Neurology Asia 2025; 30(1) : 75 – 85

Factors affecting caregiver burden in older stroke survivors, a Malaysian study

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Abstract

Background: Older stroke survivors may suffer from a wide range of disabilities. Delivering care in community impose different sets of challenges. Caregiving role may affect caregiver's physical and mental health. This study aimed to determine the caregiver burden of stroke survivors in urban Malaysia, an emerging economy. *Methods:* Caregivers of stroke patients aged 60 years and above were recruited. Socio-demographic information, stroke care details, Modified Ranking Scale and Barthel Index data were collected followed by Short Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), Modified Caregiver Strain Index and Zarit Burden Interview questionnaires. *Results:* A total of 104 stroke caregiver-survivor pairs were recruited. The mean age of the caregiver was 50.2 (SD=14.3) years with 72.1% were children of stroke survivors. The mean age of the stroke patients was 72.9 (SD=7.7) . 53.8% of caregivers experienced burden, however majority reported mild to moderate burden. The predictors of overall burden include caregiver's higher education level ($P=0.027$, $R^2=0.506$), caregiver having hypertension ($P=0.02$, $R^2=0.506$), patient having hypertension ($P<0.001$, $R^2=0.506$) and patient's worse cognitive decline ($P<0.001$, $R^2=0.506$). Other important factors include incontinence, higher dependency status and longer duration of care per day.
Conclusion: This study performed in Malaysia described the stroke care burden as mild to moderate, probably reflecting the underlying Eastern culture value with emphasis on family and filial piety.

Keywords: older, geriatric, elderly, stroke, caregiver, burden, strain

INTRODUCTION

Stroke is characterised as an episode of neurological dysfunction attributed to the focal injury of the central nervous system by vascular causes, including cerebral infarction, intracerebral haemorrhage (ICH), and subarachnoid haemorrhage (SAH).[1] It is the third most common cause of disability-adjusted life-years (DALY) and one of the most common and leading causes of mortality and morbidity worldwide, including in Malaysia.[2,3]

Stroke survivors may suffer from a wide range of physical disabilities, cognitive impairment, depression, and personality changes.[4] Within the community, their care is usually provided by the family members. Rigby *et al*. described caregiver burden as the weight or load carried by caregivers as a result of adopting the caregiving role.[4]

The prevalence of caregiver burden surrounding stroke survivors worldwide is reported to be 25–54%.[4] In Malaysia, this burden has been reported to be lower, between 25% and 35.4%.[5-7] Studies have investigated different factors contributing to caregiver burden; however, results are inconsistent both locally and abroad. Some studies found that the burden of care is related to marital status, family income, and the patient's physical disability and cognitive impairment.[5,6,8] However, Watanabe *et al*. found that caregiver burden in those caring for stroke patients was high regardless of the patient's activities of daily living (ADL) status.[9] Furthermore, caregivers with higher education level[10], lack of social support[8]

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Date of Submission: 1 July 2024; Date of Acceptance: 26 November 2024

https://doi.org/10.54029/2025cmz

and longer caregiving hours[11,12,13] were associated with higher burden.

Caregiving roles may affect the caregiver's physical health, emotional state, financial and psychosocial well-being.[14,15] The increased incidence and prevalence of stroke in Malaysia[12] has put a strain on both the patients and their caregivers, mainly because the mainstay of stroke care and rehabilitation is home-based care.

Here, we aim to evaluate the caregiver burden in a cohort of Malaysian older stroke survivor in an urban tertiary medical centre and determine its attendant risk factors.

METHODS

This cross-sectional single-centred study was conducted from the UKMMC in Kuala Lumpur from July 2020 to March 2021. Stroke patients aged 60 years and older, attending outpatient neurology clinics with their caregivers and fulfilling the inclusion and exclusion criteria, were chosen randomly via convenient sampling and were invited to participate in the study. However, in view of the Covid-19 pandemic and the commencement of Movement Control Order (MCO), stroke patients and their caregivers were also recruited from the wards.

The inclusion criteria were: (1) caregivers of stroke patients age 60 years and older, (2) caregivers aged18 years or older who understood English or Malay, and (3) if more than one caregiver is present, then the person who spent more time with the stroke patient will be identified as the study subject. Meanwhile, the exclusion criteria included caregivers taking care of other patients simultaneously and those who declined informed consent. This study was approved by UKMMC Research and Ethics Committee (FF-2020-287).

