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## **THE DEVELOPMENT OF CAREGIVERS' KNOWLEDGE ABOUT STROKE AND STROKE CAREGIVING SKILLS TOOLS FOR STROKE CAREGIVERS IN INDONESIA**

**Sukron**

Master student of Khon Kaen University 40002 Thailand

[sukron\\_90@yahoo.com](mailto:sukron_90@yahoo.com)

**Nichapatr Phutthikhamin**

Ph.D, Department of Adult Nursing, Faculty of Nursing, Khon Kaen University, 40002  
Thailand

[thithi@kku.ac.th](mailto:thithi@kku.ac.th)

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### **Abstract**

*This descriptive research aimed develop caregiver's knowledge about stroke and stroke caregiving skills tools. The study samples are caregivers of stroke patients at Neurological outpatient unit of Muhammadiyah Hospital Palembang, South Sumatera, Indonesia. Content validity was tested by five experts and Reliability was tested in 30 stroke caregivers. The reliability was tested using SPSS and internal consistency would be analyzed by KR-20 (Kuder-Richardson 20). The finding of content validity showed that stroke diseasedimensions' there were four items not agreed by experts I-CVIs = 0.80, however another items was agreed by all experts I-CVIs = 1.00. Mean of I-CVI for all experts were 0.92. The experts mentioned that the stroke dimensions were clear and relevant to assess caregiver knowledge about stroke. In reliability test, the mean score was 11.73 (SD=4.75) with variance 22.55 and KR-20 was 0.75. For stroke caregiving skills, mean of I-CVI for all experts were 0.90. In reliability test, using cronbach's alpha was 0.75. In conclusion, the*

*caregivers' knowledge about stroke and stroke caregiving skills have good properties to assess the level of knowledge about stroke and skills for stroke caregiver. Nurses who work with stroke patients on inpatient unit can use the tool to assess caregiver knowledge and skills before discharge at home. Further study should examine and modified the same tools with different setting, method, and add more sample size.*

### **Keywords**

Stroke Disease, Stroke Caregiver, Caregivers' Knowledge about Stroke and Skills

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## **1. Introduction**

Stroke is cerebral circulatory disorder which occurs suddenly and quickly and lasts more than 24 hours; it can lead sufferers to death (Adam, 2014). The most significant and lasting impact of stroke is long-term disability (Bear et al., 2007). Caregivers' roles for stroke patient are assisting in activities of daily living (ADLs) with such activities as transferring, grooming, feeding, bathing, toileting, mobility some range of motion exercise (Bowsher, 2013). They also need to manage behavioral and emotional problems of the stroke patients promote rehabilitation, and prevent secondary prevention and complications (Bakas et al., 2012). Some caregivers who do not have enough knowledge and skills will have difficulty in performing their roles as caregivers (Weltermann et al., 2009). They may experience stress and anxiety during hospital stay and at home (Phillips et al., 2011).

Being stroke caregivers requires time, energy, and encouragement. Bakas et al, (2004) said that care giving demands depend on factors such as: 1) Personality of the patient; 2) severity of disease; and 3) conditions and performance of caregivers include physical, social cognitive, management skills, skills and knowledge. Nurses need to assess care demands by evaluating the capability, family roles, knowledge, and skills of stroke caregivers (Sherwood et al., 2014). Stroke patient's with some complications have intricate intervention procedures that require stroke caregiving involvement and management (Sherwood et al., 2014). The best implementations have extended the life spans of most stroke patients, involving in caregivers roles often take many years (Given et al., 2011). Some stroke care givers reported they do not have enough knowledge and skills to take care for stroke patients lack of competence and confidence (Given et al., 2011; Bakas et al., 2004; Pinguart and Sorensen (2006).

From the above mentioned, there is limited knowledge of the condition of stroke patients and caregiver after discharge. It is necessary for the health care providers, especially nurse to assess the patient condition and caregivers' knowledge and skills before discharge.

There are some tools or instruments to assess caregivers' knowledge such as Stroke Knowledge Test (SKT), and Perception on stroke, risk factors, warning signs, and treatment assessment tool and assess care giving skills such as The Preparedness for Caregiving Scale and Caregiver's ability.

