Original Article

Caregivers of Stroke Survivors: Factors Associated with Caregiver Burden

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Abstract

Background: In Vietnam, family caregivers play a crucial role in supporting activities of daily living for hospitalized stroke survivors during the rehabilitation period.

Objectives: To identify factors related to caregiver burden among caregivers of stroke survivors and to describe the relationships among them. Factors evaluated included the functional dependence of patient, caregiver depression and anxiety, as well as demographic characteristics.

Methodology: This is a descriptive correlation cross-sectional study, with a convenience sample of caregivers of stroke survivors in Northern Vietnam (n = 114). Data was collected using a demographic questionnaire, the Zarit Burden Interview, the Barthel Index, and the Hospital Anxiety and Depression Scale.

Results: The burden among caregivers of stroke survivors in this study was mild-to-moderate. Caregiver burden correlated significantly with their anxiety and depression symptoms, the functional dependence of the patient, and caregivers' demographic characteristics, specifically, age, caring hours per day, relationship to patient, and self-perceived health status. Statistically significantly predictors of caregiver burden were anxiety symptoms, depression symptoms, and the patient's functional dependence, with functional dependence the strongest predictor of caregiver burden. Both depression and anxiety symptoms mediated the relationship between patients' functional dependence and caregiver burden.

Conclusions: To decrease the burden of care among stroke patients' caregivers, reduce their anxiety and depression, enhance their quality of life, and improve the quality of care for stroke patients, health care professionals should provide care training and health education in the early stages of rehabilitation along with mental health screening, and psychological counseling throughout the rehabilitation period.

Keywords: Caregiver burden, functional dependence, depression and anxiety symptoms

Introduction and Background

In recent years, the development of modern medicine has considerably decreased stroke mortality rates, however, cerebrovascular disease is still the second leading cause of death and disability worldwide. Globally, the incidence of stroke varies considerably. In Spain, where stroke is leading cause of death among women, and significantly impacts mortality rates and quality of life, with 147 per 100,000 population suffering from stroke each year (Karahan et al., 2014). In Southeast Asia, the lowest rate is observed in Malaysia (67/100,000 person-years), in Singapore is 180/100,000 person-years. Whilst, in Vietnam, the incidence of stroke in Vietnam is 250/100,000 person-years (Justin et al., 2018), making it one of the countries with a high rate of stroke worldwide, and stroke is the first leading cause of death, killing 112,600 thousand people in one year, accounting for 21.7% of all deaths in 2012 (Roth, 2017).

Stroke patients and their families may experience a variety of problems, including physical, psychological, social and economic problems. Two-thirds of stroke survivors in Spain needed a caregiver to support them in their daily and

weekly activities according to the 2008 Survey on Disability, Independent Living, and Dependence (Juan, Issac, Cristina, Almudena, & Alvaro, 2013). Stroke is becoming a top priority for health systems, due its considerable burdens for patients, their families and caregivers.

A study carried out in Turkey (2014) showed that 80% of stroke patients had the ability to integrate into community after the initial hospitalization and stroke rehabilitation, but they depended on the emotional and social support of family members to do so (Karahan et al., 2014). The traditional Vietnamese culture which assume that family is the basic unit of society and parents, older adults who are usually respected and looked after by family members, such as daughter or son and spouse. Thus, family caregivers play an important role in providing care and supporting activities of daily living for patients after stroke (Pham, Jullamate, & Piphatvanitcha, 2017).

The major purpose of rehabilitation is to support stroke survivors dealing with physical, psychological, social, vocational and educational problems, and this support depends greatly on the caregivers who are caring for stroke survivors during rehabilitation. In recent years, stroke rehabilitation not only concentrates on patients' recovery, but also raises awareness about the role of caregivers in long-term management of stroke survivors. In addition, in stroke rehabilitation for patients, one of the main problems of caregivers is burden which caregivers have experienced. Several studies showed the result about the caregiver burden in different levels and factors relating to burden among them including relationship to patient, caregiving hour, financial status, depression and anxiety of caregivers, their perceived social support, and functional dependence of stroke survivors (Choi-Kwon, Kim, Kwon, & Kim, 2005; Pham et al., 2017). These factors are crucial for the rehabilitation process which will be more successful if caregiving is supported and specific caregiver needs are addressed.