Four measuring parameters were used to assess each stroke survivor and caregiver pair. The stroke survivor's physical disability was measured using the modified Rankin Scale (mRS), which is a single-item, global outcome rating scale for post-stroke patients.

The patient's functional ability to perform daily activities was assessed objectively using the Barthel Index score that rates the independence to care for oneself. There were 10 items, and the score ranged from 0 to 100. Score 90- 0 depicts 'Moderate to Total Dependence' while score 91-100 depicts 'Slight Dependence to Independence'.

The stroke survivors' cognitive decline was assessed through a short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE). It is a 16-item questionnaire that extracts information on the changes in an elderly subject's cognitive performance over the previous 10 years. This assessment was adapted from a 26-item questionnaire, cross-validated, and found to perform as well as the long form. The scoring of each individual item in the Short IQCode ranges from 1 to 5. The score is calculated by summing up each question's score and dividing it by the number of questions. An average score of 3 means that the subject was rated as 'no change', 4 – 'a bit worse', and 5– 'much worse'. The scores are demonstrated to be relatively unaffected by the informant's education, premorbid ability, or proficiency in the language of the country of residence.[13]

The caregiver burden was assessed by the Modified Caregiver Strain Index (mCSI) and Zarit Burden Interview (ZBI). These questionnaires have been validated in the stroke population, demonstrating high internal consistency and providing a comprehensive assessment of both objective and subjective burden.

The Modified Caregiver Strain Index is a 13-item instrument modified from the original version developed in 1983 to screen the caregiver's strain related to care provision. At least one item is included for each of the following major domains, which include financial, physical, psychological, social, and personal.[14] Each item is assessed with a score of 2 for each 'yes', 1 for each 'sometimes', and 0 for each 'no'. Scoring ranges from 26 to 0. There is no breakdown of low, moderate, or high scores; however, the higher the score, the higher the strain.

The Zarit Burden Interview (ZBI) is a 22-item instrument measuring caregivers' perceived burden of rendering family care. The caregivers were asked to complete the questionnaires independently. Each item was assessed on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always). Item scores were summed up to give a total score between 88 and 0, with a higher score indicating a greater perceived caregiver burden. The questions focused on major topics such as the caregiver's physical and emotional health, finances, social aspect, and the relationship between the caregiver and the patient. Zarit Burden Interview is a valid and reliable instrument for measuring the burden of caregivers with Cronbach's alpha value of 0.93; the intra-class correlation coefficient for the test-retest reliability score of 0.89 (Boon , 2010)

Modified Caregiver Strain Index, Zarit

Burden Interview and Informant Questionnaire on Cognitive Decline in the Elderly English versions had been validated as questionnaires and permission had been granted by the authors via email. The Malay versions of the three questionnaires had also been validated and permission was granted via email. Modified Rankin Scale and Barthel Index were allowed to be used publically for non-commercial purposes and both questionnaires had been validated.

All data were analyzed using the IBM Statistical Package for Social Science version 21.0 (SPSS). The normally distributed continuous variables were presented as mean (standard deviation), skewed data as median (interquartile range), and categorical variables were presented as frequency and proportion. Descriptive analyses were performed on the demographic characteristics of caregivers and stroke patients and their comorbidities. Independant T-test, Anova, and Chi-Square tests were used for normally distributed variables, while the Mann-Whitney, Kruskal-Wallis and Fisher's Exact tests were used for skewed data. Spearman's correlation was used for Barthel Index and mCSI. Multivariate analysis was used to analyze the association between related factors and caregiver burden. This was done by using multiplelinear regression for mCSI; hence, a significant relationship is said to be present if the 95% confidence crosses zero. The mean difference measures the strength of this relationship. For ZBI however, as it is not normally distributed, the data were dichotomized into mild to severe burden and no to little burden, and analyzed with multiple logistic regression. The odds ratio indicates the strength of the relationship, while a 95% confidence interval which does not cross one, indicates statistical significance. Statistical significance was set at a p-value less than 0.05.