The Stroke Knowledge Test (SKT) developed by Sullivan (2001) to assess of knowledge and evaluation of stroke education programs. The final version of the test included 20 items with good content coverage, acceptable item properties, and positive expert review ratings. It can be used to assess stroke knowledge among survivors, people at risk of stroke, carers and family members, or support staff working with people who have had stroke, but some items not suitable to apply in Indonesia. Another study about Perception on stroke, risk factors, warning signs, and treatment develop by Monthira Chanakarn (2015) to assess perception and knowledge of caregiver's. The tool had 30 items including stroke disease, risk factors, warning signs, and treatment with content validity 0.97 and reliability using KR-20 with cronbach's alpha 0.84. The tool easy to apply in many settings, and the most items that cover about stroke disease such as stroke, risk factors, warning signs and treatment but some items are not clear and not appropriate in Indonesia.

The Preparedness for Caregiving Scaled developed by Archbold et al (1990) to assess how well prepared stroke caregiver at home. 8 items responses providing physical care, emotional support, setting up in-home support services, and dealing with the stress of caregiving. The tools easily self-administered by the primary family caregiver but does not ask about specific knowledge or skill needs. Another study about Caregiver's ability tool developed by Charuk Taneerut, (2002) to assess caregiver's ability in continuing care on caregiver's ability, functional ability, and complications in ischemic stroke patients. The tool composed of 4 dimensions: ADL (13 items), complication prevention (10 items), Rehabilitation (5 items) and mental support (7 items). Content validity by 5 experts and reliability using alpha Cronbach was 0.94. The tool is easy to assess and apply in many settings. The dimensions mostly cover caregiver roles except recreational activities this tool is easy to assess and apply in many settings. Some dimensions mostly cover caregiver roles except recreational activities. In additional, special care only include tube feeding but not include those patients with tracheostomy tube and who retained urinary catheter.

Assessing caregivers' knowledge and skills are importance as health care providers. Nurses as caring agents, need to assess caregivers' knowledge and skills after discharge. This study will help the nurse and other profession to assess knowledge of

caregivers about stroke and stroke care giving skills. These can be useful in clinical and community setting. From mention above, the purpose in this study is to develop the assessment tool of caregivers' knowledge about stroke and stroke care giving skills.

## 2. Method

This study is descriptive study aimed to develop caregiver's knowledge about stroke and stroke care giving skills. The target group in this study is caregivers who accompanied stroke patients who follow up at Neurological outpatient unit of Muhammadiyah Hospital Palembang, South Sumatera, Indonesia. In this study, the researcher would develop tool named Caregiver's Knowledge about Stroke and Stroke Care giving Skills based on literature review. The process of develop Caregiver's Knowledge about Stroke such as: 1) planning; the researcher had reviewed some literature as a reference consider the contents of the knowledge to develop the tools; 2) design and development: the context and conditions of assessment tool had been considered to answer the purpose and target group for stroke patients and caregivers; 3) quality checks: in this term, the tools would be rechecked regarding clarity, content accuracy, relevance, and appropriateness. Finally, the tool consists of four dimensions: stroke disease (7 items), risk factors (7 items), warning signs (7 items), and treatment (5 items) base on literature review. Some stages process of translation including translation.

For Stroke Care giving Skills, the process of develop such as: 1) planning; the researcher had been reviewed some literature as a reference and consider the contents of stroke caregiving skills to develop the tools; 2) design and development: the context and conditions of assessment had been developed in consistency with the Indonesia content; 3) quality checks: In this term, the tools will be rechecked regarding clarity, content accuracy, relevance, and appropriateness. Finally, it composes of 4 dimensions with 34 items: activity daily living including 2 items of recreation (18 items), complication prevention (8 items), rehabilitation (3 items) and mental support (5 items). In ADL dimension, it includes 2 special cares which are tube feeding(5 items) and urinary catheter(5 items).The rating scale ranges from 0 (never) to 2 (always). The total score ranges from 0 to 64. The score can be categorized into 3 levels: low (0-23), moderate (24-46), and high (47-68).

