

การสนับสนุนคำจูนของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง  
ที่เข้ารับการรักษาในโรงพยาบาล Ulin General Hospital  
เมือง Banjarmasin ประเทศอินโดนีเซีย

บทความวิจัย

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The Supportive Care Needs of Stroke  
Caregivers during Hospital Stay at Ulin General Hospital,  
South Kalimantan, Indonesia

Agilanto\* บัณฑิต นันตบุศ Ph.D.\*\*

Agilanto\* Khanitta Nuntaboot Ph.D\*\*

**บทคัดย่อ:**

การวิจัยเชิงพรรณานี้มีวัตถุประสงค์เพื่ออธิบายความต้องการการสนับสนุนคำจูนของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองที่เข้ารับการรักษาในโรงพยาบาล Ulin General Hospital เมือง Banjarmasin ประเทศอินโดนีเซีย ทำการเก็บข้อมูลจากกลุ่มตัวอย่าง 56 คน ระหว่างวันที่ 12 มีนาคม 2556 ถึงวันที่ 30 เมษายน 2556 โดยใช้แบบสอบถาม Stroke Caregiver Assessment of Needs Survey (SCANS) ที่แปลเป็นภาษาอินโดนีเซีย มีค่าความเที่ยงเท่ากับ 0.83 ทำการวิเคราะห์ข้อมูลโดยใช้โปรแกรมสำเร็จรูป SPSS version 10.0 ผลการศึกษา พบว่า ช่วงคะแนนความต้องการการสนับสนุนคำจูนของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองอยู่ระหว่าง 58-159 คะแนน(จากช่วงคะแนนของแบบสอบถาม 42-168 คะแนน) คะแนนเฉลี่ยเท่ากับ 105.87 คะแนน ส่วนเบี่ยงเบนมาตรฐานเท่ากับ 25.49 ระดับความต้องการการสนับสนุนคำจูนของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง พบว่า ส่วนมากอยู่ในระดับปานกลาง(ร้อยละ 98.21, n=55) รองลงไปคือระดับสูง(ร้อยละ 1.79, n=1) ไม่พบว่ามีระดับความต้องการการสนับสนุนคำจูนของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองในระดับต่ำ

**คำสำคัญ:** การสนับสนุนการคำจูน ผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง

**Abstract**

This descriptive research design was conducted to describe demographic data and supportive care needs (overall and each domain) among stroke caregivers at Ulin General Hospital, South Kalimantan, Indonesia. Data were collected from 56 stroke caregivers using SCANS questionnaire in Indonesian during March 12, 2013 to April 30, 2013. Its reliability was 0.83. The results consisted of a supportive care needs score and supportive care needs level as follow the total score of supportive care needs was in the range of 42 – 168 and the score of the samples was in the range of 58 – 159. The mean score and SD of supportive care needs of stroke caregivers was 105.87±25.49. Level of supportive care needs was separated into three groups using the interval score. Most of stroke caregivers were at moderate level of supportive care needs (98.21%, n=55), followed by high level of supportive care needs (1.79%, n=1). There was no caregiver who identified one's self to have low supportive care need.

**keywords:** supportive care needs, stroke caregiver.

\*Student, Master of Nursing Science (International Program), Faculty of Nursing, Khon Kaen University; Lecturer, School of Nursing, Faculty of Medicine, Lambung Mangkurat University

\*\*รองศาสตราจารย์ คณะพยาบาลศาสตร์ มหาวิทยาลัยขอนแก่น

## Background and significance

Stroke is a major cause of mortality and morbidity in developed and developing countries.<sup>1</sup> In the United States, stroke is the third leading cause of mortality,<sup>2</sup> whereas in ASEAN countries, mortality data is more varied; in ASEAN countries, stroke has been the fourth leading cause of death since 1992; number one in Indonesia.<sup>3</sup> Stroke can be prevented and treated and stroke patients can regain their quality of life with the appropriate long-term care and support of the family or caregiver.<sup>4</sup>

Stroke patients need a long-term care facility at the hospital, rehabilitation center, and their home.<sup>5</sup> Furthermore, stroke management is needed to prevent complications and mortality due to stroke in long-term care. The patient who has had stroke may fully recover or may have some residual effect from their disease. Stroke patients have a high risk of complications; these complications are potential barriers to optimal recovery.<sup>6</sup> Family member or caregiver become the care-taker for stroke patients in long-term care facility.<sup>5</sup>

