

Article

Estimating the Burden Among Informal Caregivers of Stroke Survivors in East Coast Peninsular Malaysia: A Short-Term Longitudinal Study

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Abstract: Taking care of stroke survivors can be taxing, however, it was understudied in Malaysia. This study aims to describe the burden of informal stroke caregivers within three months after hospital discharge. A longitudinal study design was conducted. Acute stroke survivors and their informal caregivers were recruited prior to hospital discharge, and the caregivers were interviewed by phone. Self-reported caregiver burdens were measured with Zarit Caregiver Burden Interview – Malay version (MZBI) and Caregiver Assessment of Function and Upset – Malay version (Malay-CAFU). The MZBI and Malay-CAFU scores were collected four times within three months. A total of 85 stroke survivors and 155 informal caregivers were recruited, with 58.1% of the caregivers were female. The stroke survivors had two caregivers on average. The mean (SD) scores for the three scales show a reduction, from 27.42 (12.73) in the first week to 17.77 (11.20) in the third month for MZBI, from 1.14 (0.94) to 0.62 (0.64) for instrumental activities of daily livings (IADL) of Malay-CAFU upset scale and 1.36 (1.00) to 0.78 (0.65) for activities of daily living (ADL) of Malay-CAFU upset scale in the same period. Stroke survivors may have several caregivers, usually their spouses or children. Within a short period, the caregiver's burden was reduced. Early psychosocial support to alleviate the caregiver burden may be necessary.

Keywords: Stroke; informal caregiver; burden; Zarit Caregiver Burden Interview; Caregiver Assessment of Function and Upset; Malaysia

1. Introduction

Stroke is one of the common chronic diseases with a spectrum of debilitating outcomes. Advancements in treatment modalities allow more stroke patients to survive their acute stroke episodes. However, many of these stroke survivors ended up with varied disabilities affecting their physical, emotional, and social aspects. Many stroke survivors also lose their jobs due to the diseases [1]. It is estimated that stroke is the third leading cause of death and disability combined, globally [2].

The abrupt incidence of a stroke may significantly change the lives of stroke survivors and those around them. In Malaysia, more than half of stroke survivors require various assistance [3], including daily living activities such as self-care (dressing, eating, toileting), communication, preparing meals, laundry, home management, and childcare. The role of caring for and supporting stroke survivors is usually taken by family members, especially spouses and children [4–6]. These family members who take care of the stroke survivors were called informal caregivers, compared to the formal caregivers who may receive payment, such as a personal nurse.

Moreover, the unanticipated role change in the family could affect stroke survivors and caregivers, particularly within the first few months after a stroke episode. Many informal caregivers experience varying degrees of burden resulting from these changes of roles, which include taking care of the stroke survivors while struggling to carry out their routine job tasks and taking over some of the responsibilities in the family [7]. The caregivers' burden may lead to stress, anxiety, and depression. Some studies have shown a higher prevalence of stress, anxiety, and depression among caregivers than in the general population [4,8,9].

Various factors were associated with high burdens, which can be due to the stroke survivors, the caregivers themselves, or the environmental factors they were involved with. For example, stroke survivors' factors include the stroke survivors' age and gender [6,9]. In contrast, the caregivers' factors include age, gender, education, care time, and lack of knowledge [9–11]. In addition, some environmental factors include limited access to healthcare services, unsuitable house conditions, and lack emotional and financial support [5,9].

Despite the challenges faced while caring for a stroke survivor, these caregivers did not give up and persistently cared for the stroke survivor in their family. A sense of responsibility was a significant motivation, and seeing stroke survivors recover is usually considered rewarding. Some caregivers also perceive their relationship with the patients as more intimate despite the unfortunate mishap [5,7,12].

As more studies have shown that the involvement of caregivers in rehabilitation may improve the outcome, support for caregivers may also be an essential consideration in developing a care plan for stroke survivors during hospital discharge [13–15].

