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ORIGINAL ARTICLE

Informal Caregiver Burden Among Stroke Survivors in Public Hospital of Selangor, Malaysia: A Cross-sectional Study

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ABSTRACT

Introduction: Informal caregivers (ICs) play a crucial role in the post-stroke recovery process, contributing significantly to the prevention of complications and functional rehabilitation of stroke survivors. Despite the well-documented stress and challenges faced by caregivers of stroke survivors globally, there is understudied examining the extent of caregiver burden within the specific context of Malaysia. Therefore, this study was to assess the burden level of care among ICs of stroke survivors and its associated factors in the Public Hospital in Selangor, Malaysia. **Methods:** A cross-sectional study was conducted in the Rehabilitation Clinic and Medical Ward in public hospital in Selangor, Malaysia. A convenience sampling was used that involved 108 ICs who brought stroke survivors to receive their treatment. The caregiver burden was assessed using the Zarit Burden Interview (ZBI) and stroke survivor functional disability was assessed with the Barthel Index. **Results:** Overall, 60.2% (65) of caregivers experienced a burden, with a high proportion experiencing a mild to moderate burden (45.4%) followed by moderate to severe 13.9% (15). There were statistically significant (r=0.210, p=0.029), a positive association where increasing the age of the ICs may increase the burden to care for the stroke survivor. There were found a significant association between the number of ICs and the level of caregiver burden (p=0.01). Simple linear regression were found functional status of stroke survivors to have significantly (p=0.001) predictor of ICs burden's level. **Conclusion:** These findings emphasize the importance of ICs to be included in the rehabilitation planning. Hence, future interventions should be aimed at decreasing ICs burden while simultaneously enhancing the effectiveness of stroke survivor rehabilitation.

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Keywords: Informal caregiver, Caregivers burden, Caregivers burnout, Stroke survivors, Cross-sectional study

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INTRODUCTION

A stroke known as a cerebrovascular accident (CVA) or cerebrovascular disease (CVD), is clinically defined as a sudden-onset neurological event (1,2) caused by disrupted blood flow to the brain, leading to significant impairments that have lasting impacts on both stroke survivors and their caregivers (3). Stroke maintains its position as the second leading cause of mortality worldwide and the third leading contributor to disability (4, 5). The global burden of stroke is projected to be disproportionately higher in low- and middle-income countries, indicating a significant public health challenge in these regions (6, 7-8). In the Malaysian context, stroke ranks as the second leading cause of mortality, surpassed only by coronary heart disease (9). The incidence of stroke in Malaysia is alarmingly high, with an average of six new cases occurring hourly (9-10) that need crucial attention from the informal caregivers (ICs).

An ICs for stroke survivors are typically unpaid family members or friends who provide essential support during the recovery process (3). Their multifaceted role includes: offering emotional support, assisting with daily activities, facilitating communication between the survivor and healthcare providers, advocating for the survivor's needs and navigating the complexities of post-stroke care (3,5). In addition, a meta-analysis revealed that several factors related to stroke survivors significantly predicted the burden experienced by their

ICs, including the survivors' ability to perform daily activities, levels of anxiety and depression, and overall neurological condition (7-8).

Furthermore, the complication of stroke including chronic disability, language and communication deficits, incontinence, and behavioral alterations, necessitate prolonged rehabilitation and substantial family support for stroke survivors (11-12). These persistent complications underscore the complex and multifaceted nature of post-stroke care. As the number of stroke survivors increases, so does the demand for ICs, typically family members or friends, who play a crucial role in the recovery and daily care of these individuals (13-15).

There are several reasons to understand the level of burden among ICs of stroke survivors. First, stroke survivors' ICs encounter diverse challenges while tending to their loved ones. These caregivers are vital in assisting with daily activities, therapy, and rehabilitation and their responsibilities can result in reduced productivity, indirect expenses, and significant personal strain, particularly when managing post-stroke spasticity (16-18). Second, research indicates that ICs and other family members provide most long-term care for stroke survivors, underscoring their crucial role in recovery and overall well-being. The level of burden on these caregivers can differ based on various factors, including geographic location (19-20). Third, understanding caregivers' experiences and needs is essential for addressing the challenges they face and ensuring they receive adequate support (16, 21). Therefore, this study was to assess the burden level and its associated factors among ICs of stroke survivors in the Public Hospital in Selangor, Malaysia. Our findings may offer valuable insights to shape the creation of impactful support mechanisms for ICs of stroke survivors.