Caregivers are people who have to care because of their close kinship or emotional bond to the care recipient.<sup>7</sup> Continuous requirements and long-term care of stroke patients with limited resources are a stark reality for many caregivers.<sup>8</sup> Healthcare teams identify the caregivers of stroke patients as key members of the team. Notwithstanding active inclusion of caregivers in planning and decision making in acute care is often missing.<sup>9</sup> Caregivers discuss the basics of managing the activities of daily living and problem solving strategies, so, caregivers need to learn their role clearly.<sup>10</sup> The caregiver's role is helping the stroke patients with regards to feeding, doing activity (activities of daily living) and rehabilitation.<sup>11</sup> The acute care phase of

stroke management is brief, and caregiver need assistance in making decisions about the next phase of care for stroke patients.<sup>12</sup> Caregivers have an important role in phase three of stroke (discharge planning), that will help the patients and caregivers adjust to their new way of life.<sup>11</sup> So, nurses need to identify the caregivers as a recipient of caring and assisting; thus supporting them as they adjust to their role.<sup>10</sup>

The negative effects often seen in caregivers of stroke patient are depression, anxiety, loss of independence and inadequate time to manage multiple roles and responsibilities, as well as disrupted pattern of roles (psychosocial).<sup>8,13,14</sup> Furthermore, caregivers also have problems (negative effects) on maintaining their own physical health, and providing assistance pertaining to activities of daily living (practical).<sup>9,13,14</sup> Additional negative effects may be mood swings, lack of motivation, sadness and grief, fear of another stroke (emotional),<sup>8,14</sup> fatigue, inadequate rest, tiredness, exhaustion, a lack of energy (physical),<sup>9,13,14</sup> suffering lost personal meaning over time (spirituality),<sup>13,15</sup> memory loss, and disrupted communication (informational).<sup>8,14</sup> These issues may arise because stroke caregivers are more than just physical entities; they also have emotional, psychological, social, and spiritual aspects to them.<sup>16</sup>

Supportive care is described as the provision of care for patients to help them meet their physical, emotional, social, psychological, informational, spiritual, and practical needs during diagnostic, treatment, and follow-up phases.<sup>17</sup> Supportive care needs (SCNs) include six domains: physical, emotional, informational, psychosocial, spiritual, and practical. SCNs can be used within the cancer care community, health professionals, patients, family and other caregivers, and composite population. The composite populations are

stroke, heart failure, chronic wounds and cancer.<sup>16</sup> It is important that health care professionals understand the caregiver role and advise them to assist managing this role.<sup>16</sup> The adult caregiver role is one that is rarely expected and this is especially true for families of individuals who have had a stroke.<sup>10</sup>

Most SCNs researches are conducted with regards to cancer patients.<sup>18,19,20,21</sup> Nonetheless, very few of these studies have been focused on supportive care needs pertaining to stroke patients and caregivers.<sup>9</sup> Though some studies about SCNs were conducted in Canada,<sup>9</sup> USA,<sup>8</sup> and Australia,<sup>21</sup> no studies have previously been conducted in Indonesia until now. Accordingly, this research is a study that will determine SCNs in stroke caregivers (six domains of SCNs). In addition, several studies were done about <sup>14</sup> years ago.<sup>8,22,23</sup> Certainly, there is the need to do an up to date research on SCNs of stroke patients and their caregivers.

Based on pilot study, the researcher interviewed five caregivers about the problems that they were experiencing related to SCNs through out their stay in the hospital in order to determine the problems or issues that they had felt or experienced. All caregivers reported that they had to provide assistance with regards to ADL for stroke patients, consequently they needed information about how to take care of the patient such as hygiene care. 80% of caregivers reported that they felt tired, had experienced insomnia and a lack of energy. What's more they also said that they need more understanding of stroke treatment and prevention, to know why certain procedures and planning are done as the first month of caregiving is very dynamic and stressful for caregivers of stroke survivors.<sup>14</sup> Stroke patient management in the neurological ward is performed by a multidisciplinary team including specialist doctors, nurses, nutritionist, physiotherapist and caregiver. In

the neurological ward itself there is no special protocol for stroke patients for instance how to prevent pressure sores in stroke patients, changing position, fall prevention, nutrition (oral and parenteral), rehabilitation or range of motion (ROM) and discharge planning. The protocol in the ward is a general protocol owned by the hospital and used for all diseases or cases in the hospital. In fact, the stroke itself is different from other diseases in treatment (management).

