

Caregiver Burden is Associated with Cognitive Decline and Physical Disability of Elderly Post-Stroke Patients

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Abstract: Caregiver burden following stroke is increasingly recognised as a significant health care concern. The present study found the prevalence of elderly patient's post-stroke depression, cognitive impairment and caregiver's burden to be 32%, 57.6% and 25%, respectively. Caregiver burden was significant, albeit weakly, correlated with cognitive decline ($r=0.362$, $P\leq 0.001$) and physical disability ($r=0.316$, $P=0.002$) of elderly post-stroke patients. Otherwise, none of the socio-demographic characteristics of caregiver or patient, including depression, were significantly correlated with caregiver burden. This study highlighted the importance of regular assessment of cognitive function and physical disability of elderly post-stroke patients for early detection of caregiver burden, in addition to assessment of caregiver psychological wellbeing.

Key words: Caregiver • Cognitive Deficit • Post-Stroke Depression • Burden • Disability

INTRODUCTION

People are living longer than ever before, often with chronic and debilitating illnesses. At the same time, recent treatment, economic and policy changes have resulted in a shift from inpatient to outpatient care for many serious illnesses placing greater demands on the caregivers [1, 2]. Stroke is one of the leading causes of morbidity worldwide. Using the WHO world standard population, the age-adjusted incidence rates of stroke range from 41 per 100 000 population per year in Nigeria (1971-74) to 316/100 000/year in urban Dar-es-Salaam [3]. The incidence of stroke in Besut, northeastern part of Malaysia peninsular was 46.0/100,000/year in 2001 [4]. Nevertheless, there has been no comprehensive database on the incidence of stroke in Malaysia [5, 6].

Caregiver burden following stroke ranged 25-54% and is increasingly recognised as a significant health care concern [7]. Although stroke is a worldwide problem, the burden of stroke is particularly serious in Asia where rapidly aging population and improved stroke care increase the number of stroke survivors who require long-term, costly care. In contrast, lower birth rate and

relatively insecure social health system markedly increase the gap between caregiver demands and the resources of the caregivers leading to caregiver strain or burden. Thus, the rapidly aging populations and increasing stroke burden potentially shrink the economy and destabilize the society, unless appropriate efforts are promptly initiated [8]. In Malaysia, a transition of age structure towards aging population was indicated by a decrease from 33.3 to 27.6 per cents of population below 15 and increase from 3.9 to 5.1 per cents of population above 65 over a 10-year period [9].

Despite the growing body of literature on the consequences of providing non-professional care to stroke survivors, the determinants of caregiver burden are still not fully established. Among the most frequently identified factors are: the patient's functional status [10-13], the caregiver's depressive symptoms [14], the time spent caregiving or the number of caregiving tasks [10, 12, 15] and the caregiver's social support [10, 11]. The aim of this study was to identify the socio-demographic determinants of caregiver burden of elderly post-stroke patients. In addition, the relationship between caregiver's depressive symptoms, patient's

cognitive impairment and disability with caregiver burden would be determined. With the information obtained from this study, further planning and actions could be taken to improve the health care for the elderly patients and the welfare of their caregivers to reduce the burden of the caregivers, the cost of the medical expenses and improve the outcome of the patients.

MATERIALS AND METHODS

Subjects: The study protocol was approved by the Research and Ethics Committee. All eligible subjects, comprising the elderly (above 60) post-stroke patients and their caregivers, attending the Medical Outpatient Clinic during a 3-month cross-sectional study period starting from December 2011 were enrolled into the study after their consent. Patients and their caregivers were interviewed to obtain the social-demographic data. The Geriatric Depression Scale (GDS)-15 was given to the patients. Short Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) and Caregiver Strain index (CSI) were given to the caregivers to complete in the allocated room without assistance from other person. The patients were also assessed by the researcher using the Modified Rankin Scale (MRS). Verbal help was provided when necessary without influencing their answers. Medical information was gathered from the patient medical records.

Instruments: The GDS-15 is a shorter version of the original GDS [16] which has demonstrated very good internal consistency (alpha 0.94), split-half and test-retest reliability of 0.94 and 0.85 over one week, respectively in assessing elderly depression. It consists of 15 short questions (yes/no) where a score of less than five indicates the absence of depression, a score 5 to 10 indicates probable depression and a score of more than 10 indicates definite depression [17]. The GDS-15 has been tested in multiple settings and countries. In Malaysia, its internal consistency reliability was found to be high with a Cronbach's α of 0.83 [18].

The MRS is commonly used to measure the disability of stroke patients in the community. The severity of the stroke is rated from 0 (No symptoms); 1 (No significant disability. Able to carry out all usual activities, despite some symptoms); 2 (Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities); 3 (Moderate disability. Requires some help, but able to walk unassisted); 4 (Moderately severe disability. Unable to attend to own bodily needs without assistance and

unable to walk unassisted); 5 (Severe disability. Requires constant nursing care and attention, bedridden, incontinent) and; 6 (Dead). It has shown good inter observer reliability with Kappa for all pair wise observations 0.56 and weighted kappa 0.91 [19].