While studies measuring the burden were numerous – both quantitative and qualitative, longitudinal studies were still limited, particularly in Malaysia. Since the high caregiver burden affects the caregivers' quality of life and mental health, it is imperative to measure the caregiver burden. In this study, we measured the burden of caregiving in a short-term period, from the time of discharge to three months post-discharge. Shedding light on the stroke caregivers' burden in Malaysia may provide critical information for policy purposes, including describing the past and current scope of the condition, assessing the potential effect of intervening/supporting stroke caregivers on a national level, and identifying areas where resources can be targeted more precisely and effectively.

2. Materials and Methods

2.1. Design

This is a short-term prospective longitudinal study involving stroke survivors admitted to three tertiary hospitals in east-coast Peninsular Malaysia, conducted between March 2021 to December 2021.

2.2. Participants

The three hospitals had a dedicated stroke team, which responsible for management of stroke patients, independently from this study. The stroke teams screened suitable stroke patients during initial hospitalisation. Subsequently, a trained research assistant approached the stroke survivors and their caregivers, and invited them to participate in the study. Inclusion criteria for the stroke survivors include adult Malaysian diagnosed with acute stroke, in which the diagnosis was made by the attending medical team. Inclusion criteria for the informal caregiver was any Malaysian adult actively taking care of the stroke survivors, which may assist the survivors for his or her activity of daily living. Paid caregiver, such as private nurse, attendant or maid were excluded. The stroke survivors and their caregivers may name more than one caregiver, if there were several people taking care of the stroke survivors. Recruitment of the survivors was done before the patient was discharged, while the caregivers can be recruited concurrently with survivors, or if there were additional caregivers, the additional caregivers can be recruited within three months after the survivors was discharged from the hospital. The recruitment was done between March 2021 and August 2021. Prior written and informed consent was obtained from every participant.

2.3. Tools

Study variables collected in this study included (i) stroke patients' disability statuses – measured by the modified Rankin Scale (mRS) and Shah-modified Barthel Index (Shah mBI), the stroke survivors' (ii) both patient's and caregivers' demographic information, and (iii) caregivers' burden measured using two commonly used tools, i.e., Zarit Burden Interview (ZBI) and Caregiver Assessment of Function and Upset (CAFU).

Both the mRS and Shah-mBI have been widely used in clinical and research settings. The mRS was used to measure stroke survivors' overview functional level, ranging from no symptoms (score 0) to death (score 6), with many studies opted to categorize the score into independence (mRS = 0 – 2), dependence (mRS = 3 – 5) and death (mRS = 6) [16,17]. In this study, stroke team record mRS and Shah-mBI as part of their management before the patient is discharged. The trained research assistant then extract the mRS and Shah-mBI score from patient's hospital record. This study recorded the mRS in numerical value and categorised it into the independence or dependence categories. Compared to mRS, which was a generalised overview of functional level, the Shah mBI was used to measure the stroke survivors' dependence level in performing specific activities of daily living. The Shah mBI has ten questions, with a possible total score from 0 (require full assistance) to 100 (fully independent), with each question scored based on whether they can perform the specific task independently or require assistance [18]. In this study, the Shah mBI was reported as the raw value in numerical format as there was a lack of cut-off point standardisation [19].

The ZBI was used to measure subjective burden or the appraisal of the impact that providing care has on the caregiver's life. The questionnaire is commonly used to assess the caregiver burden associated with caring for patients with impairment, such as stroke survivors, the elderly, and those suffering from dementia [20]. The ZBI had 22 questions, with a 5-point Likert scale ranging from 0 (never) to 4 (nearly always), making possible total scores ranging from 0 to 88. Higher scores indicate greater caregiver distress or burden. The ZBI can be used in phone interviews [21,22]. The Malay version of ZBI (MZBI) used in this study was well validated and had good reliability [23].

Compared to ZBI, the CAFU was used to measure the caregiver's perception of the stroke survivor's function level and the caregiver's reaction to caregiving related to the specific activities of daily living (ADLs) and instrumental activities of daily living (IADLs). While the CAFU measured upset, in this study, upset and burden were used interchangeably. The CAFU had 15 items - eight items for the IADLs subscale and seven items for the ADLs subscale. Items in the IADLs include the use of telephone, shopping, meal preparation, housework, laundry, travel, medicine, and finance. In contrast, ADLs include bathing, dressing the upper and lower body, toileting, grooming, eating, and getting in and out of bed. Each item in the CAFU had two dimensions, one measuring the

patients' dependence level and another measuring the caregivers' upset level. Both dimensions were scored using the Likert scale, with the dependence dimension will be scored ranging from 0 (total assistance) to 7 (complete independence), and the upset level was scored ranging from 0 (not bothering or no upset at all) to 4 (extremely upset). The score was reported by the subscale (total for IADLs and ADLs), and the questionnaire had good validity and reliability [24]. At the time of writing, the Malay-CAFU was validated with good reliability, but the validation was not published yet.