RESULTS

Socio-demographic data of stroke caregivers and stroke survivors

A total of 104 stroke caregiver-survivor pairs were recruited from the neuromedical clinic (78%) and ward (22%). The socio-demographic data of these stroke caregivers and survivors are described in Table 1. The mean age (year) of the caregivers was 50.2 (SD=14.3). The majority of the caregivers were of Chinese ethnicity (53.8%), children of stroke survivors (72.1%), and were married (72.1%); 59.6% of the caregivers had no comorbidities, and for those who did, they had hypertension (20.2%). Most of the caregivers had secondary and tertiary education levels (50% and 41.3% respectively), 60.6% of the caregivers were employed and the median household monthly income was RM 3000 (IQR=RM 1625–RM 4000).

The mean age (year) of the stroke survivors was 72.9 (SD=7.7). The most common comorbidity was hypertension (89.4%), followed by diabetes mellitus (56.7%) and dyslipidaemia (41.3%). More than half of this cohort has had a history of falling and has hearing and visual impairment, while 29.8% had incontinence.

Stroke and caregiving details

The majority of the stroke patients experienced an ischaemic stroke (83%) with a median stroke duration of 3 years (IQR=1-6.75). Most stroke patients had no history of stroke previously (64.4%). The overall median duration of care of these patients by the respondent caregivers was 2.5 years (IQR=1- 8). 79% of the caregivers stayed with the patients while 35.9% needed care for 8 hours or more daily. Only 34.6% of caregivers received support in caring for stroke patients, and 61.8% were satisfied with the support they received. Examples of support that the caregivers received include financial aid, hired helpers, and obtaining rehab or physiotherapy services.

Almost half (49%) of the patients had an MRS of 3 and above, indicating moderate to severe disability. In addition, the percentage of patients who had moderate to total dependency according to the Barthel Index was 73.1%. This shows that cohort of our stroke survivors was dependent on basic self-care.

The overall mean IQCODE score for the cognitive decline was 3.7 (SD=0.8) depicting "not much change" to "much worse" in cognitive decline

Description of caregiver burden and factors affecting it

The overall mean scores for mCSI and ZBI were 9.2 (SD=6.5) and 23.1 (SD=14.3), respectively, indicating relatively mild to moderate burden. Comparing the burden of caregivers through the Zarit Burden Interview, about half of the caregivers have little or low burden (46.2%), while another half have a higher burden (53.8%). However, when ZBI was further subdivided, the majority of the caregivers had mild to moderate burden (44.2%) compared to moderate to severe burden (8.7%) and severe burden (1%), as demonstrated in Table 3.

Table 1: Socio-demographic characters of caregivers (A) and stroke survivors (B)

	Caregivers (A)	
Characteristics	Number (N)	Percentage (%)
Age		
<40	28	26.9
40-59	49	47.1
≥60	27	26
Gender		
Male	48	46.2
Female	56	53.8
Race		
Malay	42	40.4
Chinese	56	53.8
Indian	6	5.8
Education Level		
Primary	9	8.7
Secondary	52	50
Tertiary	43	41.3
Comorbidities		
Diabetes Mellitus	9	8.7
Hypertension	21	20.2
Dyslipidaemia	9	8.7
Ischaemic Heart Disease	5	4.8
Others	14	13.5
No comorbid	62	59.6
Relationship with stroke survivor		
Spouse	24	23.1
Child	75	72.1
Relative	5	4.8
Marital Status		
Single	28	26.9
Married	75	72.1
Divorced	1	1
Working Status		
Employed	63	60.6
Unemployed	30	28.8
Retired	11	10.6
Monthly Household Income (RM)		
<1500	22	21.2
1500-3999	39	37.5
>4000	43	41.3

	Stroke Survivors (B)	
Characteristics	Number (N)	Percentage (%)
Age		
60-74	59	56.7
75-85	37	35.6
>85	8	7.7
Gender		
Male	60	57.7
Female	44	42.3

Race		
Malay	42	40.4
Chinese	55	52.9
Indian	7	6.7
Education Level		
Nil	17	16.3
Primary	27	26
Secondary	44	42.3
Tertiary	14	13.5
Comorbidities		
Diabetes Mellitus	59	56.7
Hypertension	93	89.4
Dyslipidaemia	43	41.3
Ischaemic Heart Disease	25	24
Chronic Kidney Disease	17	16.3
Peripheral Vascular Disease	6	5.8
Retinopathy / Cataract	4	3.8
Post-Infarct Seizures	9	8.7
Atrial Fibrillation	20	19.2
Others	51	49
No comorbid	1	1
History of fall	64	62.7
Incontinence	31	29.8
Hearing/Visual Impairment	67	65.7