Many studies have focused on the psychological and physical burden of caregivers of stroke patients (Akosile & Okoye, 2009; Bhattacharjee, Vairale, Gawali, & Dalal, 2012; Choi-Kwon et al., 2005; Gorgulu, Polat, Kahraman, Ozen, & Arslan, 2016; Hu, Yang, Kong, Hu, & Zeng, 2018), and similar studies are anticipated in Vietnam because of the rapidly rising number of stroke patients in recent years. For the most part, research on this topic is still lacking in Vietnam. Hence, the purpose of this study is to identify factors related to caregiver burden among caregivers of stroke survivors in Vietnam, including the functional dependence of patient, caregivers' depression and anxiety, as well as demographic characteristics, and to describe the relationships among them

Research question

1. What are the demographic characteristics of Vietnamese caregivers of stroke patients?

2. What is the functional dependence of stroke survivors?

3. What is the extent of the burden faced by caregivers of stroke patients, and their depression and anxiety?

4. What are the relationships between caregiver burden, their depression and anxiety, and the functional dependence of stroke survivors?

Research hypothesis

1. There is a relationship between caregiver burden and functional dependence of stroke survivors.

2. There is a relationship between caregiver burden and their depression and anxiety.

3. Anxiety symptoms of caregivers mediate the effect of functional dependence on caregiver burden.

4. Depression symptoms of caregiver mediates the effect of functional dependence on caregiver burden.

Methodology

Research design: This study used a cross-sectional design.

Sample site: This study was conducted in the Stroke Center of Phu Tho Provincial General Hospital, located in Northern Vietnam from August 2019 to September 2019.

Study sample: A total of 114 caregivers of stroke survivors met the ***inclusion criteria***: (1) both patients and caregivers were at least 18 years old, (2) the patients had independently performed activities in daily living before the stroke, were past the acute stage and undergoing rehabilitation, (3) caregivers of these patients identified themselves as primary, informal, and

unpaid caregivers for the stroke survivors, (4) patients and caregivers understood the study objectives and were willing to participate in research. The ***exclusion criteria*** for both patients and caregivers: (1) had had a previous stroke or were diagnosed with psychological disorders in the past, (2) suffered from cancer or severe organ failure that impaired activities of daily living, and (3) were not being willing to take part in the study.

Instruments: The data was collected using a demographic characteristics questionnaire, the Zarit Burden Interview (ZBI), the Barthel Index (BI), and the Hospital Anxiety and Depression Scale (HADS)

Demographic characteristics questionnaire: Factors potentially related to burden included caregiver's age, gender, caring hours per day, education level, relationship to patient, and self-perceived health status.

The Zarit Burden Interview (ZBI): The ZBI was developed by Zarit to provide a comprehensive assessment of both objective and subjective burden of caregivers (Zarit, Reever, & Bach-Peterson, 1980). The Cronbach's alpha value for the ZBI was 0.93 and the intra-class correlation coefficient for the test-retest reliability of the Zarit burden score was 0.89 (Seng et al., 2010). This scale has 22 items assessed on a 5-point Likert scale, ranging from never (0) to nearly always (4). The scores of the index range from 0 to 88, where 0-20 points indicates "*little or no burden*," 21-40 points indicates "*mild to moderate burden*," 41-60 points indicates "*moderate to severe burden*," and 61-88 points indicates "*severe burden*." For our study, the Cronbach's alpha value of the scale was calculated as 0.83.

