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Original Research

The Impact of Independent of Activity Daily Living among Stroke Patients on Caregivers Burden

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ABSTRACT

Introduction: Weakness among stroke patients causes obstacles when fulfilling their activities in daily living (ADL). This condition also has an impact on the caregivers who provide daily care at home. The purpose of this study was to analyze the effect of independent ADL among the stroke patients on caregiver burden.

Methods: The study used an analytical design through a cross-sectional approach. The variables included independent ADL and caregiver burden. A sample of 120 caregivers was taken from 2 community health centers in Surabaya through simple random sampling. The instruments used were Zarit Burden's Interview Schedule and the Katz Index of Independent for ADL. Regression ordinal was used to analyze the influence of independent ADL among stroke patients on caregiver burden.

Results: The results showed that the caregiver who take care of stroke patients with severe functional impairment will feel burdened 3 times more than no burden. Post-stroke care at home through a rehabilitation program plays an important role in improving the condition of patients and their families at home, especially the caregivers.

Conclusion: Nurses in a community health center through the family health care pathway provide comprehensive bio-psycho-socio-spiritual care in the rehabilitation period as expected. They are expected to improve and maintain the fulfillment of human needs comprehensively for stroke patients and their caregivers, so the quality of life of stroke patients, caregivers and their families remains optimal.

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INTRODUCTION

Brain damage due to non-traumatic cerebral circulatory disorders is increasing in society today. This is known as a stroke, which can happen suddenly, progressively and quickly. The prevalence of stroke in East Java in 2013 was 16 and it was included in the top four causes of death in Indonesia. Although the prevalence decreased in 2018 which was equal to 12.4%, East Java was still included in the 8 major provinces concerning the prevalence of stroke cases. Stroke attacks cause symptoms in the form of paralysis of the face or limbs, the speech not being smooth or clear (disartria), changes in vision, difficulty consciousness, impaired in and and swallowing speaking difficulty understanding the conversations of other. These

symptoms can settle after the acute phase (RISKESDAS, 2018) (Badan Penelitian & dan Pengembangan Kesehatan, 2013). Changes in the conditions experienced by post-stroke patients, especially the presence of weakness or paralysis of the limbs, causes the patients to experience obstacles when fulfilling their activities of daily living. Some of them experience dependency in living their lives and some even claim that their quality of life decreases (Bakas et al., 2014) (Handayani & Dewi, 2009) (Karunia, 2016) (Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014).

Stroke patients and families feel that they are in a crisis situation, not only in the acute phase of hospital care. This situation may continue until after the treatment in the hospital, namely the rehabilitative

period. The condition of the patients with sequelae after a stroke is a new situation for the patients and their families. Changes in their physical health condition, especially weakness or paralysis, are also a crisis situation for the patients. The family will carry out additional roles to maintain a more healthy condition for their family member with a stroke, especially when it comes to providing care to meet the basic needs of the stroke patients at home. A previous study showed that 10% of stroke patients were dependent on meeting their ADLs in the category of moderate dependence, severe dependence and total dependence, while mild dependence reached 70% (Setyoadi & Wihastuti, 2018). The dependence on fulfilling ADL causes burnout syndrome for caregivers. The study by Kumar (2015) of 100 caregivers looking after stroke survivors from a selected community setting and the outpatient department of different tertiary care hospitals in Punjab showed that 63% experienced a mild to moderate burden, 28% experienced no burden, 7% experienced a moderate to severe burden and 2% experienced a severe burden(Kumar, Roy, & Kar, 2012). Other previous studies about the burden of the informal caregivers of stroke survivor in secondary and tertiary health institutions experiencing the physiotherapy service in Lagos State Nigeria showed that 80 caregivers (50,6%) expressed a mild burden, 75 caregivers (47,3%) expressed that they experienced a moderate burden and 2 caregivers (2%) expressed that they experienced a severe burden (Gbiri, Olawale, & Isaac, 2015).

Continuous stressors among the stroke patients and their caregivers are a trigger for the burden of both, in the form of physical, emotional, social and financial burdens(Gbiri et al., 2015)(Kumar et al., 2012)(Pesantes, Brandt, Ipince, Miranda, & Diez-Canseco, 2017) (Vincent, Desrosiers, Landreville, & Demers, 2009). The burden experienced by the caregivers is influenced by gender (female), age (elderly), low education, employment (retired), the hours of care given and mental health. The characteristics of stroke patients that influence the burden of the caregivers includes physical disorders and motor weakness and the cognitive functioning of stroke patients, depressive symptoms, decreased verbal ability, walking difficulties and neurological deficits.