The MZBI and Malay-CAFU were collected from the caregivers via phone interview at 1-week, 1-month, 2-months, and 3-months post-discharge. Missing data due to no response was expected. To minimise the low response rate, the trained research assistance will try to contact the responded up to three times at the set time (1-week, 1-month, 2-month, and 3-month), daily up until five days later. The respondent was considered uncontactable if there was no response.

2.4. Sample size estimation

The sample size was estimated using a single mean estimation [25]; considering the standard deviation for ZBI was 6.5 [26], with a precision of 1.5 and a drop out of 10%, the minimum sample size required was 182 caregivers. Assuming each stroke survivor may have, on average, two caregivers, the required minimum sample size for stroke survivors was 90 individuals.

2.5. Statistical Analysis

Descriptive analysis was conducted using R (version 4.2.1) within the RStudio (version 2022.07.1) platforms [27,28]. After checking the data distribution, numerical values were presented in mean (standard deviation, SD) or median (inter-quartile range, IQR). Subsequently, the caregivers' burden was stratified by the caregiver's gender and survivor's dependence level. In addition, categorical data were presented in frequency (percentage, %). R packages used in the analysis were tidyverse packages – including the ggplot2 package, and the gtsummary package [29,30].

3. Results

There were 85 stroke survivors agreed to participate in this study. Most of the stroke survivors were male, with age ranging from 23 to 92 years old. Most stroke survivors had two caregivers (46.4%) – ranging from a single caregiver to six caregivers. Upon discharged from hospital, 79.1% of the stroke survivors was in dependence category (mRS 3-5). Demographic characteristics of the stroke survivors were summarised in Table 1.

Table 1. Stroke survivors Characteristic (n = 85).

Stroke Survivor Characteristic		n (%)
Gender	Female	38 (44.7)
	Male	47 (55.3)
Age (year)		60.12 (11.08) ¹
Number of Caregivers		2.0 (1.5, 3.0)
Number of Household		5.0 (3.0, 6.0)
mRS	No symptoms	3 (3.5)
	Symptoms but no disability	5 (5.9)
	Mild disability	10 (11.6)
	Moderate disability	19 (22.4)
	Moderate severe disability	25 (29.4)
	Severe disability / bedridden	23 (27.1)
Shah-mBI		21.0 (3.0, 58.8) ²

¹ Mean (SD). ² Median (IQR).

Of the 86 stroke survivors who agreed to participate, there were about 355 caregivers to support them. However, only 155 caregivers agreed to participated in this study. Out of these 155 caregivers, 24.9% of them only complete baseline (demographic) measurements, while 39.3% had complete responses for the four time events (Table S1). The caregiver's age was range from 16 to 70 years old, and most of the caregivers were female and the survivors' children. 28.4% of the caregivers were also responsible for other dependents besides the stroke survivors. Caregivers' characteristics were summarised in Table 2.

Table 2. Caregiver Characteristic (n = 155).

Caregiver Characteristic		n (%)
Gender	Female	90 (58.1)
	Male	65 (41.9)
Age (year)		38.75 (14.51) ¹
Caregiver living together with the survivor		126 (87.5)
Caregiver relation with survivor	Spouse	39 (25.2)
	Children	82 (52.9)
	Child-in-law	24 (15.5)
	Grandchildren	4 (2.6)
	Siblings	3 (1.9)
	Parent	3 (1.9)
Marital Status	Single	43 (27.7)
	Married	112 (72.3)
Education Level	Did not go to school	2 (1.3)
	Secondary School	91 (58.7)
	College / University	62 (40.0)
Occupation Status	Unemployed	58 (37.4)
	Student	12 (7.7)
	Employed	85 (54.8)
Caregiver's other dependence		44 (28.4)
No. of caregiver's other dependence		2.0 (1.0, 3.0) ²

¹ Mean (SD). ² Median (IQR).

