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THE EFFECT OF CAREGIVER EDUCATION PROGRAM ON FUNCTIONAL INDEPENDENCE AND MORTALITY IN FIRST-EVER STROKE

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ABSTRACT

Background: At present, the management of stroke focuses not only on the acute stage of saving the penumbra but also on the secondary prevention of managing the potential sequel following stroke, preventing the occurrence of another attack, and improving the quality of life. Continuous role of caregivers in supporting stroke survivor after passing the acute phase is therefore invaluable. Caregiver education program (CEP) was routinely used as a part of discharge plan on acute stroke patients in stroke unit in Indonesia. This study aims to evaluate the effect of CEP as one of stroke rehabilitation modalities using a historical data that still correlated to the practice in stroke unit nowadays.

Methods: A single-blinded randomized controlled trial was performed on 172 subjects of first-ever stroke with no other comorbidities and not having invasive treatment on the recruitment time. The subjects were randomly allocated into two groups: a group receiving CEP (n=88) as the experiment group and a control group (*n*=84). A four-session CEP, held since the second week of admission by interactive discussion using overhead projector and poster, was performed by a neurologist to the caregiver member of experiment group stroke survivor. The outcome of functional independence and mortality on the third month post-onset was assessed using Barthel activity daily living (ADL) index and the mortality report, respectively.

Results: No statistical difference was found on the baseline of the two groups. CEP significantly increased the functional independence (RR=1.30, 95% CI 1.03-1.63) of stroke survivor. Despite the insignificant effect on three-month survival, the group receiving CEP had less mortality rate over time.

Conclusion: Caregiver education program had a positive outcome on the patient's functional independence. Thus, it improves the quality of life.

Keywords: Caregiver education program, Mortality, Rehabilitation, Functional independence, Stroke

INTRODUCTION

Stroke is defined as any objective evidence, either upon pathological or imaging proof of permanent brain, spinal cord or retinal cell death due to a vascular cause with or without any clinical symptoms (Sacco *et al.*, 2013). American Stroke Association (ASA) reported that the prevalence of first-ever stroke was 10.3 million people globally, 66.67% of those were ischemic stroke and 31% of those were less than 65 years old. In the United States in 2014, on average, someone has stroke every 40 seconds and someone died of stroke every 4 minutes (Benjamin *et al.*, 2017). World Health Organization (WHO) also reported that heart disease and stroke were among the third most frequent causes of years of life lost due to premature mortality globally in 2012. Major cardiovascular event and mortality were significantly higher in low-income countries (80%) compared to high-income countries (WHO, 2014). According to the Indonesia Basic Health Research in 2013, Indonesia, classified as the low-to-medium-income country, had a stroke prevalence of 1.21% (Health Research and Development Organization of Minister of Health of the Republic of Indonesia 2013). Therefore, in low-income countries, the burden of morbidity and mortality is higher.

In addition to the high number of mortality, long-term morbidity post-stroke frequently occurred as well. Stroke was among the top 18 diseases contributing to years lived with disability (YLD) in 2010 (World Health Organization, 2014). In 2010, ASA reported that 39.4 million disability-adjusted life years (DALYs) and 62.8 million DALYs were lost due to ischemic and hemorrhagic stroke respectively (Benjamin, *et al.*, 2017). Therefore, despite an immediate acute management in-hospital, the stroke survivor still poses the risk of having some residual disability (Forster *et al.*, 2013). Those

disabilities may render a stroke survival dependent to the caregiver, who may be a professional or a caregiver member (Da Costa *et al.*, 2016).

Nowadays, the management of stroke has highly improved While stroke unit has succeeded in terms of improved survival, recovery and returning home, studies have demonstrated that 35 to 40% of the stroke survivors have limitation in basic ADLs on the sixth month post-stroke and more than 50% have limitation in more than 1 IADLs (Winstein *et al.*, 2016).

Facing the burden, an enormous effort to improve the self-dependence post-stroke is being established. Some randomized controlled trials have provided evidence that comprehensive stroke unit, which integrates early rehabilitative intervention to the comprehensive stroke unit, demonstrates the highest reduction of combined death and dependency (OR 0.5; 95% CI 0.39-0.65). The statement is also recommended by AHA/ASA (Class I, LOAA) (Chan *et al.*, 2013).