MATERIALS AND METHODS

Samples

This study was a cross-sectional study. The participants were 108 caregivers of stroke survivors attending follow up and receive treatment in Rehabilitation Clinic and Medical Ward of public hospital in Selangor. All the participants were included in this study if they provided care for at least one-month which the caregiver have an experience and feeling towards the care burden and perception. The participants were recruited using convenience sampling technique at two public hospitals in Selangor.

Measures

Participants completed a socio-demographic questionaires, Zarit Burden Interview (ZBI) (22) and Barthel Index (BI) (23). The questionnaire contains both languages Malay and English and divided into three section. Section A, covers on the general information of the ICs of stroke survivors. The items of the questionnaire include age, gender, educational level, marital status, employment status, monthly income, number of caregivers, and relationship with stroke survivors. Section B, is about the patient status which includes the duration of stroke and their functional status assessment using Barthel index by Mahoney & Barthel (23). This index measures the patient's performance in activities of daily living. This tool determines the level of functional limitation in patients. It consists of 10 items describing the activity of daily living and mobility. These include feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility and stairs use.

The ability of this tools has satisfactory test-retest reliability and sufficient responsiveness for patients with stroke (24). It was used in Domiciliary Care Services by Family Health Development Division, Ministry Of Health Malaysia and widely used in Malaysia study on stroke survivors entitle (25). Section C, covers the IC burden. The questionnaire comprises 22 items adapted from the Zarit Burden Interview: ZBI that include the personal strain question, privacy conflict, guilt, and uncertain attitude. The choosing of ZBI scale because it commonly used in Malaysia's study and other Asian countries like Thailand and India. In this study, ZBI was in Malay version from Mapi Research Trust after approval used by the sole author Zarit Steven (26).

The scoring of the questionnaire in this study was used based on the original scoring of the scale. For general information (Part A) the nominal scale scoring was used. While, in part B, the scoring system for BI was based on the Mapi Research Trust scaling and scoring system (23). The system was based on the original system by the sole author. The scores ranges were from 0 to 100, with a score of 100 representing the highest level of independence. A score of 0 was given when the patient was unable to perform the activity and a score of 0 was also given when the item was Not Applicable (N/A) to the patient. Then the score for "with help item" and independent has been stated in the scoring system. The total score 100 was the sum of all score received. Then, the score was categorized into five elements based on the previous study which includes fully dependent (0-20), severely dependent (21-60), moderately dependent (61-90), slightly dependent (91-99), fully independent (100) (27, 28).

While, in Part C which was the questionnaire on ICs using ZBI scale. The scoring system also based on the Mapi Research Trust scaling and scoring system (22). The interpretation of the score was the high score means the higher burden. The ranges score was from 0 to 88, with the total score was the sum of the score given for each question. In this scale, the 5 points Likert scale from 0 to 4 was used, with "0" represent never, "1" was rarely, "2" was sometimes, "3" was quite frequently, and "4" represent nearly always.

The validity and reliability studies had been done in the previous study. They found BI internal consistency has been described as good (0.80-0.89) to excellent (0.93) (29). ZBI seem valid and reliable to use in Malaysia since it already used is several studies to the women ICs who take care of stroke patients in University Malaya Medical Centre with Cronbach alpha score was 0.92 (30).

Data analysis

Data were analyzed by using Statistical Package for the Social Sciences (SPSS) version 23.0 for Windows. For the socio-demographic characteristics of participants, level of burden and stroke survivor's status were analyzed using descriptive statistical analysis technique (frequency). While the relationship between socio-demographic characteristics of participants and IC was tested using Spearman Correlation, Mann-Whitney U test, and Kruskal-Wallis test. While the association stroke survivors' status with caregiver burden was tested using simple linear regression. The statistical significant level (p) was set at p less than 0.05 ($p < 0.05$).

Ethical clearance

Ethical approval was obtained from University Ethics Committee for Research involving Human Subjects No JKEUPM-2018-066, Medical Research and Ethics Committee Malaysia (MREC) (NMRR-17-2944-38726) Ministry of Health, hospital Clinical Research Centers (CRC), permission from Director of the hospital and informed consent to the participants prior to conduct this study.