The Barthel Index (BI): The BI was developed by Mahoney and Barthel to assess the level dependence of patients on their caregivers by assessing the patient's ability to perform activities of daily living (Mahoney & Barthel, 1965). This study used the modified version, which achieved greater sensitivity and improved reliability compared to the original version, without causing additional difficulty or affecting implementation time. The internal consistency reliability coefficient for the modified scoring of the BI was 0.90, compared to 0.87 for the original scoring (Shah, Vanclay, & Cooper, 1989). The Cronbach's alpha was 0.935 and test-retest reliability was 0.989 among 459 stroke patients in a Middle-Eastern country (Oveisgharan et al., 2006). This scale has 10 items and the highest scores that can be attained on the scale is 100, with 0-20 points showing "*total dependence,*" 21-60 indicating "*severe dependence,*" 61-90 showing "*moderate dependence,*" and 91-99 indicating "*slight dependence,*" and 100 showing "total independence." In this study, the Cronbach's alpha value of the scale was calculated as 0.93.

The Hospital Anxiety and Depression Scale (HADS): The HADS was developed by Zigmond and Snaith (1983) and is commonly used by doctors to determine the level of anxiety and depression that a person is experiencing (Zigmond & Snaith, 1983). The term "hospital" in its title suggests that it is only valid in such a setting but many studies conducted throughout the world have confirmed that it is valid when used in community settings and primary care medical practice (Snaith, 2003). The HADS has 14 items with 7 of the items related to anxiety and 7 related to depression. The sensitivity and specificity for both HADS-A and HADS-D are high at approximately 0.80 (Bjelland, Dahl, Haug, & Neckelmann, 2002). This scale was used in research in Vietnam with total scores for each subscale between 0 and 21, in which a score equal to or more than 11 indicates anxiety or depression symptoms (Tran, Nguyen, & Tran, 2018).

Procedures: Approval for study was obtained from the Institutional Review Board of Hanoi University of Public Health and Phu Tho Provincial General Hospital before data collection. After getting permission, researchers contacted patients and caregivers in the Stroke Center, asking them to participate in research and sign informed consent. The forms were filled out via face-to-face interviews without the patient' present. The time for completing the questionnaire was around 30 minutes.

Data analysis: This study used the *The Statistical Package for the Social Sciences (SPSS) Version 20.0* for analysis. Descriptive statistics analyzed the mean and standard deviation for continuous variables; frequency and percentage for categorical variables. The relationship among study variables were analyzed using one-way ANOVA, independent Sample t-Test, Pearson's correlation coefficient and Spearman's rank correlation. Hierarchical multiple linear regression was used to discover

the predictors of caregiver burden. We used Hayes' PROCESS macro to test the mediation effects of depression and anxiety on the relationship between functional dependence and caregiver burden, after controlling for socio-demographic variables. Indirect effects were tested using bootstrapped confidence intervals (CI). The significance level of the statistical tests was set at 0.05.

Result

Caregiver' characteristics: The characteristics of participants are shown in the Table 4-1. The average age of participants was 43.12 (SD = 12.44), and 69.3% of participants were female. Just over half of participants (50.88%) were patients' daughters or sons. Nearly half of participants (48.25%) had completed primary or secondary school. The average number of hours caregivers spent taking care of patients was 10.59 (SD = 7.28) hours per day. On the participants, 60.53% reported their health status was fair.

Results showed the mean functional dependence score for the patients was 45.92±29.34 indicating severe dependence. The mean caregiver burden score was 25.59 (SD = 12.45), with possible scores ranging from 0 to 55, indicating that a majority (54.39%) of participants experienced a mild-to-moderate caregiver burden. The average score on anxiety and depression symptoms were 6.81±4.04 and 10.47±4.54, respectively. Whilst most participants did not present anxiety symptoms (82.46%), just over half (52.63%) presented symptoms of depression.

Caregiver burden according to the caregiver characteristics: In Table 3.2, caregiver burden is evaluated according to the characteristics of caregiver. Caregiver burden had a weakly positive correlation to age and hours of caring per day, and a weakly negative correlation with relationship to patient and self-perceived health status.