### Research question

What are the supportive care needs of stroke caregivers during their hospital stay at Ulin General Hospital in Banjarmasin, South Kalimantan, Indonesia?

### Objective of the study

To describe supportive care needs of stroke caregivers during their hospital stay at Ulin General Hospital (tertiary hospital) in Banjarmasin, Indonesia.

### Theoretical framework

The conceptual framework used in this study was based on the supportive care framework that was originally developed by Fitch,<sup>16</sup> the framework was designed as a tool to be used for understanding the supportive care needs of patients and their caregivers. Consequently, the framework is constructed on the basis of human needs, cognitive appraisal, and coping and adaptation. Human needs are not just in a physical aspect but also emotional, psychological, social, spiritual, practical, and informational aspects.

Based on the framework's construction, Fitch defined supportive care as the provision of care provided to those living with or affected by cancer to help them meet their physical, emotional, social, psychological, spiritual, practical, and informational needs during the

diagnostic, treatment, and follow-up phases.<sup>16</sup> For the aspect of physical needs, supportive care should promote an individual's comfort, nutrition, and usual daily function; while for the aspect of emotional needs, supportive care should promote an individual's sense of comfort, belonging, understanding, and reassurance in times of stress. Supportive care for psychological needs should be provided to encourage an individual to cope with his or her illness and its consequences, as well as to promote personal control and positive self-esteem. An individual with illness such as stroke along with their family members have supportive care needs across the illness care spectrum; their needs change over time and are influenced by many factors which include: age, gender, relationship with patient, educational, religion, family (urban, and rural), occupation, number of family members, social support, coping resources, and socio economic status. Supportive care has to be based upon and matched with an individual's needs within the context of his or her unique situation.

## Methods

The research design of this study was a cross-sectional descriptive study while the aim of this study was to describe the supportive care needs of stroke caregivers during their hospital stay in Indonesia. Data was collected from 56 stroke caregivers using SCANS questionnaire in Indonesian from March 12, 2013 to April 30, 2013.

## Population and sample

The population in this study was family caregivers (primary caregivers) of stroke patients taking care of stroke patients during their hospital stay and admitted to a neurological ward at Ulin General Hospital in South Kalimantan, Indonesia.

## Inclusion criteria for the study were:

Aged 18 years old and over.

The caregiver was currently living with and taking care of a family member who had experienced the first occurrence of stroke (hemorrhagic and ischemic) and who needed practical assistance with ADL when discharge from hospital.

Able to communicate in Indonesian language.

Willing to participate in this study.

Subjects with the following characteristics were excluded from the study:

1. The caregiver was diagnosed to have terminal illnesses;
2. The caregiver had a history of substance abuse (screened by psychiatric assessment for substance abuse);
3. The caregivers are paid or hired to provide care;
4. The caregiver had a history of major debilitating diseases, such as alcoholism and dementia (screened by psychiatric assessment for alcoholism and guideline to diagnose dementia by physician).

Simple random sampling was used to determine the sample size. The sample size was calculated based on Lemeshow's et al.<sup>24</sup> The study used level of confidence of 95%, standard deviation 0.95% and the precision of the estimate of 25%. As a result, 56 stroke caregivers were recruited in this study.

## Research Instruments

A supportive care needs questionnaire was used in this study and was modified from The Stroke Caregiver Assessment of Needs Survey (SCANS) which was used for stroke caregivers in Canada.<sup>9</sup> Fitting into the six domains of SCNs it consists of two sections; the first section, is concerned with demo-

graphic data of stroke caregivers, comprised of 8 items; age, gender, religion, marital status, level of education, relationship between caregiver and stroke patient, occupation, and previous experience of caregiving. The second section, assessed supportive care needs of stroke caregivers. It consisted of six domains and there were 42 items; each item was rated on a 4-point likert scale. The highest score of the questionnaire was 168 and the lowest score was 42. Scores were divided into three levels of supportive care needs; a score ranging from 42 to 84 was determined as low supportive care needs, a score ranging from 85 to 127 was determined as moderate supportive care needs, and a score ranging from 128 to 168 was determined as high supportive care needs.

The SCNs questionnaire in this study which was modified from the SCANS was considered for its content validity by five experts who specialized in stroke patient care, including two physicians and three nurses. The result of I-CVI from experts was 0.97. For the language validity, the SCNs questionnaire was translated from English to Indonesian language by a professional language expert using a reliable translation process.