Content validity of caregiver's knowledge about stroke and stroke care giving skills were tested by five experts. The experts were a specialist doctor in stroke from Thailand, two nurses educator specialized in stroke patients from Thailand, 2 nurses educators specialized

in stroke patients from Indonesia. According to Polit and Beck (2010), 4-point rating scale is suggested to fine expert opinion. The scale rate from 1 = not relevant, 2 = somewhat relevant, 3= quite relevant, 4= very relevant. The rating 1 and 2 would be score as 0 while the ratings 3 and 4 would be scored as 1. The item would be accepted if the I-CVI is 1.00. The tools have been translated into Indonesia language after content validity and performed.

Reliability was conducted in sample of 30 caregivers from the target population with inclusion criteria were: (1) primary caregiver who providing care for the stroke patients at least 8 hours per day; (2) can communicate in Indonesian language; and (3) willing to participate in the study. The reliability of caregivers' knowledge about stroke was tested using SPSS and internal consistency would be analyzed by KR-20 (Kuder-Richardson 20). The reliability of stroke care giving skills was tested using SPSS and internal consistency would be analyzed by Cranach's alpha.

### 3. Result

**Table 3.1: I-CVI Caregiver's Knowledge about Stroke**

No	Question	Expert I	Expert II	Expert III	Expert IV	Expert V	Number in agreement	Item CVI
<b>Stroke disease</b>								
1	Stroke is defined as "brain attack" that can occur to everyone any time if the blood circulation to brain is stopped	2	4	4	4	4	4	0.80
2	The common sign of hemorrhagic stroke is headache	3	4	4	4	2	4	0.80
3	Stroke can lead to disability and death	4	4	4	4	4	5	1
4	Stroke is preventable if risk factors are controlled	4	4	4	3	2	4	0.80
5	In general, stroke has 2 types: ischemic and hemorrhagic	4	4	4	4	4	5	1
6	The most common cause of hemorrhagic stroke is high blood pressure	4	4	4	4	4	5	1
7	Ischemic stroke is caused by the break of brain vascular	2	4	4	4	4	4	0.80

Risk factors of stroke								
8	Women and man have equal chance to develop stroke	4	4	4	4	4	5	1
9	People who have family history of stroke have a chance to become stroke.	4	4	4	4	4	5	1
10	Stroke is common in those who have high blood pressure, diabetes mellitus, and heart disease.	4	4	4	3	3	5	1
11	Smoking is one risk factor of stroke	4	4	4	4	4	5	1
12	Heavy alcohol drinking can lead to stroke	4	4	4	3	4	5	1
13	Physical inactivity is not a risk factor of stroke	4	4	4	4	2	4	0.80
14	Obese people have a chance to become stroke	4	4	4	4	4	5	1
Warning signs of stroke								
15	Sudden loss or blurring of vision in one or both eyes is the warning sign of stroke	4	4	4	4	4	5	1
16	Nausea is the warning sign of stroke	4	3	4	4	3	5	1
17	Sudden weakness of one side (arm and leg) is the warning sign of stroke	4	4	4	4	4	5	1
18	Sudden crooked mouth and trouble speaking are the warning signs of stroke	4	4	4	4	3	5	1
19	Dizziness, unsteadiness or a sudden fall is the warning sign of stroke	4	4	4	4	4	5	1
20	The whole body beriberi (numbness) is the warning sign of stroke	4	2	4	4	3	4	0.80
21	Sudden severe headache, blurred vision, and diplopia are the warning signs of stroke	4	4	4	4	4	5	1
Treatment of stroke								
22	Stroke patients who have weakness of muscle like paralysis, and hemiplegic can be recovered by	4	4	4	4	4	5	1

	continuing physical therapy.							
23	Speaking therapy focuses on communication	4	4	4	4	1	4	0.80
24	Stroke patients should not take aspirin drug forever after stroke	4	4	4	4	3	5	1
25	In acute phase, treatment of stroke is better in the patients who rush to the hospital than those who delay	4	4	4	3	4	5	1
26	If you meet someone who has sudden weakness of one side (arm and leg), you must rush him/her to the hospital or call 0711-511446	4	4	4	1	4	4	0.80
<b>Proportion relevant</b>		<b>24/26= 0.92</b>	<b>25/26= 0.96</b>	<b>26/26= 1</b>	<b>25/26= 0.96</b>	<b>22/26= 0.85</b>	<b>Mean I-CVI : 24/26 = 0.92</b>	