There was a statistically significant difference in caregiver burden among three groups of caregiver: sons and daughters, spouses, or others. The Scheffe post-hoc test indicated spouses had higher burden scores than other types of caregivers. A statistically significant difference in caregiver burden was also found among four self-perceived health status groups, and the LSD post-hoc test revealed that those with the worst self-perceived health status scored higher on caregiver burden than other groups.

Care burden was moderately negatively correlated with functional dependence, indicating increased burden with patients who were more functionally dependent. However, caregiver burden was moderately positively correlated to anxiety and depression symptoms, which means that the greater the burden, the more caregivers experienced anxiety and depression.

There was no statistically significant correlation between caregiver burden and gender, or education level.

The predictors of caregiver burden: Hierarchical multiple linear regression was computed to investigate how well functional dependence, anxiety symptoms, and depression symptoms predict caregiver burden, after controlling for demographic variables. Before conducting hierarchical multiple linear regression, the assumptions of linearity, normally distributed errors, and uncorrelated errors were checked and met.

Table 3.3 showed that 42.1% of variance in caregiver burden was predicted by functional dependence, anxiety symptoms, and depression symptoms. With these predictors combined, functional dependence had the highest absolute standardized regression coefficient value, indicating that functional dependence was the strongest predictor of caregiver burden. Anxiety symptoms and depression symptoms also contributed significantly predicting caregiver burden.

Table 1: Caregiver's characteristics (N = 114)

	n	(%)	Mean ± SD	Range
Age			43.12 ± 12.44	18-72
Gender				
Male	35	30.70		
Female	79	69.30		
Relationship to patients				
Spouse	21	18.42		
Daughter or Son	58	50.88		
Other	35	30.70		
Education level				
Illiteracy	0	.00		
Primary or Secondary school	55	48.25		
High school	37	32.46		
University or higher	22	19.30		
Caring hours per day			10.59 ± 7.28	2 - 24
Self - perceived health status				
Very good	8	7.02		
Good	32	28.07		
Fair	69	60.53		
Bad	5	4.39		
Very bad	0	.00		
Patient's functional dependence			45.92 ± 29.34	
Caregiver burden			25.59 ± 12.45	0 - 55
Little or no burden	34	29.82		
Mild to moderate burden	62	54.39		
Moderate to severe burden	18	15.79		
Severe burden	0	.00		
Anxiety symptoms			6.81 ± 4.04	1 - 18
No anxiety symptoms	94	82.46		
Anxiety symptoms	20	17.55		
Depression symptoms			10.47 ± 4.54	1 - 19
No depression symptoms	54	47.37		
Depression symptoms	60	52.63		

Table 2: Caregiver burden according to the characteristics of caregivers (N = 114)

Variable	N	Caregiver Burden	Analysis
Age			$r = .198, p = .034^a$
Caring hour per day			$r = .189, p = .044^a$
Gender			$r = .114, p = .226^b$
Male	35	23.91±12.50	**t = -.095, p = .342**
Female	79	26.33±12.44	
Education level			$r = -.168, p = .74^b$
Primary or Secondary school	55	27.55±13.32	
High school	37	23.86±12.10	**F = 1.324, p = .270**
University or higher	22	23.59±10.38	
Relationship to patient			$r = -.194, p = .039^b$
(1) Spouse	21	33.81±13.30	**F = 6.119, p = .003^c**
(2) Daughter or Son	58	23.69±11.64	
(3) Other	35	23.80±11.53	(1) > (2), (3)
Self-perceived health status			$r = -.237, p = .011^b$
(1) Very good	8	27.75±15.55	
(2) Good	32	20.72±11.31	**F = 3.126, p = .029^d**
(3) Fair	69	26.90±12.11	
(4) Bad	5	35.20±11.37	(4) > (2), (3), (1)
Functional dependence			$r = -.472, p = .000^a$
Anxiety symptoms			$r = .481, p = .000^a$
Depression symptoms			$r = .463, p = .000^a$

a: Pearson correlation test coefficient to calculate p values , b: Spearman correlation test coefficient to calculate p values
c: Scheffe post-hoc test   d: LSD post-hoc test