As measured by MZBI and Malay-CAFU, patients' dependence and caregiver burden decreased in the first three months after discharge. The dependence level on IADL was higher than on ADL; however, the mean upset score was higher on ADL than on IADL. Stratified analysis showed that caregivers taking care of dependent stroke survivors had higher burden scores at each of the time events compared to those taking care of independent stroke survivors. The trend of MZBI and Malay-CAFU were summarised in Table 3, and the stratification was presented in Table 4. Figure 1 showed the reduction of burden among caregivers of independent stroke survivors was more than caregivers of dependent stroke survivors.

Table 3. MZBI and Malay-CAFU trend at T₀ (Week 1), T₁ (Month 1), T₂ (Month 2), and T₃ (Month 3), (n = 155).

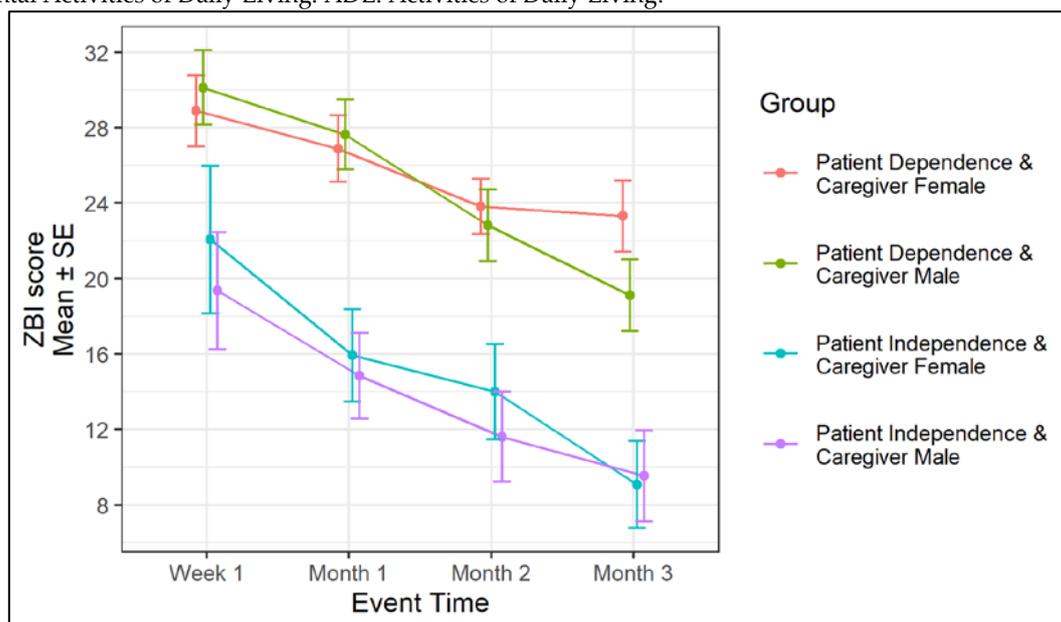
Variable		Week 1, n = 104	Month 1, n = 92	Month 2, n = 75	Month 3, n = 83
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
MZBI		27.42 (12.73)	23.87 (11.21)	20.23 (9.67)	17.77 (11.20)
Malay-CAFU (IADL)	Dependence	5.43 (1.54)	4.83 (1.80)	4.71 (1.85)	4.45 (1.91)
	Upset	1.14 (0.94)	1.07 (0.80)	0.90 (0.72)	0.62 (0.64)
Malay-CAFU (ADL)	Dependence	5.16 (1.87)	4.60 (1.99)	4.55 (2.02)	4.02 (2.11)
	Upset	1.36 (1.00)	1.21 (0.86)	1.06 (0.68)	0.78 (0.65)

* MZBI: Zarit Caregiver Burden Interview – Malay version. Malay-CAFU: Caregiver Assessment of Function and Upset – Malay version. IADL: Instrumental Activities of Daily Living. ADL: Activities of Daily Living.