Another effort of improving the quality of life (QOL) of the stroke survivors is the active participation of the caregiver themselves as the caregiver in the home-based rehabilitation. Besides the consistent evidence that both stroke survivors and their caregiver prefer home-based rehabilitation, there is a growing evidence for the effectiveness of this rehabilitation alternative albeit inconsistent (AHA/ASA recommendation Class IIa, LOA B) (Mulyatsih & Ahmed, 2008). As this alternative may be variable between countries due to the different tradition, environment and perception, this study aims to analyze the effect of caregiver education program (CEP) since the second week of admission to help prepare the caregiver or caregiver in improving the functional independence and reducing the mortality of the stroke survivors.

METHODS

Subject Enrollment

Every patient with first-time of acute stroke patient admitted at Cipto Mangunkusumo Hospital and Fatmawati Hospital, Jakarta, was included as the subject. The duration of subject recruitment was six months. Stroke is defined according to the WHO (Hatano, 1973) as a clinical syndrome of either focal or global brain dysfunction that may cause mortality or morbidity persisting more than 24 hours with no other possible etiology besides vascular abnormality. The acute stroke is a stroke in which the duration is within a period of 7 days after the onset whereas first-ever stroke is a first-time experience of the clinical symptoms of stroke or stroke-like attack. Subject presented with recurrent stroke, a confirmed diagnosis of subarachnoid hemorrhage, the need of neurosurgical intervention as part of the stroke management, or the finding of other disease causing life-threatening possibility in the near future were excluded in the early recruitment. Within one week of admission, findings of organ failure including kidney failure, heart failure, and lung failure, or uncontrollable chronic disease such as diabetes mellitus and hypertension were excluded as well.

Sampling

After passing the study criteria and giving their consent, all remaining patients were assigned using cluster randomize controlled sampling to an experiment or control group. While the experiment group received both the standard therapy and CEP, the control one received only the standard therapy. A single-blinded design was applied to the study subject.

Data Collection

Baseline data obtained were: (1) demographic data from anamnesis, including age, sex, educational attainment, socio-economic status and caregiver function based on caregiver assessment device (FAD) method by McMaster; (2) clinical data on the day of admission, including level of consciousness, location of the lesion, classification of lesion based on Oxford Community Stroke Project (OCSP) or known as Bamford Classification of Stroke and co morbidities accompanied the stroke. Two weeks after receiving the acute management, clinical data of prognostic score based on Orpington Prognostic Score (OPS), language ability based on rehabilitation activities profile (RAP), and bladder function based on the components inside Barthel index were recorded. At last, the caregiver characteristics such as the caregiver-to-subject relation and the caregiver formal education were recorded as well.

Intervention

Caregiver education program was carried out by a neurologist in the form of interactive discussion using the overhead projector and poster. The content of CEP was adapted and modified from the caregiver support program at Mount Sinai Medical Center, Cleveland, Ohio, which aimed to prepare the caregiver to adapt with the stroke survivor's disability as well as to reduce the

anxiety and to engage the caregiver in the rehabilitation process. Four-session discussion was held since the second week of admission (since the patient was still in the hospital, after passing the acute phase) with the content as follows:

Session 1: Information regarding types of stroke and their risk factors

Session 2: Information regarding types of disability possibly occurred post-stroke

Session 3: Education regarding the role of caregiver or caregiver in overcoming the morbidity post-stroke and the preparation of outpatient care

Session 4: Education regarding the effort of caregiver or caregiver in the secondary and tertiary prevention related to diet, lifestyle and emotional problem.

A 15-30 minute of discussion was performed in the end of each session, whereas a home care guidebook titled 'Penuntun Perawatan di Rumahterhadap Penderita Pascastroke' created (Mulyatsih and Ahmed, 2008) from integrated stroke care unit, was distributed in the end of the first session. This CEP was routinely applied to the caregiver of acute stroke patients in the stroke unit by a stroke unit team.

Measurements

The effect of CEP was observed at the third month post-stroke on two variables: functional independence and mortality. The functional independence of the stroke survivor was measured using Barthel index (independent if the score 17-20) whereas the mortality was asked directly by phone, during the third-month hospital visit, or by home visit to prevent loss-to-follow-up.

