the outcome of interest, which is caregivers' burdens [13]. Besides, a cross-sectional study is generally quick, easy, and cheap to perform and it is often based on a questionnaire survey [14], [15]. This study was conducted at few branches of the National Stroke Association of Malaysia (NASAM); Petaling Jaya, Ampang, Melaka, Johor Bahru and Ipoh. Ethical approval from Ethic Committee Universiti Teknologi MARA (UiTM) has been obtained to conduct this study (Approval no: 600-IRMI 5/1/6). Approval to collect data in the NASAM settings has been granted by the NASAM headquarters. Confidentiality and anonymity of the participants were guaranteed to ensure the privacy of their information

2.2 Sampling

The participants involved in this study were individuals with stroke and their caregivers. Purposive sampling was used to recruit them in this study. Individuals with stroke who fulfilled the following criteria; (i) a confirmed diagnosis of stroke from medical professionals; (ii) absence of other disabling and/or psychiatric conditions; (iii) and independent in activities of daily living (ADL) before stroke were included in this study. They were excluded if; (i) have other associated neurological problems; (ii) stay in the hospital or long-term care facilities; (iii) have a severe communication impairment; (iv) have an unstable condition; (v) and refuse to participate in the study. As for caregivers, the inclusion criteria were; (i) the main person engaged in the caregiving (ii) does not receive any payment for providing care; (iii) and does not provide long-term care for another person at the

same time, The caregivers were excluded if; (i) they refused to participate, (ii) have severe cognitive and/or communication impairment; and (iii) could not read and understand Malay to complete Zarit Burden Interview.

The sample size was calculated using G-power software. The number of sample was based on empirical guidelines for Interpreting the Magnitude of Correlation Coefficients from Hemphill[16]. By using distribution of correlation for assessment review in the upper third; the coefficients slope was chosen is 0.35, which indicates medium effect size that produces power (1- β err prob) of 0.80 resulting a total sample size of 59.

2.3 Data collection procedure

Data was collected using demographic questionnaire, Modified Barthel Index (MBI) and Zarit Burden Interview. Level of ADL performance of the stroke individuals was measured using the Modified Barthel Index (MBI) and caregivers' burden was measured by using Malay Zarit Burden Interview (ZBI).

The Modified Barthel Index (MBI) was developed by Shah et al., [17] to evaluate the physical functional ability in individuals with disabilities. The index of 10 items includes personal hygiene, bathing, feeding, toilet use, stair climbing, dressing, bowel control, bladder control, ambulation, and transfer. Each item is scored from 0 (unable to perform the task) to 15 (fully independent). A score of 0-20 indicates total dependence, 21-60 indicates severe dependence, 61-90 indicates moderate dependence, 91-99 indicates slight dependence, and 100 indicates independence. The Cronbach's alpha coefficient and KMO statistical magnitude of MBI were 0.916 and 0.854, indicating the high reliability and validity of this index [18]. This observational assessment was conducted by an occupational therapist to examine the performance of individuals with stroke in ADL.

Malay Zarit Burden Interview (MZBI) is a self-report measure was used to examine (i) the caregiver subjective burden with a 22-item questionnaire on a 5-point scale 0 (never) to 4 (nearly always); and (ii) two subscales measuring personal strain and role strain [19]. Item ratings are summed to achieve a total score that can range from 0 to 88, with higher scores represented greater burden. The score of 0-21 indicates little or no burden, 21-40 indicates mild to moderate burden, 41-60 moderate to severe burden and 61-88 indicates severe burden. The MZBI was demonstrated fairly good psychometric properties in assessing the caregivers' burdens in local Malaysian population with high internal consistency ($\alpha = 0.898$) [20].

2.4 Data analysis

Statistical Package for Social Science (SPSS) version 25.0 software was used to analyse all the data collected. The demographic characteristics of the participants were calculated using the descriptive statistic. Normality testing was done using the Shapiro-Wilk test and the assumptions of normal distribution were violated. The association between ADL performance and the caregivers' burdens was analysed using Spearman's correlation test. The associations of caregivers' burden and ADL performance of individuals with demographic characteristics were analysed using spearman correlation, Mann-Whitney U and Kruskal Wallis test.

3. RESULTS AND DISCUSSION

3.1 Description of participants

A total of N=59 participants from National Stroke Association of Malaysia (NASAM) were involved in this study. Table 1 displays descriptive statistics of participants' demographic data. The age distribution of the participants ranged between 20 to 86 years old with a median age of 68.00 (12.00) for the individuals with stroke and 60.00 (23.00) for caregiver's age. The involvement of male participants with stroke were n=29 (49.2%) and n=23 (39%) for caregivers while the involvement of female participants with stroke were n=30 (50.8%) and n=36 (61%) for caregivers. The median duration of having stroke was 24.00 (52.00).