Table 4. Stratified analysis of MZBI and Malay-CAFU trend at T₀ (Week 1), T₁ (Month 1), T₂ (Month 2), and T₃ (Month 3) by the patient's dependence level and caregiver's gender (n = 155).

Time	Variable	Independence ¹ , n = 37		Dependence ² , n = 118		
		Female ³ , n = 20	Male ⁴ , n = 17	Female ³ , n = 70	Male ⁴ , n = 48	
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	
Week 1	MZBI	22.07 (14.67)	19.36 (10.28)	28.90 (12.07)	30.13 (12.23)	
	Malay-CAFU (IADL)	Dependence	3.86 (1.38)	3.15 (1.46)	6.03 (1.06)	6.01 (0.94)
		Upset	0.82 (0.51)	0.82 (0.80)	1.12 (0.97)	1.34 (1.03)
	Malay-CAFU (ADL)	Dependence	2.89 (1.58)	2.83 (1.82)	6.01 (1.14)	5.77 (1.36)
		Upset	1.14 (0.57)	1.58 (0.83)	1.27 (0.94)	1.46 (1.18)
	Month 1	MZBI	15.92 (8.80)	14.85 (8.22)	26.89 (10.95)	27.64 (9.88)
Malay-CAFU (IADL)		Dependence	2.58 (1.02)	2.83 (1.60)	5.74 (1.28)	5.55 (1.00)
		Upset	0.63 (0.46)	0.85 (0.60)	1.11 (0.89)	1.27 (0.78)
Malay-CAFU (ADL)		Dependence	2.21 (1.03)	2.62 (1.72)	5.55 (1.53)	5.33 (1.38)
		Upset	0.97 (0.42)	1.32 (0.82)	1.17 (0.94)	1.31 (0.87)
Month 2		MZBI	14.00 (7.60)	11.62 (8.59)	23.83 (8.06)	22.83 (9.13)
	Malay-CAFU (IADL)	Dependence	2.50 (1.10)	2.55 (1.61)	5.80 (1.10)	5.38 (1.11)
		Upset	0.39 (0.50)	0.75 (0.70)	1.05 (0.76)	0.92 (0.70)
	Malay-CAFU (ADL)	Dependence	2.16 (0.99)	2.38 (1.73)	5.80 (1.19)	5.08 (1.51)
		Upset	0.78 (0.34)	0.92 (0.38)	1.06 (0.72)	1.16 (0.74)
	Month 3	MZBI	9.08 (8.01)	9.54 (8.74)	23.31 (10.73)	19.12 (9.48)
Malay-CAFU (IADL)		Dependence	2.49 (1.53)	2.38 (1.55)	5.60 (1.24)	5.09 (1.25)
		Upset	0.25 (0.36)	0.35 (0.41)	0.72 (0.70)	0.70 (0.65)
Malay-CAFU (ADL)		Dependence	1.60 (0.78)	2.12 (1.69)	5.33 (1.51)	4.59 (1.67)
		Upset	0.67 (0.58)	0.77 (0.46)	0.77 (0.73)	0.80 (0.62)

* ¹Independence Stroke survivor. ²Dependence Stroke survivor. ³Female caregiver. ⁴Male caregiver. MZBI: Zarit Caregiver Burden Interview – Malay version. Malay-CAFU: Caregiver Assessment of Function and Upset – Malay version. IADL: Instrumental Activities of Daily Living. ADL: Activities of Daily Living.



(a)