Statistics

Bivariate analysis using Chi square or Fisher exact test was performed to compare the functional independence on both CEP and non-CEP group. Furthermore, bivariate analysis of CEP group and the other independent variables were also carried out. Statistical significance was determined by p values <0.05. A multivariate analysis of risk factors affecting functional independence was also performed for every variable with p<0.25 for every variable to minimize the confounding bias. Statistical significance was determined by p values<0.05.

Mortality trend was analyzed using survival analysis of Kaplan Meier. Statistical significance was also determined by p value<0.05.

RESULTS

Of 406 patients diagnosed as stroke, 172 subjects were included into the analysis (Fig 1). A single-blinded randomized cluster sampling was performed in each hospital separately. Consequently, 88 and 84 subjects were enrolled to the experiment and control group respectively. No statistical difference was found between those two groups from the baseline data (Table 1). Three months later, subject in the CEP group was significantly more independent than the non-CEP group (72.7% vs 56.0% respectively; p=0.022, RR 1.30, 95% CI 1.03-1.63; Table 2).

To assess the effect of CEP to functional independence in relation to other variables, analysis of the influence of other independent variables to functional independence was also performed independently. Overall, there were 11 independent variables contributing to the significant outcome of functional independence (Table 3A), including (1) baseline data of age (p=0.026), sex (p=0.013), formal educational attainment (p=0.001) and caregiver socio-economy status (p=0.001); (2) clinical data on admission such as level of consciousness (p=0.021) and Bamford Classification of Stroke (p<0.001); (3) prognosis data of OPS, communication function, and bladder function (p<0.001 for all variables); (4) caregiver relation to the subjects (p<0.001). Simple logistic regression analysis of all was followed by caregiver-to-subject relation (r=0.220, p =<0.001) and communication function (r = 0.156, p = 0.006).

Of those 11 independent variables significantly affecting the functional independence, CEP was more effective independently on the subjects (table 3C) with (1) the older age (p=0.014, RR=1.55, 95% CI 1.07-2.23), (2) the low formal education attainment (p=0.027, RR=2.09, 95% CI 1.04-4.19), (3) the lower to upper lower caregiver socio-economy status (p=0.016, RR=1.88, 95% CI 1.12-3.16), (4) the CT scan result of infarct (p=0.022, RR=1.31, 95% CI 1.03-1.67), (5) the Bamford classification of lacunar stroke (p=0.029, RR = 1.24, 95% CI 1.02-1.50), (6) some abnormalities of communication function (p=0.041, RR=1.58, 95% CI 1.01-2.47); (7) caregiver of other nuclear family (p=0.041, RR=1.66, 95% CI 0.99-2.78).