Table 3: Hierarchical multiple linear regression for predicting caregiver burden (N = 114)

		Beta (β)	*F*	R^2	$\triangle R^2$	*p*
Model						
1	Age	.05	3.108	**.126**	**.126**	.012
	Caring hours per day	.09				
	Daughter or son & spouse	-.33*				
	Others & spouse	-.31*				
	Self-perceived health status	-.10				
Model						
2	Age	.02	18.046	**.348**	**.222**	.000
	Caring hours per day	.04				
	Daughter or son & spouse	-.19				
	Others & spouse	-.10				
	Self-perceived health status	.02				
	Anxiety symptoms	.34**				
	Depression symptoms	.29**				
Model						
3	Age	-.02	11.396	**.412**	**.064**	.000
	Caring hours per day	-.01				
	Daughter or son & spouse	-.22				
	Others & spouse	-.14				
	Self-perceived health status	.04				
	Anxiety symptoms	.28**				
	Depression symptoms	.22*				
	Functional dependence	-.29**				

Note: * *p* < .05, ** *p* < .001

Table 4: Means, Standard Deviations, and Inter-correlations for Functional Dependence, Anxiety symptoms, Depression symptoms, and Caregiver Burden (N = 114)

Variable	M	SD	1	2	3	4
1. Anxiety symptoms	6.81	4.04	-	.375**	-.326**	.481**
2. Depression symptoms	10.47	4.54		-	-.384**	.463**
3. Functional dependence	45.92	29.34			-	-.472**
4. Caregiver burden	25.59	12.45				-

*p < .05; **p < .01
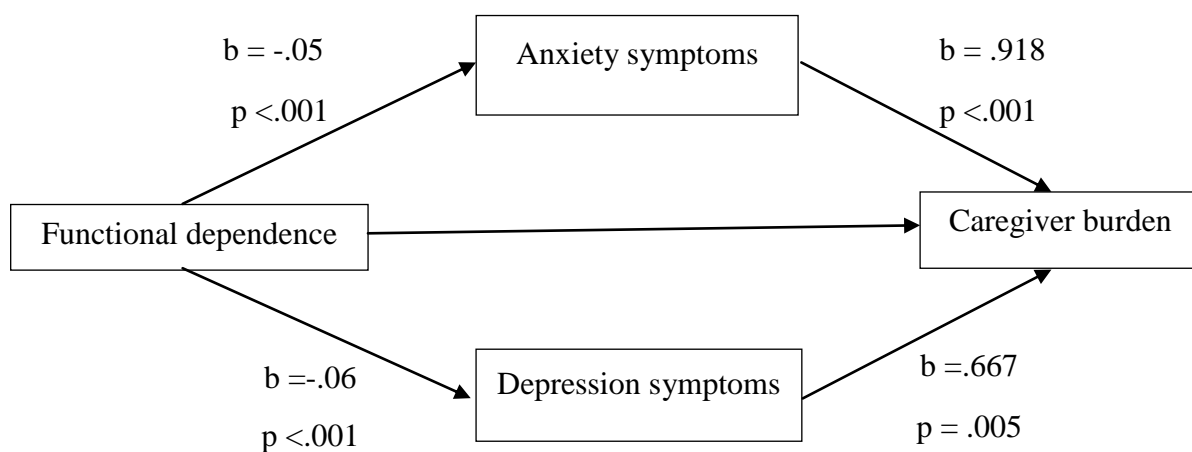
Direct effect, b = -.1195, p = .0009

Indirect effect, b = -.081, BCa CI [-.1297, -.0418]

Figure 3-1: Diagram of the Mediation Model with Regression Coefficient, Indirect Effect, and Bootstrapped CIs

Anxiety symptoms and depression symptoms mediate the relationship between functional dependence and caregiver burden

Statistical mediation analysis was conducted to determine if anxiety symptoms, and depression symptoms mediate the relationship between functional dependence and caregiver burden.