RESULTS

A total of 108 caregivers were recruited in this study with age range between 20 and 75 years (mean age, 42.02). Most of the participants 81 (75%) were women, 54 (50%) has secondary school and 76 (70.4%) are married. Details of the socio-demographic characteristics of the study participants are presented in Table I.

Level of burden among IC of stroke survivors

The mean ZBI score among caregivers of stroke survivors was 25.68 (95% CI= 23.25-28.10) with a range of score was from 5 to 62. Surprisingly, overall more than half of the participants, 65 (60.2%) was found to experienced caregiver burden. Majority IC of stroke survivors suffers from mild to moderate burden 49 (45.4%) followed by moderate to severe 15 (13.9%) and severe burden 1 (0.9%). See Table II for the details of the result.

Table I: Socio-demographic characteristics of the study participants

Socio-demographic characteristics of the IC	n=108	%
Age (Mean, 95% CI)	108	42.02 (39.65-44.39)
Gender		
Male	27	25.0
Female	81	75.0
Educational level		
Primary	12	11.1
Secondary	54	50.0
Tertiary	42	38.9
Marital status		
Single	32	29.6
Married	76	70.4
Employment status		
Self-employed	13	12.0
Government	21	19.4
Private sector	41	38.0
Unemployed	33	30.6
Monthly income		
< RM3000	55	50.9
≥ RM3000	53	49.1
Number of caregiver		
Single caregiver	44	40.7
More than one caregiver	64	59.3
Relationship with stroke survivors		
Spouse	59	54.6
Children	40	37.0
Parents	9	8.3

Table II : Level of burden among IC of stroke survivors

IC burden (n=108)	N=108	%	Mean (95% CI)
Burden (ZBI score)			25.68 (23.25-28.21)
No burden or little burden (0-20)	43	39.8	
Mild to moderate burden (21-40)	49	45.4	
Moderate to severe burden (41-60)	15	13.9	
Severe burden (61-88)	1	0.9	

Association between functional status of stroke survivors and IC burden

Stroke survivors' functional status averaged 59.07 (53.77-64.37) on the Barthel Index. 41.7% were severely dependent, while 5.6% were fully independent. The mean duration since first stroke was 15.33 months (11.54-19.12), ranging from 1 to 96 months. Details of the functional status of stroke survivors are presented in Table III.

Stroke survivors' functional status significantly predicted caregiver burden (p=0.001). The standardized coefficient Beta of -0.302 indicated a negative relationship: higher functional status (greater independence) correlated with lower caregiver burden scores on the ZBI scale.While, the study found no significant relationship between the duration of stroke and the level of caregiver burden (p=0.341). See Table III for the details of the result.

Table III: Simple Linear Regression for stroke survivor status and IC burden

Stroke survivor's status	Frequency (n=108)	Mean, 95% CI (%)	Beta	p-value
Functional status (BI score)		59.07 (53.77-64.37)	-0.320	0.314
Fully dependent (0-20)	15	13.9		
Severely dependent (21-60)	45	41.7		
Moderately dependent (61-90)	33	30.5		
Slightly dependent (91-99)	9	8.3		
Fully independent (100)	6	5.6		
Duration of stroke		15.33 (11.54-19.12)	0.093	*0.001
≤ 2 years	90	83.3		
> 2 years	18	16.7		

*Significance at $p<0.05$

Association between socio-demographic characteristics of the IC and the burden perceived by IC

For age, there was a weak positive correlation between age and burden level, which was statistically significant (rs=0.210, p=0.029). There is a positive association where increasing the age of the caregiver may increase the burden to care for the stroke patient. Details of the result are presented in Table IV.