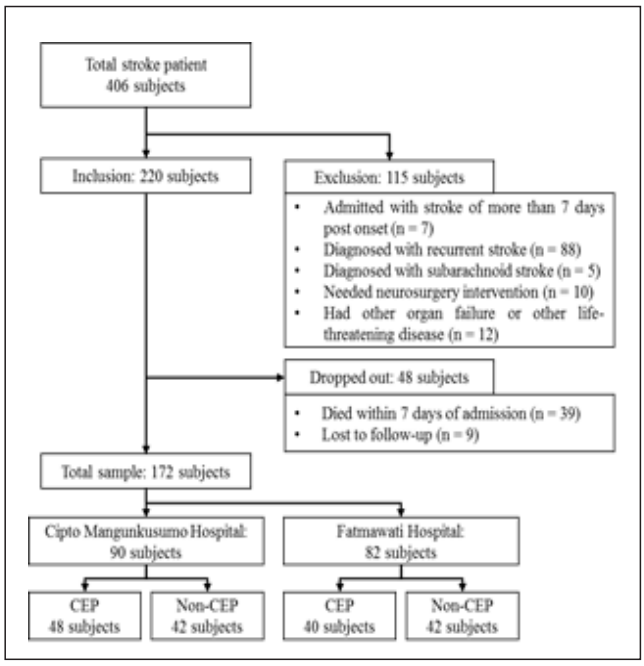

Figure 1: Subject recruitment flowchart

Table 1: Baseline characteristics of the subject

Variables	Day of admission		
	CEP *n* = 88	Non CEP *n* = 84	*p* value
Demographic Data			
Age			
• ≥ 55 years old	51	47	0.070
• < 55 years old	37	37	
Sex			
• Male	54	44	0.234
• Female	34	40	
Formal educational attainment			
• High (> 9 years)	22	23	
• Middle (7-9 years)	39	37	0.924
• Low (≤ 6 years)	27	24	
Caregiver socio-economy status			
• Upper middle to upper	4	2	
• Middle	56	44	0.171
• Lower to upper lower	28	38	
Caregiver function			
• Healthy (FAD > 2.2)	44	34	0.210
• Unhealthy (FAD ≤ 2.2)	44	50	
Clinical Data on Admission			
Consciousness			
• Fully alert	71	59	
• Somnolen-stupor	11	12	0.162
• Coma	6	13	
CT scan result			
• Infarct	66	60	0,780
• Hemorrhagic	22	24	
Location of lesion			
• Right hemisphere	44	40	
• Left hemisphere	43	43	0.952
• Both hemisphere	1	1	
Bamford Classification of Stroke			
• LACS	46	46	
• PACS	27	21	0,840
• TACS	10	12	
• POCS	5	5	
Comorbidity			
• No comorbidity	8	9	
• 1 comorbidity	53	51	0,684
• 2 comorbidities	23	19	
• 3 comorbidities	5	5	
Prognostic Data Assessed Two Weeks After Admission			
Orpington Prognostic Score			
• Mild	37	25	
• Moderate	30	32	0,329
• Severe	21	27	
Communication Function			
• No abnormalities	52	42	
• Some abnormalities	25	26	0,307
• Total abnormalities	11	16	
Bladder Function			
• No abnormalities	65	53	0,307
• Abnormalities	23	31	
Caregiver Characteristics			
Relation to subject			
• Couple	48	45	
• Other nuclear caregiver	31	27	0,702
• Mixed / not caregiver	9	12	
Caregiver's formal education			
• High	32	20	
• Moderate	17	19	0.339
• Low	30	33	
• Unknown	9	12	

Table 2: The effect of CEP on functional independence three months post-stroke

	Self-independent N (%)	Dependent N (%)	*p*	RR	95% CI
CEP	64 (72.7%)	24 (27.3%)	0.022	1.30	1.03-1.63
No CEP	47 (56.0%)	37 (44.0%)			

CEP, Care giver education program

Before proceeding to multiple logistic regression including CEP as an neuro-rehabilitative intervention, some independent variables were grouped in accordance to the similar correlation score (partial *r*, table 3B) and their relationship to each other based on either literature study or clinical judgment of the investigator into 5 major variables including (1) age; (2) sex; also representing the caregiver-to-subject relationship (r=0.538); (3) caregiver socio-economy status, also representing formal educational attainment (r=0.330); (4) Bamford Stroke

Classification representing all variables of the clinical data; (5) OPS representing all variables of the prognosis.OPS was not included in the multiple regression analysis due to its very huge correlation that may influence the analysis of the other factors.

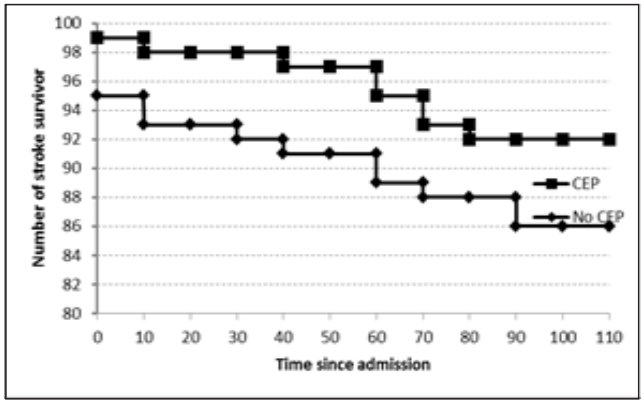

Figure 2. Kaplan Meier survival curve of CEP and non-CEP group

***p*=>0.05 in all time points**

Multiple regression analysis between those 4 variables and CEP showed that functional independence was mostly influenced by Bamford classification of Stroke (r=0.245, p<0.001), caregiver socio-economy status (r=0.130, p=0.016), age (r=0.118, p=0.024), sex (r=0.109, p=0.031) and CEP (r=0.097, p=0.043) in a descending order (table 3D).

Analyzing the outcome of mortality, there was no statistical difference between CEP and non-CEP group in affecting the mortality. However, the mortality tended to be lower in the CEP group (Fig 2).