We examined the relationship between the caregiver burden using mCSI and ZBI and the caregiver and patient's characteristics. Table 2 and Table 3 show the association of the caregiver and patient's socio-demographic data with caregiver burden. Using the Modified Caregiver Strain Index, it was found that the caregiver's higher educational level (p=0.02), caregiver's comorbidity of hypertension (p=0.0241), patient's comorbidity of hypertension (p=0.001) and incontinence (p=0.014) were significantly associated with caregiver burden. Meanwhile, the caregiver's comorbidity of hypertension (p=0.035) and the patient's comorbidity of hypertension (p=0.049) significantly impacted caregiver burden through the Zarit Burden Interview.

None of the other socio-demographic variables, including age, gender, ethnicity, stroke survivor's educational level, patient's history of falls or visual and/or hearing impairment, caregivers' employment status, and household income had a significant contribution to caregiver burden.

With regards to stroke characteristics and caretaking details, factors associated with high caregiver burden include MRS score (mCSI, p=0.004; ZBI p=0.044), the cognitive decline of stroke survivors (mCSI, p<0.001; ZBI p=0.008) and longer duration of care per day (mCSI, p<0.001; ZBI, p=0.001). With the Zarit Burden Interview, Barthel Index was also a significant factor associated with caregiver burden (ZBI, p=0.015).

Factors related to burden on multiple regression

To understand the relative contributions of these factors in determining caregiver burden, we performed a multivariate analysis. In this analysis, we included significant factors (p<0.05) from the univariate analyses. The predictors of overall burden (Modified Caregiver Strain Index) included the caregiver's higher education level (p=0.027), hypertension in caregivers (p=0.02), hypertension in patients (p<0.001) and worsening of the patient's cognitive decline (p<0.001). Other important factors associated with caregiver burden include patients having incontinence, poor MRS score, lower Barthel Index, and longer duration of care which are significant in bivariate analysis, but not in the multiple linear regression analysis.

Although the abovementioned factors were important factors contributing to caregiver burden, they were not defined as statistically significant independent risk factors when we ran multiple logistic regression analyses with the Zarit Burden Interview.

Table 2: Association between caregivers (A), stroke survivor (B) and stroke details (C) with caregiver burden (Modified Caregiver Strain Index)

Character / Items	Number (N)	Mean (±SD) / Median (IQR)	T or F statistic (df) / Z or X^2 statistic (df)	P-value
A. CAREGIVERS				
Education Level				
Primary	9	3.44 (3.78)	6.531 (2, 101)	**0.020***
Secondary	52	8.48 (6.08)		
Tertiary	43	11.19 (6.59)		
Comorbidities				
DM	9	9.33 (8.5)	0.822 (102)	0.937
Hypertension	21	6.33 (5.83)	-2.291 (102)	**0.0241***
Dyslipidaemia	9	6.67 (5.03)	-1.212 (102)	0.228
IHD	5	8 (7.97)	-0.413 (102)	0.681
Others	14	10.36 (6.98)	0.744 (102)	0.462
No comorbid	62	9.95 (6.6)	-1.520 (102)	0.133
B. STROKE SURVIVORS				
Comorbidities				
DM	59	8.66 (6.78)	-0.905 (102)	0.367
Hypertension	93	8.45 (6.32)	-3.426 (102)	**0.001***
Dyslipidaemia	43	8.65 (6.37)	-0.681 (102)	0.501
IHD	25	8.72 (6.15)	-0.391 (102)	0.696
CKD	17	10.41 (5.87)	0.868 (102)	0.387
AF	20	9.05 (5.13)	-0.103 (36.697)	0.919
History of fall	64	9.58 (5.92)	1.083 (100)	0.282
Incontinence	31	11.55 (6.62)	2.512 (102)	**0.014***
Hearing/Visual Impairment	67	9.52 (6.91)	0.590 (100)	0.550
C. STROKE DETAILS				
Types of stroke				
Ischaemic	87	8.97 (6.6)	0.353 (2,101)	0.704
Haemorrhagic	6	11.17 (2.85)		
Both Ischaemic and Haemorrhagic	11	9.64 (6.9)		
Duration of stroke (S)				
<3 years	46	7 (2-13.25)	-0.675	0.499
3 years and above	58	9 (2-13.25)		
Number of previous stroke				
Nil	67	9.15 (6.7)	-0.03 (102)	0.976
1 or more	37	9.19 (6.12)		
MRS (Modified Rankin Scale)				
0 (No symptoms)	5	4.6 (3.51)	3.721 (5, 98)	**0.004***
1 (No significant disability)	22	5.82 (4.69)		
2 (Slight disability)	26	8.92 (6.97)		
3 (Moderate disability)	20	10.05 (5.72)		
4 (Mod severe disability)	20	10.65 (7.13)		
5 (Severe disability)	11	14.18 (5.62)		