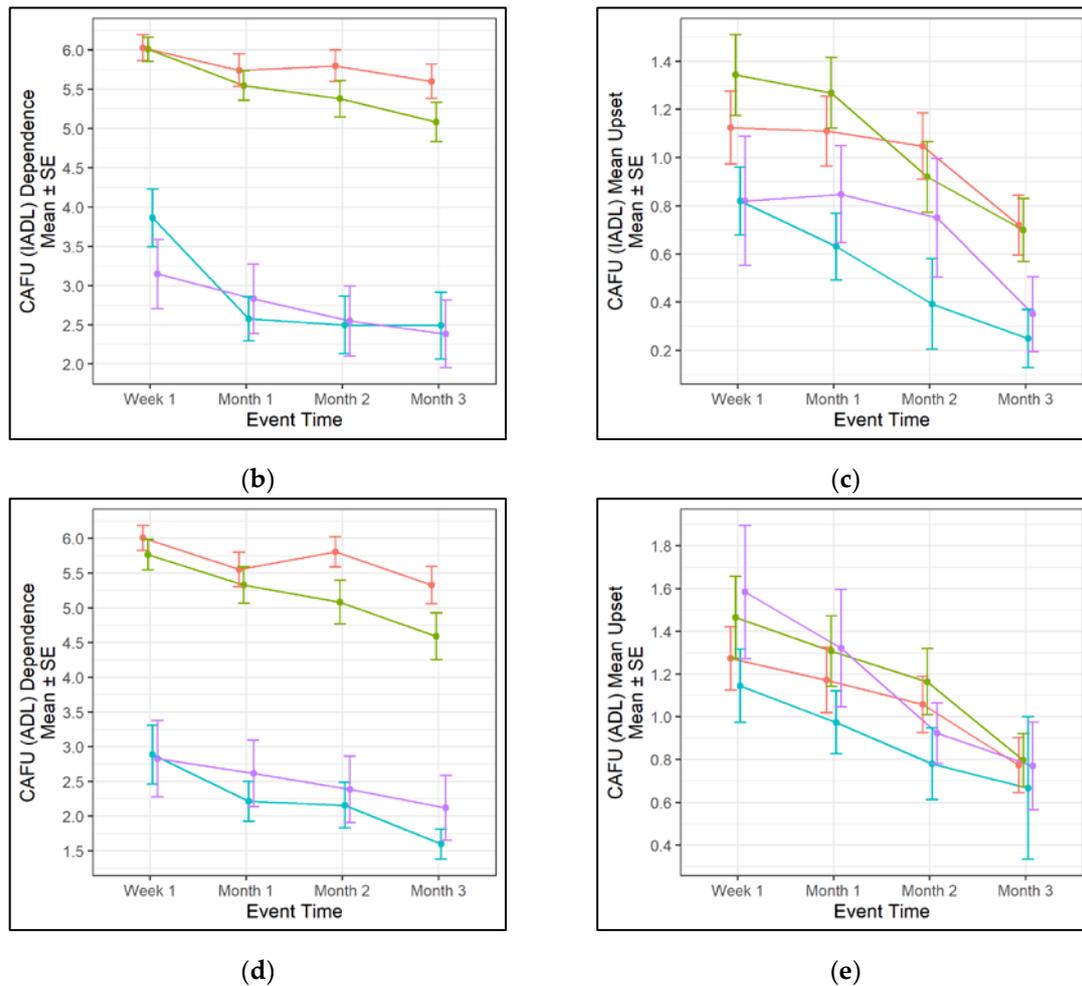


Figure 1. MZBI and Malay-CAFU trend at T_0 (Week 1), T_1 (Month 1), T_2 (Month 2), and T_3 (Month 3); (a) MZBI; (b) Malay-CAFU IADL Dependence; (c) Malay-CAFU IADL Mean Upset; (d) Malay-CAFU ADL Dependence; (e) Malay-CAFU ADL Mean upset, when stratified to patient's dependence level and caregiver's gender, ($n = 155$).

4. Discussion

Taking care of loved ones can be challenging, and taking care of stroke survivors is no exception. Many studies have already established that stroke caregivers endured various forms and severities of burdens. However, most studies on caregivers' burden among stroke caregivers involved caregivers-only studies [4–6,31] or single patient-single caregiver dyad approaches [10,32]. This study took a step further in which, in addition to the dyad approach, we recruited several caregivers for each stroke survivor.

This study highlighted the burden trend among stroke caregivers in Malaysia over the first three-months post-discharge/admission. The results demonstrated three key findings. First, most stroke survivors were taken care of by female caregivers, had relationships as stroke survivors' children, and most of the caregivers were married. Second, the caregivers' burden was reduced over the first three months post-discharge. Third, caregivers taking care of dependent stroke survivors had a higher burden. To our knowledge, this study was the first prospective study to measure the burden among stroke caregivers longitudinally in Malaysia.