Table 3: Bivariate and multivariate analysis of risk factors of the independent variables in relation to functional independence

Risk Factor	All subjects								Experiment (CEP) Group							
	A. Bivariate analysis					B. Logistic Regression			C. Bivariate Analysis					D. Multiple Regression		
	I	D	*p*	RR	95% CI	B	*p*	R	I	D	*p*	RR	95% CI	B	*p*	R
Demographic Data																
Age • ≥ 55 years old • < 55 years old	57 54	42 19	0.026 *	0.78	0.63- 0.97	0.042	0.07 5	0.072	28 36	8 16	0.014* 0.468	1.55 1.11	1.07 2.23 0.84-1.45	0.852	0.024*	0.118
Sex • Male • Female	71 40	27 34	0.013 *	1.34	1.05- 1.71	0.534	0.43 0	0.000	42 22	12 12	0.193 0.092	1.18 1.44	0.91-1.52 0.94-2.20	0.786	0.031*	0.109
Formal educational attainment • High (> 9 years) • Middle (7-9 years) • Low (≤ 6 years)	43 47 21	8 29 24	0.001 *	1.50	1.23- 1.83	0.612	0.15 8	0.000	23 27 14	4 12 8	0.857 0.173 0.027*	1.02 1.28 2.09	0.81-1.30 0.89 1.84 1.04-4.19	Represented by the caregiver socio-enomy status		
Caregiver socio -economy status • Upper middle to upper • Middle • Lower to upper lower	3 77 31	2 24 35	0.001 *	0.93 1.59 0.62	0.45- 1.91 1.22- 2.08 0.47- 0.82	0.205	0.68 2	0.000	3 43 18	1 13 10	0.400 0.886 0.016*	- 1.02 1.88	- 0.82-1.27 1.12-3.16	0.816	0.016*	0.130
Caregiver function • Healthy (FAD > 2.2) • Unhealthy (FAD ≤ 2.2)	51 60	26 35	0.675	1.05	0.84- 1.31	- -	- -	-	- -	- -	- -	- -	- -	- -		

Clinical Data on Admission																
Consciousness • Fully alert • Somnolen-stupor • Coma	90 14 7	40 9 12	0.021 *	- 1.38 0.94 0.54	- 1.00- 1.91 0.66- 1.32 0.30- 0.99	-0.725	0.15 1	-0.017	54 8 2	17 3 4	0.065 0.275 0.834	1.25 1.45 0.87	0.98-1.59 0.74-2.85 0.23-3.26	Represented by the Bamford Stroke Classification		
CT scan result • Infarct • Hemorrhagic	64 20	30 18	0.095	1.29	0.93- 1.80	0.359	0.51 4	0.000	52 12	14 10	0.022* 0.555	1.31 1.19	1.03-1.67 0.67-2.12	Represented by the Bamford Stroke Classification		
Location of lesion • Right hemisphere • Left hemisphere • Both hemisphere	59 50 2	25 36 0	0.147	1.19	0.95- 1.49 0.65- 1.03 -	-0.451	0.41 3	0.000	- - -	- - -	- - -	- - -	- - -	Represented by the Bamford Stroke Classification		
Bamford Stroke Classification • LACS • PACS • TACS • POCS	76 23 3 9	16 25 19 1	<0.00 1*	1.89 0.68 0.19 1.43	1.45- 2.46 0.49- 0.93 0.07- 0.54 1.13- 1.81	0.260	0.43 7	0.000	42 15 2 5	4 12 8 0	0.029* 0.235 0.438 0.317	1.24 1.46 2.40 1.25	1.02-1.50 0.77-2.77 0.25-22.75 0.81-1.94	0.793	<0.001*	0.245
Comorbidity • No comorbidity • Other comorbidity • Heart-related comorbidity • Heart & other comorbidities	11 73 3 24	7 41 1 12	0.264	0.94 0.98 1.17 1.04	0.64- 1.38 0.78- 1.23 0.66- 2.08 0.80- 1.36	- - - -	- - - -	- - - -	- - - -	- - - -	- - - -	- - - -	- - - -	-		
Prognostic Data Two Weeks After Admission																
Orpington Prognostic Score • Mild • Moderate • Severe	60 42 9	2 18 41	<0.00 1*	2.09 1.14 0.22	1.80- 2.56 0.91- 1.42 0.12- 0.39	2.161	<0.0 01*	0.244	35 24 5	2 6 16	0.241 0.094 0.367	1.06 1.33 1.73	0.98-1.14 0.95-1.88 0.53-5.67	Omitted to observe the effect of other variables		
Communication Function • No abnormalities • Some abnormalities • Total abnormalities	75 32 4	16 20 25	<0.00 1*	1.85 0.93 0.18	1.43- 2.41 0.73- 1.20 0.07- 0.46	0.456	0.00 6*	0.156	44 19 1	8 6 10	0.386 0.041* 0.535	1.09 1.58 0.52	0.89-1.34 1.01-2.47 0.06-4.35	Represented by the Orpington Prognostic Score		

