

# Assessing informal caregiver burden as well as knowledge on positioning and feeding of stroke patients in a tertiary hospital in Kelantan, Malaysia

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## SUMMARY

A significant proportion of stroke patients in Malaysia are supported by informal caregivers who often lack sufficient training. This lack of preparation contributes to an escalation in caregiver burden. A cross-sectional study was conducted using Caregiving Knowledge Questionnaire (CKQ-my) and Zarit Burden Interview (ZBI) with convenient sampling. The findings revealed that caregivers had limited knowledge regarding proper positioning, and most of them reported experiencing mild burden. Multiple logistic regression analysis showed that informal caregivers who were also the primary caregivers for severe stroke patients experienced a higher burden. Recognising and understanding the factors that contribute to caregiver burden in stroke cases is essential for developing effective programs to improve the quality of life for both stroke survivors and their informal caregivers.

## KEYWORDS:

Stroke, caregiver, positioning, feeding, burden

## INTRODUCTION

Approximately 54% of stroke patients in Malaysia suffer from physical and cognitive disabilities upon discharge from hospital.<sup>1</sup> Therefore, they require long-term care and varying degrees of assistance to perform daily activities after discharge. In Malaysia, most stroke care is provided by informal caregivers such as family members of patients.<sup>2</sup> Without proper knowledge, the application of poor or wrong techniques when caring for stroke patients may lead to secondary complications such as pressure ulcers, aspiration pneumonia and shoulder pains.<sup>3</sup>

There is a need for more extensive information regarding the background knowledge regarding such issues among stroke caregivers in Malaysia. Additionally, there is no Malaysian data on the correlation between stroke care knowledge and caregiver burden. Measuring the level of this knowledge among caregivers at our centre, focusing on stroke patients' positioning and feeding, will allow us to explore the level of their understanding regarding stroke patients' care. Knowing the correlation between knowledge and caregiver burden will

alert us to the importance of educating caregivers. Consequently, we plan to use the findings of this study to design caregivers' education programs to benefit our local population.

## MATERIALS AND METHODS

A cross-sectional study was conducted using convenient sampling involving informal caregivers of stroke patients who attended the Rehabilitation Unit of Hospital Universiti Sains Malaysia from December 2021 to February 2022. This study was a questionnaire-based research that consisted of three questionnaires: a proforma capturing caregiver demographic data; a validated questionnaire, CKQ - My that assessed knowledge on positioning (28 items) and feeding (6 items),<sup>4</sup> and the Zarit Burden Interview (ZBI)<sup>5</sup> which measured caregiver burden (22 items). The 'patient positioning' subscale has a cut-off score of 20 to differentiate between good and poor knowledge, while the 'feeding' subscale has a cut-off score of 10. Respondents experiencing caregiver burden may be classified as having mild, moderate or severe burden.

Inclusion criteria were adult informal caregivers aged more than 18 years old and taking care of stroke patients for more than three months. Exclusion criteria were caregivers who could not complete the questionnaire due to illiteracy and language barriers. Sample size was calculated using a web-based sample size calculator (Ariffin, W.N. 2020).

Statistical analyses were performed using SPSS version 26. Descriptive analysis was used to characterise subjects' sociodemographic characteristics and knowledge scores. Based on their normality distribution, numerical data were presented as mean (SD) or median (IQR). Categorical data were presented as frequency (percentage). Associated factors of caregiver burden were analysed using single and multiple logistic regression. A two-tailed  $p < 0.05$  was considered statistically significant for all analyses.

Ethical approval was obtained from the Human Research and Ethics Committee, Universiti Sains Malaysia (USM/JEPeM/21120839).

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**Table I: Score of knowledge in positioning and feeding among informal caregivers of stroke patients in Hospital Universiti Sains Malaysia.**

Variables	Total (%)
Knowledge positioning (Range of score 0 – 29)	
Good ( $\geq 20$ )	10 (13.2)
Poor ( $< 20$ )	66 (86.8)
Score of knowledge positioning	15.88 (3.74)*
Knowledge feeding (range of score 0 – 19)	
Good ( $\geq 10$ )	45 (100)
Poor ( $< 10$ )	0 (0)
Score of knowledge feeding	15.69 (2.29)*

\*Mean (SD)

**Table II: Burden score among informal caregivers of stroke patients in Hospital Universiti Sains Malaysia (n=76).**

Variables	Total (%)
Burden score	
No burden	39 (51.3)
Mild to moderate	32 (42.1)
Moderate to severe	5 (6.6)
Very severe	0 (0)

**Table III: Sociodemographic factors for caregivers' burden among informal caregivers of stroke patients in Hospital Universiti Sains Malaysia using simple and multiple logistic regression model (n=76).**