The IQCODE is a 26-item questionnaire which asks the informant about cognitive changes over the previous 10 years [20]. The IQCODE has been shown to be less influenced by education, proficiency in the language of the country of residence and premorbid ability [21], in contrast to cognitive screening tests such as the MMSE which have been shown to be affected by gender, age, education, cultural background, language spoken at home, socio-economic status, occupation and presence of a mood disorder. Subsequently a 16-item Short IQCODE was developed. It correlated 0.98 with the full version as well as had comparable validity when judged against clinical diagnosis [20]. As it was developed for informant self-completion, it has also been used as a face-to-face and a telephone interview [21]. It was validated in Malay with Cronbach's alpha 0.94 [22].

The CSI is a 13-item self-rated questionnaire that measures strain related to care provision which covers five major domains; employment, financial, social, time and physical. Participants answer the items as Yes (1) or No (0). Positive answers given to 7 or more items on the scale indicates a high level of stress and the subjective care load as perceived by the caregiver. There is no age limit for the individuals that could be assessed using the tool [23]. The Malay Caregiver Strain Index has shown a good validity with internal consistency (Cronbach's alpha 0.79) [24].

RESULTS

Table 1 shows the socio-demographic variables of the caregivers. About two thirds of caregivers in this study stayed with the patients (70.7%) and were female (65.2%), consistent with nursing roles that are traditionally associated with women. The Malay, Chinese, Bidayuh and Iban make up 26.1, 58.7, 4.3 and 7.6 percents of all caregivers, respectively. About half of caregivers were educated up to secondary level (51.1%) and employed (54.3%). As shown in table 2, majority of patients had ischemic (93.5%) with no previous history (90.2%). About 70% had 2 or more medical co-morbidity. The mean duration of stroke was 38.3 ± 37.6 months.

Overall mean score for GDS, short IQCODE and CSI were 5.9 ± 3.4 , 3.6 ± 0.6 and 4.4 ± 3.1 , respectively. There were 28 (32%) patients with depression (GDS ≥ 8), 53 (57.6%) patients with

Table 1: Socio-demographic characteristics of caregivers and post-stroke patients

	Caregivers (N=92) Frequency (%)	Patient (N=92) Frequency (%)
Age (mean ± SD)	47.9 ± 13.80	71.5 ± 7.53
Gender		
Female	60 (65.2)	44 (47.8)
Male	32 (34.8)	48 (52.2)
Ethnicity		
Malay	24 (26.1)	-
Chinese	54 (58.7)	-
Iban	4 (4.3)	-
Bidayuh	7 (7.6)	-
Others	3 (3.3)	-
Educational Level		
Nil	4 (4.3)	33 (35.9)
Primary	21 (22.8)	41 (44.6)
Secondary	47 (51.1)	16 (17.4)
Tertiary	20 (21.7)	2 (2.2)
Religion		
Islam	25 (27.2)	25 (27.2)
Buddhism	33 (35.9)	34 (37.0)
Christian	30 (32.6)	27 (29.3)
Others	4 (4.3)	6 (6.5)
Employment Status		
No	42 (45.7)	-
Yes	50 (54.3)	-
Staying with Patient		
No	27 (29.3)	-
Yes	65 (70.7)	-

Table 2: Clinical characteristics of post-stroke patient (N=92)

Clinical characteristics	Frequency (%)
Type of Stroke	
Ischaemic	86 (93.5)
Heamorrhagic	6 (6.5)
Stroke Lesion Location	
Left	47 (51.1)
Right	33 (35.9)
Both	12 (13.0)
Duration of Stroke (Mean ± SD)	38.3 ± 37.6
Number of Previous Stroke	
Nil	83 (90.2)
One	9 (9.8)
Number of Comorbidity	
Nil	1 (1.1)
1	27 (29.3)
2	34 (37.0)
3	12 (13.0)
4	12 (13.0)
5	5 (5.4)
6	1 (1.1)
GDS-15 (Mean ± SD)	5.9 ± 3.4
MRS (Mean ± SD)	2.5 ± 1.4
IQCODE-short (Mean ± SD)	3.6 ± 0.6

Table 3: Association between burden and socio-demographic characteristics of caregivers