Bladder Function • Abnormalities • No abnormalities	93 18	26 36	<0.001*	1.72 0.58	1.19-2.49 0.40-0.84	-0.416	0.544	0.000	56 8	9 15	0.031* 0.847	1.23 1.08	1.01-1.51 0.51-2.30	Represented by the Orpington Prognostic Score		
Caregiver Characteristics																
Caregiver relation to subject • Couple • Other nuclear caregiver • Mixed / not caregiver	40 21 3	8 10 6	<0.001*	1.84 0.80 0.20	1.41-2.40 0.61-1.03 0.07-0.57	1.983	<0.001*	0.220	61 3	18 6	0.005 0.063			Represented by the sex variable		
Caregiver's formal education • High • Moderate • Low	41 25 41	11 11 22	0.264	1.18 0.97 0.87	0.97-1.44 0.76-1.25 0.70-1.58	- - -	- - -	- - -	- - -	- - -	- - -	- - -	- - -	-		
Intervention • CEP • Non-CEP	64 47	24 37	0.022*	1.30	1.03-1.63	-	-	-	-	-	-	-	-	0.738	0.043	0.097

CEP, caregiver education program; D, functional dependent; FAD, caregiver assessment device, I, functional independent; LACS, lacunar stroke, PACS, partial anterior circulation stroke; POCS posterior circulation stroke; TACS, total anterior circulation stroke.
*p=<0.05, Chi square test or logistic regression test (depending on the analysis column).

DISCUSSION

Despite the achievement of decreased post-stroke mortality, the high disability rate is still a burden. After passing the acute phase, stroke survivors need assistance in having their needs fulfilled. As many as 50% of the stroke survivors returned home with difficulties performing daily life activities (Cameron *et al.*, 2014).

The role of caregiver is still important after passing the acute phase of stroke (Da Costa *et al.*, 2016). An investigation by (Galvin *et al.*, 2011) showed that caregiver-mediated exercise intervention contributed to the facilitation of patient's functional recovery (Galvin, *et al.*, 2011). To prepare the caregivers in fulfilling their role, an education regarding the home-rehabilitation method is needed (Hong *et al.*, 2017). The Cochrane Collaboration found that the education improved the patient's and caregiver's knowledge while also slightly decreased the patient's depression (Mulyatsih & Ahmad, 2008).

Hong, *et al.*(2017) observed the effect of CEP in Korea, also stated caregiver participation, especially from the stroke survivor of low ADL, may benefit from CEP in reducing the physical, social, and emotional burden (Hong, *et al.*, 2017). It was supported by the fact that early recovery in stroke survivors usually occurs in the first three months of onset, resulting in the potential of maximum recovery from an early intensive rehabilitation treatment (Hong, *et al.*, 2017). Unfortunately, few studies have described the effect of CEP on the outcome of stroke survivors in Indonesia.

Due to its strong caregiver-oriented culture (Claramita, *et al.*, 2013), CEP is expected to play a role in Indonesia. Independent analysis between CEP and the outcome of functional independence proved that CEP carried out after passing the acute phase was significantly related to the increased functional independence (p=0.022; RR=1.30; 95% CI 1.03-1.63).