Table 1. Descriptions of participants' demographic statistics

Demographic characteristics	N	%	Median (IQR)
Age of stroke' Individuals	-	-	68.00 (12.00)
Duration of stroke	-	-	24.00 (52.00)
Caregivers' age	-	-	60.00 (23.00)
Gender of			
<i>Male</i>	29	49.2	-
<i>Female</i>	30	50.8	-
Caregivers' gender			
<i>Male</i>	23	39	-
<i>Female</i>	36	61	-
Caregivers' marital status			
<i>Single</i>	13	22	-
<i>Married</i>	46	78.0	-
Caregivers' employment status			
<i>Yes</i>	12	20.3	-
<i>No</i>	47	79.7	-
Caregivers' monthly income			
<RM4,000	46	78.0	-
>RM4,000	13	22.0	-
Caregivers' race			
<i>Malay</i>	9	15.3	-
<i>Chinese</i>	43	72.9	-
<i>Indian</i>	6	10.2	-
Relationship with stroke's individuals			

<i>Spouse</i>	34	57.6	-
<i>Family members</i>	25	42.4	-
Receiving help from others			
<i>Yes</i>	33	55.9	-
<i>No</i>	26	44.1	-

* Interquartile Ranger (IQR)

Majority of the participants were Chinese (n=43, 73.9%), while the minority of the participants were Malay (n=9, 15.3%) and Indian (n=6, 10.2%). More than half of the caregivers were married (n=46, 78%), while (n=13, 22%) were single. 47 caregivers (79.7%) were not working and the rest (n=12, 20.3%) were still working. Most of the caregiver has monthly income of <RM4,000 (n=46, 78%), while the other (n=13, 22%) has a monthly salary of >RM4,000. The number of caregivers receiving help from others in caregiving was n=33 (55.9%) while caregivers that does not receive help was n=26 (44.1%). Most caregivers were the spouse for the individuals with stroke (n=34, 57.6%), and the rest were family members.

3.2 Level of performance in ADL and caregivers' burdens

Table 2 shows the median and IQR of MBI and MZBI were 74.00 (47.00) and 25.00 (22.00) respectively. The minimum score was 5.00 while the maximum score was 100.00 for ADL performance of individuals with stroke. Meanwhile, the minimum score for MZBI was 1.00 and the maximum is 66.00 for the caregivers' burdens. Out of the 59 participants with stroke, there were five participants with total dependency level, 18 participants with severe dependency level, 20 participants with moderate dependency level, 15 participants with slight dependency level and one was independent.

Table 2. Level of ADL activities and Level of Caregivers' burdens

(N=59)	Minimum	Maximum	Median (IQR)
MBI	5.00	100.00	74.00 (47.00)
MZBI	1.00	66.00	25.00 (22.00)

3.3 Relationship between performances in ADL and caregivers' burdens

A Spearman correlation coefficient was conducted to examine the correlation of ADL performance of individuals with stroke and the caregivers' burdens. The results showed the ADL performance was not statistically correlated with the caregivers' burdens (r= -0.086, p=0.52). Table 3 showed the result of relationship between level of ADL performance and caregivers' burdens.

Table 3. Relationship between level of ADL performance and level of caregivers' burden

Correlation	Zarit Caregivers' burdens
Modified Barthel Index	r = -0.086 p-value = 0.52

3.4 Association between socio-demographic data with caregivers' burdens and ADL performance of individual with stroke

As for the association between sociodemographic characteristics and caregivers' burden, the duration of having stroke and caregivers' burdens was found to have significant negative weak correlation through Spearman correlation coefficient ($r = -0.281$, $p = 0.03$). Surprisingly, the result suggests the higher the duration of stroke, the lower the caregivers' burden. Other demographic characteristics of individuals with stroke and their caregivers were found not to be associated with burdens.

Results of the association between demographic characteristics and individuals' with stroke ADL performance indicate there was a significant negative moderate correlation between age of individuals with stroke and ADL performance ($r = -0.414$, $p < 0.01$). It can be concluded that the older the age of the individual with stroke, the poorer the performance in ADL. Additionally, there was significant association between the relationship of caregiver and the ADL performance of individuals with stroke ($z = -2.54$, $p = 0.01$). This result suggests that individuals with stroke who was taken care by spouse had greater ADL performance ($M = 84$, $IQR = 28.25$) than those who was taken care by other family members ($M = 50.00$, $IQR = 48.00$). Other demographic characteristics of individuals with stroke and their caregivers were found not to be associated with ADL performance.