	Caregiver Burden n (%)		χ^2 value (df)	P value
	Insignificant	Significant		
Age				
40 and below	23 (74.2)	8 (25.8)	0.016 (1)	0.899
41 and above	46 (75.4)	15 (24.6)		
Gender				
Female	47 (78.3)	13 (21.7)	1.022 (1)	0.312
Male	22 (68.8)	10 (31.3)		
Ethnicity				
Chinese	41 (75.9)	13 (24.1)	0.060 (1)	0.807
Others	28 (73.7)	10 (26.3)		
Education Level				
Primary & Below	3 (75.0)	1 (25.0)	0.000* (1)	1
Secondary & Above	66 (75.0)	22 (25.0)		
Religion				
Buddhism	26 (78.8)	7 (21.2)	0.394 (1)	0.53
Others	43 (72.9)	16 (27.1)		
Employment Status				
No	33 (78.6)	9 (21.4)	0.526 (1)	0.468
Yes	36 (72.0)	14 (28.0)		
Staying with Patient				
No	19 (70.4)	8 (29.6)	0.473 (1)	0.509
Yes	50 (76.9)	15 (23.1)		

df = degree of freedom

*Fisher's Exact Test

Table 4: Correlation of GDS-15, Short IQCODE and MRS with CSI

Variables	Spearman's rho	P value
GDS-15 vs. CSI	0.158	0.145
Short IQCODE vs. CSI	0.362	< 0.001
MRS vs. CSI	0.316	0.002

cognitive decline (short IQCODE ≥ 3.38) and 23 (25%) caregivers with high level of burden (CSI score ≥ 7) when providing care to post-stroke patients.

None of the socio-demographic variables including age, gender, ethnic, education level, religion and employment status of caregivers were significantly different with regard to burden. Table 4, showed weak but significant correlation of caregiver's burden with patient's cognitive impairment ($r=0.362$, $P\leq 0.001$) and physical disability ($r=0.316$, $P=0.002$). Correlation between patient's depression and caregiver's burden was not significant.

DISCUSSION

Post-stroke depression (PSD) is a common neuropsychiatric consequence of stroke affecting at least one third of patients within the first year of stroke onset [25]. It has been reported to negatively affect functional recovery and quality of life [26]. The 32% prevalence rate of PSD in this study was comparable to findings from 2 local studies; 36% in UMMC [27] and 31.6% in UKMMC [28]. Pooled data from studies conducted throughout the world have found prevalence rate of PSD in out-patient setting was lower at 23% [29]. However, the prevalence of PSD was higher at 60-66% in 2 other local studies using inpatients population [30, 31]. The difference could be due to variation in time and methods of assessment used.

The prevalence of cognitive decline in elderly post-stroke patients in this study was 57.6%. A study on 190 patients within 3 weeks of stroke demonstrated that cognitive deficits was present in 74% of patients with cortical stroke, 46% of patients with subcortical stroke and 43% of patients with infratentorial stroke [32]. Cognitive functions tend to improve with time. The greatest improvement after stroke occurs from onset to 3 months [33]. Between 3 months and 1 year after onset, although the rate of recovery slows down, it continues to improve in stroke survivors [32]. In this study, the mean duration after stroke was 38.3 months which explained the slightly lower prevalence of cognitive impairment.

A quarter (25%) of the caregivers reported high burden. In a local study using the Zarit Burden Interview, the prevalence of high caregiver burden of elderly with

stroke was 35.4% [35]. In a cross-sectional study of 51 caregivers of older persons attending the Geriatric Clinic at an urban hospital in Kuala Lumpur, the prevalence of high caregiver burden was 31% with 81% of them were short-term caregivers. The study concluded longer duration of caregiving was associated with lower level of burden and vice versa [36]. Although duration of caregiving was not directly measured in this study, more than two third (70.7%) of caregivers in this study stayed together with the patients implying they were not short-term caregivers and thus explaining the slightly lower prevalence of high caregiver burden.

The main findings of this study were significant, albeit weak, correlation of caregiver burden with cognitive decline and physical disability of elderly post-stroke patients. In a systemic review [25], physical disability, stroke severity and cognitive impairment were consistently associated with caregiver burden. This was supported by the finding in the study among principal caregivers that burden was consistently associated with stroke severity [37]. A few Asian studies on the relationship between caregiver burden and severity of stroke produced similar conclusion [38-41].

The current study revealed cognitive decline in post-stroke patients was associated with caregiver burden. Several studies concluded cognitive impairment in dementia patients was associated with caregiver burden [42-45]. These findings suggest that mental impairment of the patients has a more negative effect on caregiver burden than the physical problem [46]. In addition, the cognitive decline and severity of stroke might have an additive effect on caregiver burden. This study, however, did not find any significant correlation between caregiver burden and depressive symptoms of the patients. The socio-demographic characteristics of caregiver and patient were also not significantly associated with caregiver burden.

CONCLUSION

In the present investigation, caregiver burden study was significant, albeit weakly, correlated with cognitive decline and physical disability of elderly post-stroke patients. Otherwise, none of the socio-demographic characteristics of caregiver or patient, including depression, were significantly correlated with caregiver's burden.

The caregiver burden and psychological wellbeing of the caregivers should be assessed in view of their crucial roles in recovery of stroke survivors.

Setting up of stroke unit with multidisciplinary team at the hospital level would provide a better care for the stroke patients as recommended by the ministry of health in the Clinical Practice Guideline on Management of Ischemic Stroke. Post discharge stroke care guidelines and access to rehabilitation services at primary care is needed to ensure optimal care of post stroke patients residing at home in the community [47]. Particularly, caregivers should be educated on identification of emotional changes and cognitive decline so that early intervention could be provided.

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