A study carried out by (Rahman *et al.*, 2016) in low-

resource setting in Bangladesh by giving a written and verbal instruction to the experiment group at the end of the admission showed significant increase of Barthel index score in the experiment group (6.2 ±4.0 during discharge vs 56.3 ± 9.0 after two months) compared to the control group (4.9 ± 4.0 during discharge vs 28.2 ± 7.8 after two months; $p<0.001$) (Rahman *et al.*, 2016). Chinchai *et al.*(2010) also studied the effect of CEP in the QOL of stroke survivor in Thailand and reported that the QOL did not differ before intervention, but significantly differed after CEP in physical ($F(1,29)=41.05$; $p<0.05$), psychological ($F(1,29)=37.96$; $p<0.05$), and environmental areas ($F(1,29)=9.58$, $p<0.05$). However, there was no statistical difference in the social relationship domain (Chinchai *et al.*, 2010). Pitthayapong *et al*.(2017) after observing in the Thailand population regarding post-stroke care program within community setting, also reports the benefit of CEP in improving functional status of stroke survivor ($F=46.01$, $p<0.001$) (Pitthayapong *et al.*, 2017). Hong, *et al.* (2017) also reported the same result after giving CEP on outpatient post-stroke Korea population. Consequently, CEP at the end of the post-stroke management gave an advantage in improving the outcome of functional independence in first-ever stroke survivor.

Taking into account of the relations to other independent variables, CEP had a better effect on the elderly, low formal education attainment, low caregiver socio-economy status, stroke type of infarct, Bamford stroke classification of lacunar stroke, the subject having some abnormalities in communication and bladder function, and the caregiver of nuclear caregiver.

The effect of CEP in elderly ($p=0.014$; RR=1.55; 95%CI=1.07-2.23) to improve the functional independence was thought to occur due to the longer duration of exposure to the caregiver. Indonesia's culture respected elderly and tended to give more attention to the elderly (Chinchai *et al.*, 2010). Shebl *et al.* (2014) also reported the same result in the geriatric population in Egypt. This result occurred due to the increased knowledge and practice level of caregivers in relation to the delivery of CEP (Shebl *et al.*, 2014).

Low formal education attainment ($p=0.027$; RR=2.09; 95%CI=1.04-4.19) and caregiver socio-economy status (p=0.016; RR=1.88; 95%CI=1.12-3.16) also influence CEP in improving the functional independence. It was thought that higher formal education attainment and caregiver socio-economy population may already know, search, or have an access to search the information, or may have a professional caregiver whereas the low ones may take more benefit from CEP.

Nuclear caregiver as the caregiver was also significantly co-related to the functional independence of the CEP group ($p=0.041$; RR=1.58, 95% CI=0.99-2.78). This was thought due to the Indonesia's caregiver-oriented culture as well. Care from the nuclear caregiver would bring a thought that the stroke survivor was still important to the caregiver function.

Clinical data of infarct stroke ($p=0.022$; RR=1.31; 95%CI=1.03-1.67) and Bamford stroke classification of lacunar stroke (p=0.029; RR=1.24; 95%CI=1.02-1.50) as well as some prognostic data of abnormalities in communication ($p=0.041$; RR=1.58; 95% CI=1.01-2.47) and bladder function ($p=0.031$; RR=1.23; 95%CI=1.01-1.51) described a mild-to-moderate stroke presentation. Therefore, CEP had a more effect on mild stroke presentation in reducing the dependence. It was consistent to the fact that the more severe the stroke was, the more damage the CNS had, which results in the need of more advanced rehabilitation method.

Reviewing the other studies conducted in Thailand, one of their subject inclusion criteria was moderate disability according to Modified Ranking Scale (Pitthayapong *et al.*, 2017). Another study in Korea showed a positive effect of CEP in functional independence outcome using Korean version of the National Institutes of Health Stroke Scale (K-NIHSS) on mild (-1.33±1.60 vs. -1.18±1.14 on CEP vs. non-CEP, respectively) and moderate (-5.21±4.03 vs. -3.30±3.61 on CEP vs. non-CEP; $p<0.05$) stroke severity(Hong *et al.*, 2017). The effect on the mild experiment group was explained by a 'ceiling' effect due to the higher chance of spontaneous recovery (Rahman *et al.*, 2016). Therefore, CEP was proven more effective on the mild-to-moderate presentation of stroke.

After grouping the individual independent variables into 5 groups (age, sex, caregiver socio-economy status, Bamford Stroke Classification, and OPS), a multiple regression analysis was performed.OPS was omitted from the analysis due to the very huge correlation that may influence the analysis of the other factors. In a descending order, functional independence

was influenced by Bamford classification of Stroke (r=0.245, p<0.001), caregiver socio-economy status (r=0.130, p=0.016), age (r=0.118, p=0.024),sex (r=0.109, p=0.031) and CEP (r=0.097, p=0.043). Therefore, despite the positive effect of CEP, OPS and Bamford Stroke Classification have a higher influence to the outcome of functional independence.