Table IV: Association between socio-demographic characteristics of the IC and the burden perceived by IC

Socio-demographic characteristics of IC	Caregiver Burden	
	Mean (95% CI)	p-value
Age	42.02 (39.65-44.39) 0.210	*0.029a
Gender		0.725b
Male	23.74 (20.12-27.36)	
Female	26.32 (23.29-29.35)	
Educational level		0.761c
Primary	22.75 (17.19-28.31)	
Secondary	25.19 (22.46-27.91)	
Tertiary	27.14 (22.04-32.25)	
Marital status		0.177b
Single	23.44 (18.60-28.28)	
Married	26.62 (23.78-29.45)	
Employment status		0.608c
Self-employed	29.23 (20.02-38.45)	
Government	25.24 (19.18-31.29)	
Private sector	23.50 (19.89-27.11)	
Unemployed	27.15 (22.59-31.70)	
Monthly income		0.201b
< RM3000	27.11 (23.57-30.65)	
≥ RM3000	24.19 (20.80-27.57)	
Number of caregiver		*0.01b
Single caregiver	30.02 (25.61-34.42)	
More than one caregiver	22.58 (19.94-25.21)	
Relationship with stroke survivor		0.126c
Spouse	27.39 (24.40-30.37)	
Children	23.17 (18.45-27.89)	
Parents	24.78 (16.57-32.98)	

a) Spearman test was used for, b) Mann-Whitney U test was used for, c) Kruskal-Wallis test was used for.
*Significance at $p<0.05$

Mann-Whitney U and Kruskal-Wallis tests revealed no significant associations between caregiver burden and gender (p=0.725), educational level (p=0.761), marital status (p=0.177), employment status (p=0.608), monthly income (p=0.201), or relationship with stroke survivors (p=0.126). However, a significant association was found between the number of caregivers and caregiver burden (p=0.01). Detailed results are presented in Table IV.

DISCUSSION

Stroke survivors often rely heavily on ICs, typically family members, for support and assistance in their daily lives. In this study, we found that the demographic profile of ICs aligns with trends observed in other Asian countries. Specifically, the majority of caregivers were female, married, and either the spouse or child of the stroke survivor with the range of age between 20 to 75 years old. This pattern is consistent with findings from similar studies across Asia (3, 35-36). This study's findings reflect Malaysian cultural norms, where women typically care for ill family members. Female spouses and daughters often show respect and gratitude to husbands and parents through caregiving. Other Malaysian studies similarly report that most caregivers are women (35, 37-39).

Our study revealed that 50.9% of stroke survivors' families had monthly incomes below RM3000, closely aligned with Malaysia's average urban household income of RM2662 in 2015-2016 (42). Notably, financial stress significantly impacts caregiver burden, as corroborated by a parallel study in Nepal (40). The high prevalence of stroke-related disability and morbidity, coupled with substantial care costs (43), may contribute to economic dependence for both survivors and ICs, potentially exacerbating financial and psychological strain.

This study also demonstrated that 59.3% of stroke survivors' families had multiple caregivers, suggesting a support network beyond the primary caregiver. This finding aligns with Malaysia's predominant nuclear family structure, often extended to include elderly parents or adult children. The prevalence of extended family households varies among Malaysian ethnic groups, being most common among Chinese Malaysians and least among Malays (19). This pattern stems from cultural traditions emphasizing filial piety and respect for elders, particularly strong in Chinese and Indian Malaysian communities, these values foster intergenerational bonds and mutual support systems (19, 44). This cultural context significantly influences caregiving practices for stroke survivors, potentially mitigating caregiver burden through shared responsibilities while simultaneously reinforcing traditional familial obligations.

It is important to note that majority (60.2%) of stroke survivors in this study experienced a burden from care, with a high proportion experiencing a mild to moderate burden followed by moderate to severe. This study indicate a lower prevalence of caregiver burden compared to study conducted in other countries. Specifically, studies from China and India reported that 67.1% and 65% of ICs respectively experienced various levels of burden (31-32). Our findings suggest a comparatively lower incidence of caregiver strain in our study population.

However, contrary with the finding of a study conducted in Texas, USA which found that 51% of caregivers experienced burden, 34% experiencing mild to moderate burden and 17% experiencing moderate to high burden, and moderate to severe burden (5). The dissimilarity in the finding might be attributed to socioeconomic, cultural, and lifestyle differences between ,the countries studied. For instance, the USA study included only participants who had completed at least high school education and found that about 47% ICs of stroke survivors' experienced substantial or moderate burden (33). These disparities in findings might be due to different assessment tools that used to measure ICs burden, variety in sample sizes and distinct caregiving supportive systems across the region (33).

Furthermore, functional status of stroke survivors emerged as a significant predictor of caregiver burden, with higher levels of independence associated with reduced caregiver burden. This finding aligns with previous study indicating that substantial ICs burden negatively impacts caregivers' quality of life (14, 19, 34). The high global prevalence of stroke exacerbates the challenges faced by ICs (6, 7-8, 14). These findings underscore the importance of addressing both ICs and stroke survivor needs to effectively manage the caregiving burden.