Character / Items	Number (N)	Mean (±SD) / Median (IQR)	T or F statistic (df) / Z or X^2 statistic (df)	P-value
Modified Barthel Index				
Moderate to total dependence (0-90)	76 (73.1%)		-3.286	**0.001***
Independence to slight dependence (91-100)	28 (26.9%)			
Cognitive Decline (IQCODE)				
A bit improved (Score 2)	3	9.33 (4.51)	8.523	**<0.001***
Not much change (Score 3)	43	5.79 (4.67)	(3, 100)	
A bit worse (Score 4)	40	11.18 (6.77)		
Much worse (Score 5)	18	12.72 (6.03)		
Carer Staying with Patient				
Yes	79	9.01 (6.78)	-0.418 (102)	0.675
No	25	9.64 (5.51)		
Duration of care per day (S)				
Less than 8 hours	66	6 (2-12)	-3.899	**<0.001***
More than 8 hours	37	13 (7.5-17)		
Duration of Care (Years) (S)				
1 year or less	37	8 (2.5 - 13.5)	-0.048	0.961
More than 1 year	67	8 (3 - 13)		
Received caregiver training				
Yes	59	9.02 (6.61)	-0.281 (97)	0.782
No	40	9.4 (6.52)		
Received Support (S)				
Yes	36	10.5 (2-13)	-6.732	0.5
No	66	8 (2-14)		

Abbreviations: (S) Skewed, (SD) Standard Deviation, (IQR) Interquartile Range, IQCODE: Short Informant Questionnaire on Cognitive Decline in the Elderly, T statistics (Independant t-test), F statistics (One-way Anova test), Z statistics (Mann-Whitney test), X^2 statistics (Kruskal-Wallis test), (df) degree of freedom, *Significant P-value (<0.05)

DISCUSSION

The overall caregiver burden of older stroke survivors using the Zarit Burden Interview was 53.8%, similar to the reported prevalence of caregiver burden of stroke patients worldwide.[4] However, when the burden index from the Zarit Burden Interview score was further subdivided into mild to moderate, moderate to severe, and severe burden, they were 46.2%, 8.7%, and 1%, respectively, indicating that the majority had mild to moderate caregiver burden, while moderate to severe burden was much less compared to other local studies.[5,6]

The low prevalence of high burden in this study may be attributed to several reasons. Cultural values may contribute to this as the majority of the stroke caregivers were children and spouses who may view caring for stroke patients as part of their responsibility as family members. The filial obligation was reported as the primary reason for caregiving amongst female caregivers in Taiwan[19], while in Japan, children providing care to elderly family members were considered to be morally desirable and natural.[20]

The caregivers also reside in urban areas where access to support and help is easier. Those who received support in this study reported receiving financial aid and help from family members or by hiring helpers. They were also able to access services like hired nurses, physiotherapy, and rehab centers.