Analyzing the effect of CEP in reducing mortality, CEP showed a decrease in the mortality rate. However, the result was not statistically significant. This result was correlated to the previous result discussed above and supported by the finding and it is stated that CEP had a significant effect only on the mild-to-moderate stroke presentation (Hong *et al.*, 2017). Severely-disabled stroke survivor was less tolerable to the additional treatment, required more time and effort of the caregiver, and had a more severe injury on the brain which results in more severe cognitive deficit. Furthermore, this dramatic changing condition had a potency to increase the depression level of both the survivor and the caregiver, which eventually had a negative effect to the recovery (Rahman *et al.*, 2016).

Besides those variables discussed above, timing of CEP delivery may influence its effect in reducing post-stroke disability as well. A multi center cohort study conducted by (Forster, *et al*., 2013) performed CEP at the immediate post-stroke period and reported an insignificant result between CEP and the reduction of disability (adjusted mean Nottingham Extended Activities of Daily Living score of experiment vs. control group 27.4 vs. 27.6, respectively, p=0.866). It was purposed that immediate inpatient post-acute stroke period, a condition in which the caregiver was still adapting with a new situation, might not be an ideal time of the delivery of CEP. The effect to the reduction in self-reported burden by the caregiver as well as the QALY was insignificant as well (Forster, *et al.*, 2013).

On the other hand, to achieve the better functional outcome, rehabilitation should start as soon as possible in accordance to the patient's readiness (AHA/ASA recommendation Class I, LOA B) (Winstein *et al.*, 2016, Chan, *et al.*, Mulyatsih & Ahmad 2008).

An aspect that was not being observed in this study, but must be considered in the following study, is the QOL of the caregiver. This highly-stressful care may affect the patient care at home (Da Costa *et al.*, 2016). While neglected caregiver may neglect the stroke survivor resulting in the decreased QOL of them, caring caregiver may suffer from emotional distress, of which the most common is depression (Da Costa *et al.*, 2016).

It is reported that 12% to 55% of caregiver had some emotional distress (Chen, *et al.*, 2010). Another study concluded that the number of caregiver depression was estimated about 20-40% (Shin, *et al.*, 2013). This condition is CEP table due to changes in the dynamics between the caregiver and the stroke survivor post-stroke (Da Costa *et al.*, 2016). Therefore, education for the caregiver regarding the best home-rehabilitation method as well as the need of taking the QOL of the caregiver into account for the outpatient stroke management was recommended (AHA/ASA Class IIb, LOA A).In addition, the caregiver needs either caregiver or friends to provide physical and emotional assistance as well as healthcare providers to help establishing and maintaining the rehabilitation over time (Mulyatsih and Ahmad, 2008). A study by (Jung *et al.*, 2014) in Korea also proved that CEP, despite giving benefit to the stroke survivor, significantly reduced the depression and burden of the caregiver as well (Jung *et al.*, 2014).

AHA/ASA states that the most effective educational program should include an active involvement and follow-up by the educator. The education program should include supportive problem solving and skill development as well as how to fulfill physical care needs, financial assistance, medications, respite, domestic assistance, and reassurance (Mulyatsih & Ahmad, 2008).

In South-East Asia, this role has been assigned to the primary care and caregiver doctor (WHO, 2014). However, there is still no established structure and certification of merging this unit to the comprehensive stroke unit in Indonesia. A study of whether primary care and caregiver doctor are knowledgeable enough in carrying this role has not ever been studied.

CONCLUSION

Caregiver education program (CEP) modified from the caregiver support program at Mount Sinai Medical Center, Cleveland, Ohio has benefit in improving the functional independence of stroke survivor, especially in the elderly, low formal educational attainment and caregiver socio-economy status, milder presentation of stroke and the caregiver of nuclear caregiver. However,

this type of CEP has no significant effect in reducing the mortality rate. Therefore, while this type of CEP may be applied to every population, a more comprehensive approach, such as stroke unit using certified professional, may be applied to the more severe presentation of stroke.

More studies should be performed on a larger multicenter institution to further ensure the consistency of this study's result on low-to-middle countries with a strong caregiver-oriented culture. In addition, another method of rehabilitation such as early initiation of CEP, upgrading the stroke unit to accommodate this early initiation and the impact of primary care or caregiver doctor on the rehabilitation of stroke survivor still need to be addressed.

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