Assumptions of linearity, normally distributed errors, and uncorrelated errors were checked and met, and the mediation effect model was evaluated using the PROCESS package, which is an add-on package of SPSS (Hayes, 2011).

Anxiety symptoms statistically significantly mediated the relationship between functional

dependence and caregiver burden (b = -.0413, and the bias-corrected confidence interval (BCa CI) was [-.0920, -.0125]). In addition, depression symptoms also mediated the relationship between functional dependence and caregiver burden (b = -.0397, BCa CI = [-.0802, -.0102]).

Discussion

In developing countries, stroke is one of the leading causes of disability and death, Vietnam is being no exception. The chronic nature of stroke and long period recovery are reasons why it puts a great burden on informal caregivers.

Caregiver's characteristics: The mean score on functional dependence of patients in our study indicated a high level of dependence on their caregivers (Ngo, Pinyopasakul, Pongthavornkamol, & Panitrat, 2019; Roopchand-Martin & Creary-Yan, 2014). However, in a study in Spain showed that the dependence level of most patients at 3 months post-stroke was low (Juan et al., 2017). The difference might be explained by the fact that the patients in our study were recruited after the acute stage of stroke, and they needed a period of time for recovery. Therefore, the functional dependence level of patients in our study is higher than those of Juan's study whose patients had already experienced 3 months of rehabilitation.

In this study, the burden on caregivers was mild-to-moderate, but with wide variation (Kaur & Kumar, 2015; Yeh & Chang, 2015). However, a few studies showed results indicating caregiver burdens were higher than in these studies (Pham et al., 2017; Tosun et al., 2017). These different findings might be explained by reasons including the difference in culture and duration of care of caregivers for stroke survivors.

As regards depression and anxiety symptoms among caregivers, the findings showed the percentage of caregivers with depression symptoms was higher than the percentage of caregivers with anxiety symptoms (Hu et al., 2018; Loh, Tan, Zhang, & Ho, 2017).

Caregiver burden according to the characteristics of caregivers: In the present study, age of caregivers was positively but weakly correlated with caregiver burden in the initial analysis (Akosile & Okoye, 2009). However, studies from different societies have produced contradictory results regarding the relation between caregiver burden and age

(Bhattacharjee et al., 2012), even other study have found no significant correlation between age of caregivers and burden (Gribi, Olawale, & Issac, 2015). Thus, this is thought to limit or remove the effect of caregiver's age on care burden.

Regarding the time spent per day caring for stroke patients, the results showed that there was a positive correlation between hours of caring per day and caregiver burden (Gribi et al., 2015; Pham et al., 2017). It is generally true that the more time caregivers take care of patients, the less private time they have for themselves, which thus reduces their time for paid work, socializing and entertainment. The caregivers who spend fewer hours caring for stroke survivors, have more time for themselves and thus a reduced burden.

The result showed that and the relationship to patient was negatively correlated with caregiver burden, and caregivers who were wives or husbands of stroke patients, had higher burden levels than children or other relatives of stroke survivors. Although the relationship between spouses is as close as that between parents and children, spouses perceived the greatest burden when they were the primary caregiver. This finding is similar with other studies (Pham et al., 2017; Yeh & Chang, 2015).

Regarding self-perceived health status, there was a negative relationship between self-perceived health status and caregiver burden, with the group reporting bad health showing the highest caregiver burden level (Jeong, Jeong, Kim, & Kim, 2015; Ostwald, Bernal, Cron, & Godwin, 2009; Pham et al., 2017). Caregiver in this study said that the task of taking care of patients lead to their health problems.