Advanced stroke treatment, known as the rehabilitative phase, is a treatment that requires a long time. Patience and the continuity of care by the family needs to be applied at home. Data on the control of stroke patients to health care facilities among the population aged ≥ 15 years in Indonesia were routinely controlled 39.4% (n = 8,042), and in East Java patients who routinely controlled were slightly 40% (n = 1,452) (RISKESDAS, 2018). The low patient data for routine control shows that the possibility of patients not getting maximum care may mean that they do not receive further treatment. This condition will result in the physical weakness and paralysis of stroke patients continuing to worsen,

leading to complications and death. The caregivers will feel that the burden continues to increase and extend. In the end, the whole family feels the impact.

Stroke patients, caregivers and/or their families together need a comprehensive bio-psycho-sociospiritual care intervention to overcome the crisis situation created due to a stroke. Various interventions for stroke patients and their families can be obtained from the time of hospitalization up until the rehabilitation phase which continues to coordinate with public health facilities (Puskesmas). Discharge planning interventions given at the end of the acute phase of hospital care and interventions during the rehabilitation phase in the form of physiotherapy for patients, therapeutic counseling, psycho-education, skills training, and family and group supportive therapy are alternative interventions that have been proven to improve the physical condition of patients, reduce the burden of care, improve satisfaction, well-being and the quality of life of patients and their caregivers (Damawiyah, 2015)(Björkdahl, Nilsson, Sunnerhagen, & 2007)(Suprobo, Wiyono, & Setyanto, 2015)(Wahyuningsih, 2011). The purpose of this study was to analyze the effect of the independent ADL of the stroke patients on the burden of caregivers among the patients suffering from a stroke at home

MATERIALS AND METHODS

The study used an analytical design through a crosssectional approach. The variables included the independent activities of daily living and caregiver burden. The sample consisted of 120 informal caregivers of stroke survivors that were their relatives who stayed at home with the stroke survivor for at least 3 months. The samples were taken in 2 community health centers in Surabaya (Puskesmas Pegirian and Puskesmas Pucang Sewu) using the simple random sampling technique in the period of July - September 2018. The burden of caregiver was measured using Zarit Burden's Interview Schedule designed by Steven H Zarit with a 5 point rating scale ranging from never (0) through to rarely (1), sometimes (2), quite frequently (3) and nearly always (4). The burden score was categorized in 4 categories: no burden (0-21), mild to moderate burden (22-40), moderate to severe burden (41-60) and severe burden (61-80) (Kumar et al., 2012). The activities of Daily Living of the stroke survivors were measured using the Katz Index of Independence in Activities of Daily Living. It measured the 6 functions of bathing, dressing, toileting, transferring, continence and feeding. The stroke survivors were scored yes (independence/no supervision, direction or personal assistance/score 1) or no (dependence/with supervision, direction, personal assistance or total care/score 0) for the independence of each function. This was then classified into full function (5-6), moderate impairment (3-4) or severe functional impairment (2 or least)(Wallace & Shelkey, 2006). The regression ordinal test was used to analyze the influence of the independent ADL among the stroke patients and how it related to the caregivers' burden. The ethical approval letter was granted by the Health Research Ethics commission of Health, Ministry of Health, Surabaya number: 194/S/KEPK/V/2018 date 8th June, 2018.

RESULTS

Table 1 showed that most of the stroke patients were 56-65 years old (late elderly) (40,8%), male (64,2%) and with an illness lasting1-2 years (58,3%). Almost all of the patients had had a stroke once (95%) and most of the stroke patients had 1-2 deficit neurological conditions related to having a stroke (56,7%).

Table 2 shows that most of the caregivers are 46-55 years old (early elderly) (40,2%), women (75,2%), the wife of the stroke patient (53%), educated up t senior high school (35%) and not an employee (housewives) (47,9%). They had been caring for 1-2 years (58,1%), the longest duration of caring was 1-2 hours a day (62,4%) and most of them had 1-2 health problems (42,5%).

Table 3 showed that most of the independent ADLs were full functioning (60,8%) while it was almost the same between moderate impairment and severe functional impairment at 19,25% and 20%. The burden of the caregivers was mild to moderate (50%), next to no burden at 44,2% and moderate to severe burden at 5,8%.