In our study, the majority of the caregivers were female. This is consistent with other studies [4,6,11,33]. The higher percentage of females might be due to several factors. While other studies reported that a higher proportion of female caregivers were due to a higher proportion of male stroke survivors, and many of the caregivers tend to be the spouses of the stroke survivors [4,10,33,34]. Meanwhile, in our study, most caregivers were the stroke

survivors' children. Apart from that, caregiving was also traditionally viewed as a female role [5,7,31,35].

Our study also demonstrated that the caregivers were younger than in other studies [4,10,32]. This was most likely because of our study design, in which we recruited more than one caregiver for each stroke survivor, while other studies recruited only the primary caregiver. The primary caregiver was mostly the spouse, and since in other studies, most of the survivors were in their 50s, so did their spouse [4,11,34]. Meanwhile, since the majority of the caregivers recruited in our study were the survivors' children, this reflected the younger caregiver age in our study.

The numbers of caregivers for each patient in our study ranged from single caregivers to six caregivers, with an average of two caregivers for each stroke survivor. This was expected, as stroke survivors were discharged home and taken care of by their family members [36,37].

The level of burden measured among the caregivers in our study at baseline was similar to other cross-sectional studies [4,33], including a study previously in east-coast peninsular Malaysia [26]. However, none of the longitudinal studies used the same instrument as in our study. Otherwise, our study found that the burden and the reaction or upset toward both ADLs and IADLs were reduced over the first 3-months. This finding was consistent with multiple studies [6,32]. While the initial part of caregiving was challenging, the burden was reduced over time.

Various factors were linked to caregivers' burden. Our study found that caregivers taking care of stroke survivors with higher dependence had a higher burden. While the burden reduces over time, the burden reduction among caregivers of independent stroke survivors was more remarkable than among caregivers of dependent stroke survivors. Similar results have been seen in numerous studies when independent stroke survivors had a better outcome in terms of caregivers' burden [6,11,34]. It was expected that independent stroke survivors would require less assistance from their caregivers regarding time and effort. Independent stroke survivors were also expected to recover more quickly and even go to work, thus releasing the burden on the caregivers [38].

Interestingly, while we found that the caregivers' burden reduced over the three months, the caregivers' perception of the stroke survivors' dependence level for both IADLs and ADLs showed a slight improvement. We suspected that there was possibility that the baseline perceived dependence level was already low; thus, any improvement might have been imperceptible to the caregivers. Other possible explanation was that, regardless of the stroke survivors' dependence level (or lack of improvement of the dependence level), the caregivers' burden will still improve over time [39]. Otherwise, evidence from other studies showed that patients' function and dependence would improve over time [10,32]. In addition, several factors were known to affect the trend of survivors' functions and caregiver burden, including caring hours per day, type of rehabilitation, stroke severity, caregivers' age and caregivers' education level [6,13,32,40], and improvement of patient's function was associated with improvement of caregivers' burden.

Several studies have found conflicting findings regarding the effect of caregivers' gender on caregivers' burden [35,41]. In our study, we did not find any substantial difference in burden scores when comparing between caregivers' gender, which was also reported in some studies [32], but not in other studies [6,9,35]. We, however, agreed that while we did not find the difference here, more or less the caregiver's gender may affect the caregiver's burden. It was postulated that male caregivers might underreport their burden, as they may perceive a higher burden as their failure to fulfil their caregiver responsibilities [31]. In addition, male caregivers take pride in providing care, are occasionally reluctant for social support, and most care for the patient alone [7].

Other factors that may affect the caregiver burden, which were not explicitly explored in this study, are worth discussing here, as these factors may affect the burden that the caregivers in our study have reported. The major reason that caregivers often feel a burden taking care of stroke patients is due to their difficulty in adapting to their new role. Many of these caregivers had to adjust their lifestyles, some lost their jobs, and many

had to take over roles that were previously held by the patients [7,14]. In a short time, these caregivers also had to learn new skills, either formally or non-formally, such as bathing and feeding patients, basic physical therapy for patients, and coping mechanisms skills [5,7]. Even worse, some caregivers may feel abandoned if there is a lack of supports – financial, emotional, and social support [14,42]. Lack of access to patient care services may also contribute to the burden, whether the caregiver is unable to bring the patient due to lack of time, money, or logistics, or the services that were required by the patients or the caregivers were not available [7,12,42]. If the caregiver's burden is not dealt with appropriately, it may progress to other issues such as poor quality of life, anxiety, and depression [4,6,8,33].