Reliability was tested by using the SCANS questionnaire with 20 stroke caregivers who had the same characteristics as the study's subjects and who were admitted to H.M. Ansari Saleh Hospital in South Kalimantan, Indonesia. The Cronbach Alpha Coefficient ( $\alpha$ ) was 0.83.

### **Ethical considerations**

This study was approved by the ethical committee of Khon Kaen University, Thailand for protection of human subjects. Information regarding the study was distributed to the study site (a neurological

ward). With collaboration between the researcher and nurses at the study site, the potential subjects were identified and contacted in person by the researcher. Accordingly information about the study objective and procedure were provided to the potential subjects; they were interested in participating, and subsequently signed a consent form.

All subjects were informed that the interview would take no longer than 30 minutes; they had the right to refuse to participate in the study, and could withdraw from the study at anytime without any effect on their care and treatment. All information obtained from each subject was treated confidentially; their identities remained anonymous and, instead, were identified via a numerical code. The results of the study were presented as a whole, not individual specific.

### **Data Collection Procedures**

Prior to data collection, the study was approved by the ethical committee of Khon Kaen University. After approval, the official letter was sent to a director of the study site to explain about the study and ask for permission for data collection. After obtaining permission, the researcher met the head nurse of the neurological ward and a head of neurological department to explain the purpose of the study and its benefits. After that, the researcher liaised with the nurse specialist of the neurological ward for subject recruitment. As a consequence the researcher met potential subjects and asked them to participate in the study by giving a questionnaire to the participant who then answered it independently (30 minutes).

### **Data Analysis**

Through the Statistical Package for Social Sciences (SPSS) 10.0 program, data was statisti-

cally analyzed using frequency, percentage, mean, and standard deviation distribution.

**Results**

The detailed demographic characteristics of the subjects are presented in Table 1:

**Table 1** The frequency and percentage of demographic characteristics of stroke caregivers (n=56)

Demographic characteristics	Frequency	Percentage
Gender		
Male	21	37.5
Female	35	62.5
Age (year)		
Min, 19, Max, 73		
Mean, 39.86, SD=13.15		
18 – 29	16	28.6
30 – 39	13	23.2
40 – 49	11	19.6
≥ 50	16	28.6
Religion		
Muslim	55	98.2
Christian	1	1.8
Marital status		
Married	48	85.7
Widowed	1	1.8
Never married / single	7	12.5
Level of education		
Elementary school	18	32.1
Junior high school	7	12.5
Senior high school	16	28.6
Diploma	4	7.1
Bachelor degree (under graduate)	4	7.1

Master degree (graduate school)	1	1.8
No education	6	10.7
Relationship of caregiver to the patient		
Wife	14	25
Husband	10	17.9
Son	8	14.3
Daughter	20	35.7
Sister	2	3.6
Others	2	3.6
Occupation		
Government employee	7	12.5
Farmer	5	8.9
Others	6	10.7
No working	38	67.9
Previous experience of caregiving		
Yes	43	76.8
No	13	23.2

The supportive care needs score of the samples is shown in table 2 as follows:

**Table 2** Range score, Min score, Max score, Mean, Standard deviation (SD), and Mean rank of Supportive care needs of stroke caregivers

SCNs domains	Estimated score	Min score	Max score	Mean $\pm$ SD
Emotional	14 – 56	16	52	29.98 $\pm$ 8.18
Psychosocial	10 – 40	15	38	27.70 $\pm$ 5.93
Informational	7 – 28	13	28	22.75 $\pm$ 4.78
Practical	7 – 28	10	25	15.90 $\pm$ 4.30
Spiritual	2 – 8	2	8	6.09 $\pm$ 1.09
Physical	2 – 8	2	8	3.45 $\pm$ 1.21
Total score	42 – 168	58	159	105.87 $\pm$ 25.49

The level of supportive care needs was categorized into three groups, low level, moderate level, and high level as is shown in table 3 as follows:

**Table 3** : Supportive care needs level

Supportive care needs	Frequency (n=56)	Percentage
Low level of supportive care needs (42-84)	0	0
Moderate level of supportive care needs (85-127)	55	98.21
High level of supportive care needs (128-168)	1	1.79

## Discussion

### Physical domain

More than half of subjects (62.5%) agreed that they felt a lack of energy and tiredness, 32.14% strongly disagreed to felt a lack of energy and tiredness; around 3.57% disagreed that they felt a lack of energy. Around 58.92% of subjects agreed that they were not sleeping well during the hospital stay with the stroke patient.