Table 4 shows that the Chi-square value through the deviance method is 1.057 with df 2 and a significance value of 0.589, it is concluded that the model is feasible to use.

Table 1. Characteristics	of the Stroke Patients
(n=120)	

Variable	n	(%)
Age (year):		
36-45 years old	9	7.5
46-55 years old	39	32.5
56-65 years old	49	40.8
>65 years old	23	19.2
Gender:		
Male	77	64.2
Female	43	35.8
Length of illness (year):		
<1 years	23	19.2
1-2 years	70	58.3
3-4 years	17	14.2
>4 years	10	8.3
Frequency of attacks:		
1-2 times	114	95
3-4 times	5	4.2
>4 times	1	0.8
Deficit neurology of stroke		
0 symptom	10	8.3
1-2 symptoms	68	56.7
3-4 symptoms	35	29.2
>4 symptoms	7	5.8

Table 2. Characteristics	of the Caregivers
(n=120)	

(n=120)			
Var	iable	n	(%)
Age (year)			
<26 years old	1	10	8.5
26-35 years o	old	14	12.0
36-45 years of	old	22	18.8
46-55 years o	old	47	40.2
56-65 years of	old	19	16.2
>65 years old	1	5	4.3
Gender			
Male		29	24.8
Female		88	75.2
Family relation	shin		
Hushand	Ship	16	137
Wife		62	53.0
Child		25	21.4
Others		14	12.0
Education		11	12.0
Not school		10	85
Flomentary	chool	33	28.2
Lunior high s	chool	24	20.2
Sonior high s	chool	41	20.3
Diploma or P	ciluul 'achalar'a	41 E	33.0
Dipiona or b		3	4.5
Fosigraduate		4	3.4
Employment		E C	47.0
No employee		50	47.9
Pensioner	1	2	1./
Government	employee	0 10	5.1
Private empl	oyee	18	15.4
Entrepreneu	rsnip	34	29.1
Others		1	0.9
Length of carin	g (year)		10.0
<1 year		22	18.8
1-2 years		68	58.1
3-4 years		1/	14.5
>4 years		10	8.5
Duration of car	ing (hour/day)	70	(2.4
1-2 hours/da	ıy	73	62.4
3-4 hours/da	ıy	27	23.1
5-6 hours/da	ıy	9	7.7
>6 hours/day	y	8	6.8
Health problem	15		
No problem		41	34.2
1-2 problems	5	51	42.5
3-4 problems	5	25	20.8
>4 problems		3	2.5
Tahle 3 Variah	le Descriptions (n=120)	
Var	riable	n <u>n</u>	0/2
Independent of		11	70
Sovere functi	ional impairment	24	20
Moderate im	nairmont	27	19.2
Full function	employee 6 5.: yee 18 15. ship 34 29. 1 0. 0. (year) 22 18. 68 58. 17 10 8. 17 10 8. 17 10 8. 17 10 8. 17 10 8. 17 10 8. 17 10 8. 18 10 8. 18 10 8. 18 11 10 8. 12 27 23. 13 27 23. 14 34. 51 25 20. 3 2. e Descriptions (n=120) 14 iable n 9 0 73 60 19 0 17 19 73 14 24 20 20 0 19 73 60		
Carogivor Burdo	n.	75	00.8
No hurden	.11.	E 2	117
Mild to mode	arata hurdan	55	50
Modorata ta	00 7	50 50	
Source hund	severe buluell	/	0.0
Severe burde	511	U	U
Table 4. Goodn	ess of Fit		
	Chi-Square	df	Sig.
Pearson	1.105	2	0.575
Deviance	1.057	2	0.589

Table 5. Model Fitting Information

Model		-2 Log Lik	celihood		Chi-So	quare	df	Sig.
Intercept Only Final		38.430 19.698						
					18.731		2	.000
Table 6. Wald	d Test							
		Estimate	Std. Error	Wald	df Sig.		95% Confidence Interval	
							Lower Bound	Upper Bound
Threshold	[No burden = 1.00]	.265	.235	1.275	1	.259	195	.726
	[Mild to moderate burden = 2.00]	3.734	.506	54.497	1	.000	2.743	4.725
Location	[Severe functional impairment =1.00]	2.162	.554	15.215	1	.000	1.076	3.248
	[Moderate impairment=2.00]	.809	.479	2.853	1	.091	130	1.748
	[Full function=3.00]	0 a	•	•	0		.a	•
Table 7. Pse	eudo R-Square							
Cox and Sn	nell					0.1	45	
Nagelkerk	e					0.1	75	
McFadden						0.0	89	

Table 5 shows that the statistical value G is 18.731, thus it can be concluded that there is one $\beta p \neq 0$ (H1 accepted). Table 6 shows that the ADL variable within the severe functional impairment category has a significant effect on the burden of the caregiver (p value = 0.000) while the ADL variable within the moderate impairment category did not have a significant effect on the burden of the caregiver (p value = 0.91).