Alternatively, it could also be that many of the caregivers found it difficult to express their concerns and anxieties and were reluctant to seek help, fearing that such a request would represent a sign of failure or inadequacy of what is expected of them as family members.[21]

Table 3: Association between caregivers (A), stroke survivors (B) and stroke details (C) with caregiver burden (Zarit Burden Interview)

Character / Items	Number, (N)	Mild to severe Burden (N%)	No or little Burden (N%)	P-value
A. Caregivers				
Education Level				
Primary	9	3 (33.3)	6 (66.7)	0.200
Secondary	52	26 (50)	26 (50)	
Tertiary	43	27 (62.8)	16 (37.2)	
Comorbidities				
DM				
Yes	9	4 (44.4)	5 (55.6)	0.729 (F)
No	95	52 (54.7)	43 (45.3)	
Hypertension				
Yes	21	7 (33.3)	14 (66.7)	0.035*
No	83	49 (59)	34 (41)	
Dyslipidaemia				
Yes	9	3 (33.3)	6 (66.7)	0.296 (F)
No	95	53 (55.8)	42 (44.2)	
IHD				
Yes	5	2 (40)	3 (60)	0.661 (F)
No	99	54 (54.5)	45 (45.5)	
B. Stroke Survivors				
Comorbidities				
DM				
Yes	59	30 (50.8)	29 (49.2)	0.482
No	45	26 (57.8)	19 (42.2)	
Hypertension				
Yes	93	47 (50.5)	46 (49.5)	0.049*
No	11	9 (81.8)	2 (19.2)	
Dyslipidaemia				
Yes	43	23 (53.5)	20 (46.5)	0.951
No	61	33 (54.1)	28 (45.9)	
IHD				
Yes	25	13 (52)	12 (48)	0.832
No	79	43 (54.4)	36 (45.6)	
Incontinence				
Yes	31	20 (64.5)	11 (35.5)	0.155
No	73	36 (49.3)	37 (50.7)	
C. Stroke Details				
Types of stroke				
Ischaemic	87	46 (52.9)	41 (47.1)	0.792
Haemorrhagic	6	3 (50)	3 (50)	
Both Ischaemic and Haemorrhagic	11	7 (63.6)	4 (36.4)	
Duration of stroke				
<3 years	46	25 (54.3)	21 (45.7)	0.927
3 years and above	58	31 (53.4)	27 (46.6)	

Character / Items	**Number, (N)**	**Mild to severe Burden (N%)**	**No or little Burden (N%)**	**P-value**
Number of previous stroke				
Nil	67	34 (50.7)	33 (49.3)	0.393
1 or more	37	22 (59.5)	15 (40.5)	
MRS (Modified Rankin Scale)				
0 (No symptoms)	5	1 (20)	4 (80)	0.044*
1 (No significant disability)	22	8 (36.4)	14 (63.6)	
2 (Slight disability)	26	14 (53.8)	12 (46.2)	
3 (Moderate disability)	20	11 (55)	9 (45)	
4 (Mod severe disability)	20	12 (60)	8 (40)	
5 (Severe disability)	11	10 (90.9)	1 (9.1)	
Barthel Index				
Moderate to Severe Dependence (0-90)	76	44 (57.9)	32 (42.1)	0.172
Slight Dependence to Independence (91-100)	28	12 (42.9)	16 (57.1)	
Cognitive Decline (IQCODE)				
A bit improved (Score 2)	3	2 (66.7)	1(33.3)	0.008*
Not much change (Score 3)	43	15 (34.9)	28 (65.1)	
A bit worse (Score 4)	40	25 (62.5)	15 (37.5)	
Much worse (Score 5)	18	14 (77.8)	4 (22.2)	
Carer Staying with Patient				
Yes	79	41 (51.9)	38 (48.1)	0.475
No	25	15 (60)	10 (40)	
Duration of care per day				
Less than 8 hours	66	27 (40.9)	39 (59.1)	0.001*
More than 8 hours	37	28 (75.7)	9 (24.3)	
Duration of Care (Years)				
1 year or less	37	20 (54.1)	17 (45.9)	0.975
More than 1 year	67	36 (53.7)	31 (46.3	
Received caregiver training				
Yes	59	32 (54.2)	27 (45.8)	0.94
No	40	22 (55)	18 (45)	
Received Support				
Yes	36	23 (63.9)	13 (36.1)	0.178
No	66	33 (50)	33 (50)	

Abbrevations: IQR: Interquartile Range, IQCODE: Short Informant Questionnaire on Cognitive Decline in the Elderly, (F) Fisher's exact test * Significant P-Value (<0.05), X^2 value (Chi-Square test)