Caregiver burden was negatively correlated with functional dependence, meaning that level of functional dependence increased caregiver burden (Pham et al., 2017; Yeh & Chang, 2015). In this study, most of the caregivers had mild-to-moderate levels of burden, and most of the stroke survivors were moderately or severely dependent. These stroke survivors could only partially perform their activities of daily living and caregivers needed to provide help. These tasks constitute caregiver burdens.

Anxiety and depression symptoms were significantly positively correlated with caregiver burden (Choi-Kwon et al., 2005; Hu et al., 2018;

Souza et al., 2017). A majority of caregivers are not professionals and having limited disease related knowledge may require more time and energy in caring for patients. Furthermore, taking care of stroke survivors for a long time also affects their work and life. One result is a deterioration of caregivers' mental health. The burden of caring for someone not only leads to emotional problems among caregivers, it also reduces caregivers' enthusiasm and negatively impacts the patients' treatment and rehabilitation process. This suggests professional health care providers should comprehensively assess burden for caregivers of stroke survivors in the early stages to provide appropriate support.

The predictors of caregiver burden: The most noteworthy finding of the present study was demonstrated after adding functional dependence variable into the third step of hierarchical multiple linear regression, patient's functional dependence emerged as most important predictor of caregiver burden, followed by caregiver anxiety and depression. This result is inconsistent with study Choi-Kwon with showing the most significant predictor for overall caregiver burden was caregiver anxiety followed by patient's functional dependence (Choi-Kwon et al., 2005). The reason can be understood in this situation because in our study, patients who recruited were inpatients, just experienced acute stage, and had high dependence level; comparing with outpatients in that study, experienced acute stage for a period of time, and had low dependence level. Functional dependence in our study, therefore, proved being the most important predictor for caregiver burden. However, further studies which combine with various dimensions need to be performed to improve its ability to predict caregiver burden.

Mediation effect of anxiety symptoms and depression symptoms on the relationship between functional dependence and caregiver burden: In mediation models, a mediator variable explains why a relationship exists between the predictor and outcome variable. Findings from the mediation model indicated that depression symptoms and anxiety symptoms statistically significant mediated the relationship between functional dependence and caregiver burden. It means that if depression symptoms and anxiety symptoms are reduced, this will reduce the effect of functional dependence on caregiver burden. This suggests health professionals pay particular attention to the

mental health of caregivers and then provide early interventions to reduce the development of their depression and anxiety symptoms.

Conclusion: In summary, we found that caregiver burden was influenced by the patient's level of functional dependence, caregivers' depression and anxiety levels, and caregivers' demographic characteristics (age, caring hours per day, relationship to patient, and self-perceived health status). Of these, functional dependence of the patient was the strongest predictor of caregiver burden. Anxiety symptoms and depression symptoms had mediation effect on the relationship between functional dependence and caregiver burden.

Although functional dependence is the primary predictor of caregiver burden and reducing dependence is the goal of rehabilitation, this may not be easy to achieve. In such situations, individualized interventions aimed at easing symptoms of depression and anxiety in caregivers could reduce their burden while caring for patients with severe functional dependence. These interventions should consist of psychological counseling, care training and health education in early stages aimed at decreasing caregiver burden, improving quality of care for stroke survivors, enhancing quality of life for caregivers.

Because of cross-sectional design, the present study has several limitations, including small sample size, interview bias, and social desirability bias. Furthermore, this study did not conduct a complete assessment of all potentially important risk factors for caregiver burden, such as the duration of caregiving, and income status of the caregiver, variables which have been demonstrated to affect caregiver burden.

Notwithstanding these limitations, this study revealed that caregivers' depression and anxiety symptoms significantly mediate the effect of stroke patients' functional dependence on Vietnamese caregivers' perception of burden. Further research should look at other factors associated with caregiver burden, including the duration of caregiving, financial incomes, and sample diversity such as distinguishing sole caregivers, and full-time caregivers. Moreover, a prospective or longitudinal study should be conducted to observe changes in caregiver burden over a period of time. After that, studies should be designed to find appropriate

interventions that can reduce caregiver burden for caregivers of stroke survivors.

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