3.5 Discussion

This study examined the caregivers' burdens and its' association with ADL performance of individuals with stroke. The main finding emphasized in the present study was that there is no significant correlation between caregivers' burdens and ADL performance of the individuals with stroke. The finding contradict with a study that reported there is statistically significant difference between impairment in activity of daily living of older people with the level of caregivers' burdens in India [21]. This contradiction is probably due to the caregivers in this present study felt it is their responsibility to provide care to the needy family members[22]. A study reported that personal fulfilment is one of the several benefits when taking care of their loved ones[23].

Findings of the study show that 20 out of the 59 (33.9%) participants has moderate dependency level, followed by 18 (30.5%) participants having severe dependency, 15 (25.4%) participants with slight dependency, 5 (8.5%) participants with total dependency level and 1 (1.7%) is totally independent. Most of the stroke survivors are able to perform ADL with maximum to moderate help from caregivers. The level of independency in ADL performance are diverse across cultures and diagnosis. For instance, a study reported

that there is high dependency level in ADL among elderly in India[21].

As for the caregivers' burdens, 25 out of 59 (42.4%) participant felt little to no burden, 21 (35.6%) participants felt mild to moderate burden, 9 (15.3%) participants felt moderate to severe burden and only 4 (6.8%) of the participants felt severe burden when caring for individuals with stroke. This finding contradicts with a study that found the caregivers of people with dementia have high and persistent rates of burden[24].

Previous studies reported that the relationship with stroke survivor, receiving help in caregiving of the individuals with stroke, duration of having stroke, income level of the family, caregivers' health status and hours of caregiving per day were the factors that significantly increase the level of burden and strains experienced by the informal caregivers[7], [25], [26]. However, in this study the duration of having stroke was the only variable that has significant difference with level of burden among caregivers. The other demographic characteristics such as individuals' with stroke and caregivers' age, gender of individuals with stroke and their caregivers, caregivers' marital status, caregivers' working status, caregivers' monthly income, race of individuals with stroke and their caregivers, caregivers' relationship with individuals with stroke, and receiving help in caregiving seemed not to have any association with caregivers' burdens. A study discovered that some of the factors that could contribute caregivers' burdens among Korean population includes caregiver's mental health states, caregiver's anxiety, caregivers being daughter in law, individual's with stroke mental health states, and their physical deficits [27], which were not addressed in this present study. Thus, a future study needs to consider these factors when trying to untangle the caregivers' burdens of the individuals with stroke.

In this study, it was found that the age of individuals with stroke is associated with ADL performance. The younger the stroke individuals, the better the performance in ADL. The relationship between stroke individuals and their caregiver was also found to be associated with ADL performance. Those who were taken care by their spouse were found to be having a higher ADL performance as compared to those who were taken care by other family members. It can be said that the ability to perform ADL tasks were influenced by vast variation of physical and emotional problems that the individuals with stroke had to deal with[28]. The environmental and sociodemographic characteristics also plays a significant role in ADL performance of individuals with stroke.

The major limitation of this study is the samples were relatively small and might not represent the number of individuals with stroke who attended NASAM for rehabilitation. As this is a cross-sectional study, it could not describe the experience of caregivers' burdens in taking care of individual with stroke more details. Thus, a future study with a larger sample is required and it will be good to incorporate qualitative data to describe the experience of caregivers in taking care of a family member with stroke.

4. CONCLUSION

This study suggests that there is no significant association between ADL performance of stroke individuals and the caregivers' burdens. The caregivers can experience little to no burden, despite the stroke individuals have total dependency in ADL performance. This study found that some of the sociodemographic characteristics of the stroke individuals and the caregivers have significant association with burdens of caregivers and ADL performances. It is found that the duration of having stroke significantly associated with caregivers' burdens. The longer the duration of having stroke, the less burden felt by the caregivers. The age of individuals with stroke and the individual's relationship with caregivers were found to be associated with performance in ADL.

ACKNOWLEDGEMENTS

We would like to thank all participants involved in the study and NASAM for their great cooperation. This study was supported by LESTARI Grant (Ref no: 600-IRMI/Dana KCM5/3/LESTARI(223/2017), Universiti Teknologi MARA.

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