**Table 3.2: I-CVI Stroke Caregiving Skills**

No	Statement	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Number in agreement	Item CVI
1	Motivate/give a bath/shower for the stroke patient at least 2 times/day (morning and evening)	4	4	4	4	4	5	1
2	Motivate/do mouth care for the stroke patient at least 2 times/day	4	4	4	4	4	5	1
3	Motivate/do shampoo care for the stroke patient at least 2 times/week	4	4	4	4	4	5	1
4	Choose the proper clothes which are easy and comfortable to wear and take off	4	4	4	3	3	5	1
5	Train and stimulate the stroke patient to eliminate feces on schedule	4	4	4	4	4	5	1
6	Motivate/assist the stroke patient to change position or sit up	4	4	4	4	1	4	0.80
7	Take the patients to go for picnic or shopping once a month	4	2	4	4	4	4	0.80
8	Carry out stroke patient to join in some social activities	4	4	4	1	3	4	0.80
9	Provide quiet environment and dim light when the stroke patient	4	4	4	4	1	4	0.80

	sleep/rest							
<b>Nutrition: In case of eating by oneself</b>								
10	Provide sufficient food which cover 5 main food groups (protein, carbohydrate, fat, mineral, vitamin) for the stroke patient	4	4	4	4	2	4	0.80
11	Motivate the stroke patient to eat by oneself	3	4	4	4	4	5	1
12	Motivate/help the stroke patient to sit upright/high head during the meal	4	4	4	3	4	5	1
13	Prepare fruits or refreshment between meals	4	4	4	3	3	5	1
<b>Nutrition: In case of tube feeding</b>								
10	Check and clear secretion before feeding	3	4	4	4	4	5	1
11	Check residual content before feeding	4	4	4	4	4	5	1
12	Keep the stroke patient high head position during feeding AND after feeding 30-60 minutes	4	4	4	4	4	5	1
13	Check tube position before feeding	4	4	4	4	4	5	1
<b>In case of self urination</b>								
14	Motivate/assist the stroke patient in urine elimination	4	4	4	4	4	5	1
15	Clean after the stroke patient pass urine and keep the clothes dry and clean	4	4	4	4	4	5	1
16	Motivate/assist the stroke patient to take oral fluid at least 2000 cc per day	4	4	4	1	4	4	0.80
17	Modify walking hand bar for the stroke patient to walk to the bath room	4	4	4	4	4	5	1
18	Monitor/observe urine sediment, colour and volume	4	4	4	4	4	5	1
<b>In case of urinary catheter</b>								
14	Observe urethra area for sign of infection	1	4	4	4	4	4	0.80
15	Keep urine bag clean and keep the urine outlet 6 inches above the	1	4	4	4	4	4	0.80