Variables	Simple logistic regression			Multiple logistic regression <sup>a</sup>		
	(b)	Crude OR (95% CI) <sup>a</sup>	p-value	(b)	Adjusted OR (95% CI) <sup>a</sup>	p-value
Stroke Severity (MRS)						
1-3	0	1	0.065	0	1	0.032
4-5	0.87	2.39		1.59	4.9 (1.5, 15.96)	
Type of caregiver						
Primary	0	1	<0.001	0	0.06 (0.02, 0.247)	0.001
Non-primary	-2.26	0.1		-2.72		

## RESULTS

Seventy-six participants were enrolled in this study. The mean age of caregivers was 44.0 years, while the mean age of patients was 63.3 years. The majority of caregivers were female (57.9%). In terms of ethnicity, most were Malay (93.4%), followed by Chinese (2.6%) and Indian (3.9%). Nearly half had tertiary education (48.7%) and high household income (40.8%). Around half were children's caregivers (53.9%), and around a third were spousal caregivers (32.9%). Only a small percentage (1.3%) had received extra training. The most common duration of diagnosis was less than one year (51.3%).

The CKQ-My questionnaire component on knowledge regarding proper positioning consists of 28 items where respondents are required to indicate the correct pictures of patient positioning. Results show that most caregivers for this study have a poor (86.8%) rather than a good knowledge of proper positioning (13.25%). The mean score for positioning was 15.88, with a standard deviation of 3.74. Meanwhile CKQ-My regarding feeding consists of six questions pertaining to knowledge on proper Ryle's tube patient feeding. Respondents need to select the correct answer for each question. In our study, all participants had good knowledge of feeding techniques, with a mean score of 15.69 and a standard deviation of 2.29. Approximately half

(48.7%) of participants had a burden, while the rest (51.3%) had no burden. Most caregivers had a mild to moderate burden (42.1%), followed by (6.6%) with a moderate to severe burden, and there were no caregivers with a very severe burden in this study.

Multiple linear regression showed that informal caregivers of severely dependent stroke patients (MRS 4-5) increased the risk of experiencing burden by 4.9-fold as compared to those taking care of independent to moderately dependent stroke patients (Adjusted Odds Ratio, aOR: 4.9; 95% Confidence Intervals, 95%CI: 1.5, 15.96), Primary informal caregivers of stroke patients had an increased risk of experiencing burden by 16-fold as compared to non-primary caregivers (aOR: 0.06; 95%CI: 0.02, 0.247).

## DISCUSSION

This study found that the majority (86.8%) of informal caregivers of stroke patients had poor knowledge of positioning, which is consistent with a previous Malaysian study.<sup>6</sup> A similar result was also observed in an Indian study.<sup>7</sup> These findings indicated that most informal caregivers of stroke patients need to obtain prior knowledge on how to take care of stroke patients. Thus, they should be educated and appropriately trained. This result differs from a study

conducted among formal caregivers who showed higher levels of good knowledge. Knowledge may be improved by giving the caregiver more specific and frequent training, as several studies from Thailand<sup>8,9</sup> and the US<sup>7,8</sup> have shown regular and proper training from rehabilitation experts will increase caregivers' knowledge and improve patient outcomes.<sup>3</sup>

The ZBI is used as a survey to assess burden, as it considers various aspects of life such as health, finances, social life, emotional well-being, personal life, and interpersonal relationships. Our study discovered that the severity of stroke, as measured by the Modified Rankin Scale (MRS), and the category of caregivers (primary vs. non-primary caregivers) were the only significant risk factors for caregiver burden in this study. Otherwise, no other significant factors were found for caregiver burden, including caregiving knowledge. The more dependent the patients, the more tasks for the caregivers and the more hours of care required, eventually increasing their burden. Therefore, we proposed that the functional disability of stroke patients is the primary determinant factor of the caregivers' burden in the present study.<sup>10,11</sup>

Primary caregivers had more tasks than non-primary caregivers, leading to longer time spent caring for the patients, resulting in a higher burden on caregivers. Various literature have linked the duration of caring (hours) with caregivers' burden.<sup>11-13</sup>

However, our study failed to find other associated factors for caregiver burden. Our result shows that the knowledge of burden and non-burden caregivers could be improved. Additional studies should be conducted with a larger number of participants to assess the correlation between all burden categories and caregiver knowledge.

The results for knowledge and caregiver burden in this study are consistent with other recent papers despite a small sample size. However, it is important to note that this study used a self-reporting method, which is vulnerable to social desirability bias and may be influenced by respondents' honesty, understanding, and reflective ability. A recommendation is to include a larger number of subjects to better understand association between knowledge and caregiver burden. Additionally, conducting a multicentre study would be ideal, as it would provide a more representative assessment of the burden faced by caregivers who manage patients with stroke.

## CONCLUSION

This brief study on informal caregivers of patients with stroke revealed a need for education on knowledge regarding proper positioning techniques. These results underscore the significance of caregiver training and support programs as essential resources for caregivers to enhance their comprehension of caring for patients with stroke. Additionally, our findings highlight the fact that primary informal caregivers and those coping with patients that have a more severe stroke are particularly susceptible to experiencing high levels of burden.

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