Table 7 shows the determinant coefficient value of Negelkerke 0.175 or 17.5%. It can be concluded that ADL with a severe functional impairment category affects the burden of the caregiver by only 17.5%, while 82.5% are affected by other factors that were not included in the model test.

The interpretation of the model was done using the odds ratio test. The odd ratio of ADL with the severe functional impairment category was 3, so it can be concluded that a caregiver who takes care of a stroke patient in the severe functional impairment category will feel burdened 3 times more than no burden. The Odd ratio of ADL within the moderate impairment category was 1, so it can be concluded that a caregiver who takes care of stroke patients in the moderate impairment category will feel only a small burden or no burden.

DISCUSSION

The research data shows that almost all of the patients (91.7%) had deficit neurology symptoms, with the most common symptoms being foot and/or hand weakness or paralysis (81.67%). The characteristics of the patients included aggravated physical weakness experienced by the elderly

patients (40.8%) and most were dependent for 1-2 years after the stroke attack (58.3%). Ischemia in most lesions in the right hemisphere or parietal lobe due to stroke biologically affect the inability of the patient to perform several physical functions such as limb movements, speech changes and changes in memory (Munir, 2018). The neuromuscular process will reduce the physiological functions of the extremities which effects the independent of ADL among the stroke patients(& & Bunner, 2013). Their health conditions change due to deficit neurology symptoms. There are severe stressors not only for the patients but also for their families.

The research data shows that for almost all of the patients who experienced the first attack (95%), most of the patients were male (64.2%) and almost all of them were the head of their family. This data can be used to aggravate the feelings of disability and helplessness due to stroke attacks. The data on the independent ADL is based on the Katz Independence Index in which the ADL shows that the 3 lowest ADLs are bathing, dressing and toilets that require adequate limb function. A real feeling of a lack of pleasure in reference to the physical difficulties after illness makes the patient feel disabled and helpless, which can improve the feelings of depression in the patients. The study by Ratnasari concluded that the majority of stroke patients had moderate depression (60%). Their experience was that they were very dependent in terms of ADL (45%) (Ratnasari, P; Kristiyawati, S.P.; Solechan, 2015). The weakness in the motor function is aggravated by psychological disorders.

The majority of caregivers in this study were 46 -55 years old (early elderly) (40.2%). Women were the most common gender (75.2%), most of the patient's education was elementary school level (36.7%), most of the caregivers were the wife of the stroke patient (53%), most were not employees (housewives) (47.9%), the longest treatment was 1-2 years (58.1%), the most common duration of treatment was 1-2 hours a day (62.4%) and most of them had 1-2 health problems (42.5%). The results of this study are in line with the previous research which states that caregiver burden is influenced by age (elderly), gender, low education, employment (retirement), the hours spent taking care and mental health (Chow, Wong, & Poon, 2007) (Rigby, Gubitz, & Phillips, 2009) (Vincent et al., 2009). Family members who mainly take care of stroke patients at home feel continued stress due to their role. They can also experience strain and burden.

The regression ordinal test was computed between the independent ADL among stroke patients and caregiver burden. The results of the testing showed that ADL in the severe functional impairment category affects the burden of the caregiver by only 17.5%, while 82.5% were affected by other factors that were not included in the model test. The interpretation of the model using the odds ratio test concluded that a caregiver who takes care of a stroke patient in the severe functional impairment category will feel burdened 3 times more than no burden. The results of this study are in line with the predicting factor of caregiver burden according to the characteristics of the stroke patients. This includes physical disorders such as weaknesses in the motor and cognitive functions of the stroke patients, decreased verbal ability, walking difficulties and neurological deficits (Vincent et al., 2009) (Rigby et al., 2009) (Chow et al., 2007). Independence in fulfilling the ADL, especially those that require adequate physical functioning, namely bathing, dressing and toileting, are the 3 types of ADL with the lowest independence, thus increasing caregiver burden, especially in the physical burden (1.24 ± 67.56) and emotional burden category $(0.96 \pm 74,632)$. These 3 ADL activities require greater energy related to motion and mobilization, thus aggravating the physical fatigue of the caregivers. The burden of the caregiver got worse because the caregivers also suffered from diseases including non-communicable diseases. The diseases suffered by the caregivers in this study included hypertension, diabetes mellitus, gastritis, hypercholesterolemia and hyperuricemia.