This study showed that there was clear evidence for the need for early intervention, both for the stroke survivors and their caregivers. These interventions could be started as early as the patient is still in hospital, as the caregiver's preparedness will ease the burden [43,44]. To ensure continuity of care and to prevent caregivers from feeling lost when transferring patient care from the hospital to community-based care, stroke teams, including tertiary teams, should have clear documentation and communication with primary care or community-based care providers [14,42]. The interventions should not be implemented separately but rather in a dyadic approach [15], with various modalities, either in silo or in combination, including cognitive behavioural therapy, coping mechanism skills, psychoeducation, and counselling [14]. While some of these therapies may require highly specialised professionals such as psychiatrists or psychologists, well-trained paramedics such as nurses can also deliver the interventions. Individualised regimes tailored to the needs of patients and the caregivers were more preferable, but lack of resources may limit some care providers to only delivering "one-size-fits-all" interventions [14,45]. Care providers should be aware of the availability of other types of support services available for the patients and their caregivers, including social, financial and spiritual support, both from government and non-governmental organisations [5,7,12].

This study was conducted on east-coast peninsular Malaysia and may reduce its generalisability. This study was also limited by the missing data. Only 39.4% of the caregivers complete all the responses at $T_0 - T_3$, and 76.1% complete responses at least once at $T_0 - T_3$. While we tried our best to reach all the caregivers to complete the response, some of the caregivers were unable to respond to some of the time events, due to the ongoing COVID-19 epidemic in Malaysia. This study also only described the levels of caregiver burden, which may limit the findings. Advanced statistical methods such as repeated measure analysis of variance (RM ANOVA) or multilevel modelling may be required to measure any mediating effect upon the caregiver burden [6,32,46], which was beyond the scope of this paper.

5. Conclusions

This study showed that stroke survivors might have several caregivers, often those close to them. A stroke usually happens suddenly, and caregivers were often unprepared. Therefore, they may feel a different degree of burden related to caregiving, especially caregivers taking care of stroke survivors with poor high dependency function levels, as they may require more assistance. Overall, our results demonstrate a caregiver burden reduction over the first three months post-discharge. However, it is strongly recommended to develop a scalable solution or intervention regarding the post-stroke and initiate it as early as during admission to alleviate the caregivers' burden and ensure both stroke survivors and caregivers have good physical and mental health after an unprecedented stroke incidence. However, the burden may reduce over time. Thus, physical, emotional, and financial support should be offered early, and any intervention to alleviate the caregiver burden can be initiated as early as in the ward.

Supplementary Materials: The following supporting information can be downloaded at: www.mdpi.com/xxx/s1, Table S1: Number of responses; Table S2: Number of responses for each time event; Figure S1: Correlation matrix between Rankin Score (rankin), Barthel Index Score

(barthel), Zarit Burden Interview Score (zbi), IADL care-hour (iadl_ch), IADL Dependence Score (iadl_d), IADL Total Upset Score (iadl_ut), IADL Mean Upset Score (iadl_um), ADL care-hour (adl_ch), ADL Dependence Score (adl_d), ADL Total Upset Score (adl_ut) and ADL Mean Upset Score (adl_um), at overall; Figure S2: Correlation matrix between Rankin Score, Barthel Index Score, Zarit Burden Interview Score, IADL care-hour, IADL Dependence Score, IADL Total Upset Score, IADL Mean Upset Score, ADL care-hour, ADL Dependence Score, ADL Total Upset Score and ADL Mean Upset Score, at a) 1 week, b) 1 month, c) 2 month, d) 3 month; Figure S3: MZBI and Malay-CAFU trend, when stratified to patient's dependence level; Figure S4: MZBI and Malay-CAFU trend, when stratified to caregiver's gender; R script.

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Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: The de-identified data can be publicly accessed via <https://zenodo.org/record/6998141> after the embargo period, which ended on 31st December 2022.

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