This study highlighted the burden trend among ICs, females more likely to experience mild to moderate and high burdens compared to males, corroborating findings from India (32, 40) and Singapore (36). This disparity likely stems from sociocultural norms and ethical expectations that shape gender-specific caregiving patterns. Female caregivers often dedicate more time to caregiving while simultaneously managing household responsibilities (41). This dual role, rooted in societal constructs, potentially exacerbates the burden on women caregivers relative to their male counterparts. The intersection of caregiving duties with traditional gender roles may result in disproportionate strain on female caregivers, reflecting broader societal dynamics in care provision (34, 41).

There was a positive correlation between age and ICs burden level. Additionally, a Mann-Whitney U test indicated a significant association between numbers of ICs and the level of burden experienced. However, other socio-demographic factors did not demonstrate significant association with caregiver burden. The positive correlation between age and caregiver burden observed in this study may be attributed to age-related physical health decline, potentially diminishing the quality of life for older caregivers. Our findings, based on ICs aged 20-75 years, align with recent research demonstrating a significant positive association between caregiver burden and age (45). This consistency across studies emphasizes age as a crucial determinant of ICs burden, underscoring the need for age-specific support interventions.

Furthermore, this study has identified a negative correlation between age and IC quality of life, coupled with an inverse relationship between burden and quality of life (46-48). This suggests that as caregivers age (particularly beyond 35 years), their quality of life may decrease, potentially intensifying the burden of caring for stroke survivors. These findings highlight the complex interplay between caregiver age, burden, and quality of life in the context of stroke survivor care.

On the other hand, the relationship between ICs and caregiver burden might be influenced by the distribution of caregiving responsibilities. A similar result is obtained indicated that caregiving burden of single caregivers is greater, due to single caregivers receiving less support from other people (28). The nuclear family system ensures that every member of the family helps in caregiving, for example children help in financial support or physical management, as their mother might help in the daily care and improving the environment (49). This condition might affect the perceived burden among caregivers as their burden had been shared, with the principle that the more ICs, the less burden they experience. The situation might not be a problem for the children as caring for their sick parents was a gratitude from them to the parents.

CONCLUSION

This study confirms the presence of perceived burden among ICs of stroke survivors, with a mean ZBI score of 25.68 indicating predominantly mild to moderate burden. Three key factors significantly associated with burden were identified which ICs age, number of caregivers involved, and stroke survivor's functional status. These findings provide valuable insights for tailoring support interventions and contribute to the broader understanding of caregiver experiences in chronic illness management. Observed differences from previous literature may be attributed to variations in population, environment, and cultural contexts. To mitigate caregiver burden, we propose a comprehensive intervention strategy for outpatient settings, encompassing such as assessment of caregiver-specific concerns, evaluation of ICs understanding of patients' conditions and collaborative care plan development with family involvement. This multifaceted approach addresses the complex factors contributing to ICs burden. Integrating caregiver perspectives and family engagement in care planning may enhance support mechanisms and improve outcomes for both ICs and stroke survivors.

IMPLICATIONS AND SUGGESTION

This study underscores crucial implications for healthcare strategies and policies. ICs frequently endure substantial emotional and physical stress, which is often intensified by the stroke's severity and the survivor's level of dependence. To alleviate this burden and enhance outcomes for both caregivers and survivors, it is imperative to implement effective interventions, including caregiver education programs and psychological support services. Furthermore, addressing socioeconomic factors and establishing robust support systems can bolster caregiver resilience and overall well-being. These findings emphasize the necessity for comprehensive caregiver training initiatives and the development of community-based resources to mitigate the challenges confronted by ICs. Such measures are essential for promoting sustainable caregiving practices and improving the quality of life for both caregivers and stroke survivors.

STUDY LIMITATION

The cross-sectional design inherently restricts our ability to establish causal relationships between the various variables examined and caregiver burden. Additionally, the use of convenience sampling may have introduced selection bias, potentially skewing the representativeness of the sample. These limitations underscore the need for future research to employ more robust sampling techniques and expand the geographical and institutional scope to enhance the external validity of the results.

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