The financial burden of the patients was felt by males the most (64.2%). They have a family role as the patriarch or husband. One of the roles of the patriarch based on the family functions is that of a wage earner (Friedman, Marilyn M; Browden, Vicky R; Jones, 2010). This condition is in line with the previous research which states that all of the families of stroke patients experience family economic changes. This is considered to be a high stressor for families (Hariyati, Sumarwati, & Handiyani, n.d.)(Pambudi, 2009)(Asrul Sani, 2018). Almost all of the stroke patients in this study (91.7%) reported the presence of sequelae, with the most common symptoms being weakness and paralysis of the feet and hands (81.67%). The weakness or paralysis that occurs causes the patients to no longer be able to work to earn an income to finance the needs of all family members, so their role is ultimately assisted or replaced by other family members (the wife or child of the patients) through small traders at home while caring for the patient. Continued stroke care that requires long term attention will also increase the family financing both in terms of medical/control costs and the cost of transportation to visit the health care facilities.

Feelings of being helpless even related to the condition of depression in stroke patients will have an impact on the interaction of the patients and their caregivers. The caregiver in this study revealed that the patients often showed an irritable response when treated and assisted. They did not regularly take their medication, they did not want to routinely control their feelings and they did not regularly do physiotherapy or a range of motion exercises. The anger responses shown by the patients often trigger the caregivers to respond angrily. If the caregivers feel tired or bored, they may leave the patient for a moment. This is in line with the predicting factor of the caregiver symptoms of depression(Rigby et al., 2009)(Chow et al., 2007)(Vincent et al., 2009). The efforts of stroke patients to meet their needs independently according to their ability are gradually needed in the rehabilitation phase, especially related to neuro-muscular function so then the remaining symptoms of weakness/paralysis are reduced. A previous study states that stroke patients are advised to continue trying to carry out the routine control of medical personnel in order to monitor repairs or the deterioration caused by a stroke (Fadilah, Kusnanto, Nursalam, Minarti, & Asnani, 2018). Efforts to increase independence in ADL will have a broad impact on the patients, not only related to the impact of increasing the motor skills but it will also increase self-esteem, confidence and reduce anxiety due to feelings of helplessness (Rigby et al., 2009).

The nursing interventions for families, especially for the caregivers of stroke patients, also need to be carried out together with interventions focused on the patients. The previous studies concluded that the families are more motivated and more ready to provide care at home with the provision of discharge planning at the end of the acute phase of hospital care (Damawiyah, 2015). Interventions during the rehabilitation phase come in the form of therapeutic counseling, psycho-education, skills training, family supportive therapy and health education through home visits which are alternatives that are proven to reduce the burden of care and to improve caregiver satisfaction and quality of life (Björkdahl et al., 2007). Post-stroke care at home through rehabilitation programs plays an important role in treating patients and their families at home, especially when related to

the caregivers. Nurses at the community health center, through family health care, can provide comprehensive bio-psycho-socio-spiritual care in the rehabilitation period. This is expected to improve and maintain the fulfillment of human needs for stroke patients and their caregivers. This means that the quality of life of stroke patients, their caregivers and their families members remains optimal(Fadilah et al., 2018).

CONCLUSION

A caregiver who takes care of stroke patients with severe functional impairment will feel burdened 3 times more than feeling like there is no burden. Changes in the physical and psychological condition of stroke patients cause difficulties in terms of the independent fulfillment of ADL stroke patients. This situation causes stress to be experienced by the caregivers when caring for patients with stroke. This means that caregiver burden occurs. Nurses as family health care providers can play an important role in providing comprehensive bio-psycho-spiritual care in the rehabilitation period for stroke patients and their nurses. This is so then related diseases can reduce and improve the quality of life for stroke patients and nurses to remain in an optimal living situation.

LIMITATION

The Activities of Daily Living of stroke survivors were measured only once by the Katz Index of Independence in ADL; this was a limitation of this study. The data should be measured focused on home care and more than once, so then we can progressively evaluate the patient and caregiver's condition.

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