	floor							
16	Perineum care with boiled water twice a day (morning and evening)	1	4	4	4	4	4	0.80
17	Monitor/observe urine sediment, colour and volume	1	4	4	4	4	4	0.80
18	Provide oral fluid for the stroke patient at least 2000 cc/day	1	4	4	3	4	4	0.80
<b>Complication prevention and secondary prevention</b>								
19	Keep the bed linen dry and smooth	4	4	4	4	4	5	1
20	Change the cloth and bed linen immediately after getting wet from urine or feces	4	4	4	4	4	5	1
21	Check the patient's skin, especially coccyx and tubercle areas	4	4	4	4	4	5	1
22	Motivate/remind the stroke patient to take medication regularly	4	4	4	4	1	4	0.80
23	Manage risk factors to prevent recurrent stroke	4	4	4	4	1	4	0.80
24	Observe and identify risk for falls during ambulation	4	4	4	4	4	5	1
25	Motivate/ help the patient to change position every 2 hours	4	4	4	4	4	5	1
26	Monitor/observe the stroke patient's fever	4	4	4	4	3	5	1
<b>Rehabilitation</b>								
27	Keep the stroke patient's body alignment	4	4	4	1	4	4	0.80
28	Keep the stroke patient's proper side position, not press/lean over the weak arm and leg	4	4	4	1	4	4	0.80
29	Assit/motivate the stroke patient to do range of motion exercise 2 times per day (morning and evening)	3	4	4	1	4	4	0.80
<b>Mental support</b>								
30	Wait and give time for the stroke patient to express feeling	4	4	4	4	4	5	1
31	Empower and encourage the stroke patient when the patient can do	4	4	4	4	4	5	1

	ADLs by oneself							
32	Accept and understand the stroke patient's behaviors	4	4	4	1	3	4	0.80
33	Touch gently and keep the stroke patient's comfort when the patient feel sad, blue, or upset	4	4	4	4	4	5	1
34	Promote the stroke patient's sleep by massage, music, pray, etc	4	4	4	4	1	4	0.80
<b>Proportion relevant</b>		<b>29/34=0.85</b>	<b>33/34=0.97</b>	<b>34/34=1</b>	<b>29/34=0.85</b>	<b>28/34=0.82</b>	<b>Mean I-CVI :31/34 = 0.9</b>	

As can be seen table 3.1 the finding of content validity Caregivers' knowledge about stroke showed that stroke diseasedimension there were four items not agreed by experts I-CVIs = 0.80, however another items was agreed by all experts I-CVIs = 1.00. The dimension of Risk factors of stroke and Warning signs of stroke viewed that only one item the expert was not agree, and for Treatment of stroke there were two items was not agreed by expert. Mean of I-CVI for all experts were 0.92. In reliability test, the mean score was 11.73 (SD=4.75) with variance 22.55 and KR-20 was 0.75. As shown in table 3.2 the finding of content validity Stroke Care giving Skills viewed that the dimension of urinary catheter were disagree by one expert. The reason was the items did not suitable to apply in Indonesia. However, most of items were agree by experts but need to made simply and easy to understand. Mean of I-CVI for all experts were 0.90. In reliability test, using cronbach's alpha was 0.75.

#### 4. Discussion

There were 4 dimensions of Stroke caregivers' knowledge about stroke such as stroke disease (7 items), risk factors (7 items), warning signs (7 items), and treatment (5 items) and stroke caregiving skills composes of 4 dimensions with 34 items: activity daily living including 2 items of recreation (18 items), complication prevention (8 items), rehabilitation (3 items) and mental support (5 items). In ADL dimension, it includes 2 special care which are tube feeding(5 items) and urinary catheter (5 items). The finding of content validity viewed I-CVI were acceptable. The experts agreed that four dimensions of stroke knowledge related with the target population. The experts mentioned that the stroke dimensions were clear and relevant to assess caregiver knowledge about stroke and stroke care giving skills. The

content validity index can be acceptable because of the items are clear the instrument have to match with the target population (Scholtes et al, 2010). The suggestion by the expert, the item should be appropriate and common in Indonesia condition. However, there were some items need to revises and modify to be simple word and easy to understand. The acceptable criteria of reliability are 0.7 for new instrument and 0.8 for return instrument). If the coefficient is more than 0.7, it means that the tool is reliable and if the coefficient less than 0.7, it means that the tool is not reliable. In reliability test using KR-20, caregivers' knowledge about stroke was 0.75 and stroke caregiving skills was 0.75. It means that the tool sare reliable.

## 5. Conclusion

The caregivers' knowledge about stroke and stroke care giving skills have good properties to assess the level of knowledge about stroke and skills for stroke caregiver. Nurses who work with stroke patients on in patient unit can use the tool to assess caregiver knowledge and skills before discharge at home. Further study should examine and modified the same tools with different setting, method, and add more sample size.

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