Caregivers with a higher education level possess a higher burden, in contrast to the findings by Mandowara *et al*.[11] Perhaps this is because the caregivers also need to provide for the family; hence, they carry multiple tasks in caring for their family. This factor is also described by Goh *et al*., where most informal caregivers were still working and juggling between work and family.[10] Rahman *et al*. also outlined multiple responsibilities held by the caregivers, and the lack of social support during caregiving aggravates their burden.[8] Caregivers with higher education levels may also feel mentally burdened, which may be related to the loss of self-fulfillment and autonomy[22]

High blood pressure was Malaysia's most significant contributor to disability-adjusted life-years (DALYs).[3] It was the most common risk factor for ischaemic stroke, followed by diabetes mellitus.[3] This is reflected in our study, where hypertension was the most common comorbidity. Hence, it is also no surprise that this research found hypertension in caregivers and stroke survivors to be a predictor for caregiver burden. This finding, however, differs slightly from Choi-Kwon *et al.*'s report, where the presence of diabetes mellitus in stroke patients was associated with caregiver burden.[12] It is interesting to speculate that whereas hypertension contribute to development of stroke, the burden of caring for the stroke survivors may also contribute to the development of hypertension among the caregivers.

The prevalence of cognitive impairment is reported to be as high as 41% in the elderly population.[13] The association between cognitive decline and caregiver burden in our study was similar to several studies that concluded that cognitive impairment in post-stroke contributed to caregiverburden.[6,12] Furthermore, Anderson *et al.* suggested that mental impairment in stroke patients negatively affects the caregivers more than physical disability.[21] This is perhaps because of the communication barrier and behavior problems that come with it. In addition, cognitive decline and stroke severity might have an additive effect on caregiver burden.

Many studies demonstrated poor MRS scores, bedridden patients, and physical disability associated with caregiver burden[5,6,11,12,13] which concur with our findings. Physical disability and dependency on daily activities require a longer time for the caregiver to attend to stroke survivors. Patients with lower functional abilities also need more physical assistance, which may lead to physical and emotional fatigue of the caregiver.[23] The majority of our elderly stroke patients were relatively independent, and more than half were still able to look after their personal affairs without much assistance, which may also explain the lower occurrence of high burden in this study.

The worse the physical disability of stroke patients, the more physical strain and the longer time spent caring for the patients. Therefore it is no surprise that longer caregiving hours were also associated with higher burden in our study, similar to findings by Choi-Kwon *et al.*, Mandowara et al., and Bhattacharje *et al.*[11,12,13], which was not previously demonstrated in other local studies.

There are several limitations to this study. Firstly, this study has a small sample size, and many variables were included; hence false negative results may be present. Secondly, this study was also conducted by asking the caregivers to fill in several sets of questionnaires during the clinic visits. Meanwhile, in cases where ward patients were recruited, interviews were done in person or by phone, which might cause response bias. Lastly, two outcome measurements for caregiver burden used were the Modified Caregiver Strain Index and Zarit Burden Interview. Both methods have been applied in studies involving caregivers of older adults and the stroke population. While they explore similar domains, no studies have used both questionnaires concurrently to measure caregiver burden. However, the differences between these two outcomes, including the sensitivity and specificity of these tools, are beyond our study scope.

In conclusion, the caregivers in this study reported relatively mild to moderate caregiver burden. Considering the significant factors associated with caregiver burden in our study, measures can be taken to alleviate caregiver burden in the community. This includes providing rehabilitation support, home visits, and home care services for the caregivers to allow respite for the caregivers. Subjectively, the caregivers in our cohort described financial aid, equipment and medicine, physical assistance, nursing and rehab services, home visits, and support groups as the support they would like to receive.

Future studies should involve interventions such as caregiver support targeted at those managing older persons with more severe stroke and who have higher dependency levels. Understanding the limiting factors and the factors mentioned above, we would also like to draw attention to the group that was missed during this study: the caregivers and older stroke survivors who did not attend their clinic follow-ups. Future research addressingthis population group would be useful in understanding the support and services they need. There may also be differences between the factors, support, and services required by the caregivers of acute stroke versus long-term stroke survivors; hence, future research looking into these factors and variables would be beneficial.

DISCLOSURE

Conflict on interest: None

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