Family caregivers felt a lack of energy and tiredness. It was caused they always were near the patient to provide care. So, for sleeping was also less.

During this time, the nurse did not teach the caregivers how to do the hygiene care in stroke patients. Family caregivers did routine care with their own skills and knowledge for hygiene care. It took their energy since stay in the hospital with the stroke patients.

These results were consistent with Chow et al.<sup>25</sup> study where the stroke caregivers are at a higher risk of developing poor physical health than neurological disease caregivers. In another study, the stroke caregivers also have many physical problems such as fatigue, inadequate rest, tiredness, exhaustion, a lack of energy, and problems in maintaining physical

health.<sup>9,13,14,26,27</sup> The physical domain is about comfort and freedom from pain, optimum nutrition, and the ability to carry out one's usual day to day functions (i.e., activities of daily living).<sup>16</sup> However, another study stated that physical needs were reported more frequently than informational needs.<sup>9</sup>

#### **Emotional domain**

The mean score of emotional domain in this study was<sup>28</sup> (SD=8.18). The item with the highest score; "Getting the healthcare team to acknowledge, and show sensitivity to your feelings and emotional needs" (Mean=3.29, SD=0.71) showed that 44.64% of subjects were in high need, and 42.86% of subjects were in moderate need. More than half of subjects felt anxiety or stress (58.92%), and also felt sadness (64.29%).

Most of the caregivers (75%) felt anger and confusion about why this happened to their family, but 85.71% of the caregivers were trying not to worry and keep a positive attitude. They still believed in god that the problem they face was a trial and will soon pass. Despite the severe problems experienced by patients and family caregivers, they still continued to be calm and think positive in a way such as prayer, dhikr and surrender to god. Even this domain is related to emotional of family caregivers, this domain is certainly very relevant also to the spiritual domain.<sup>16</sup>

Beside that, the caregivers felt anxiety about their family member having an opportunity to go to rehabilitation (60.71%), fear of another stroke (severity/recurrence of stroke) (55.36%), uncertainty about what is going to happen to them and their family member (73.21%), an uncertain future (71.43%), concern about their family's fears and worries (82.14%), and concern about caring for the stroke survivor (69.64%). The results are consistent with Brereton et al.<sup>27</sup> study

in which caregivers felt anxiety, uncertainty and were faced with uncertain futures and lack of a definitive recovery path for their family member. Another study<sup>9</sup> stated that 90% of caregivers were dealing with stress and anxiety, 80% sadness and grief, and 80% fear of another stroke. Similarly, a longitudinal, mixed methods descriptive design (n=58), signified a component of emotional distress, both of anxiety and depression, which is significantly related indicates ( $p < .05$ ).<sup>28</sup> Emotional domain need for a sense of comfort, belonging, understanding and reassurance in times of stress and understanding.<sup>16</sup>

Moreover, the stroke caregivers are at a higher risk of developing poor emotional health than neurological disease caregivers.<sup>25</sup> Professionals' reassurance and encouragement has been cited by caregivers as reinforcing their self worth.<sup>29</sup> Caregiver described the feeling of being invisible and critically lacked acknowledgement of their personal expertise from the health care team which in turn further decreased their confidence in the care giving role they were expected to take on.<sup>16</sup>

#### **Informational domain**

The informational domain was the major factor of high needs of supportive care of stroke caregivers. The subjects stated that they had high need for the information in relation to factors that could influence recovery of stroke (67.86%). The item; "Getting to speak with healthcare team members when needed" (Mean=3.29, SD=0.71) and "Having someone to help you understand stroke, treatment and prevention" (Mean=3.29, SD=0.73) showed a similar indication respectively. 51.79% of subjects had a high need of information pertaining to support for themselves, family and stroke survivor, 35.71% had moderate need. The whole items in this



domain showed that all of subjects need information except one subject. That subject no need information for talking to family and/or friends about the stroke (1.79%).

Informational domain among stroke caregivers was the highest score when compared to the other domains, with the mean score 22.75, SD=4.78 and range score from 7 to 28. Similar findings were displayed<sup>16,30</sup> that informational needs were the most frequently reported. Information can inform and help the person's or family's decision making and also, to assist in skills acquisition.<sup>16</sup> Moreover, Fitch explained that in the acute phase of stroke, caregivers are struggling to deal with the adoption of a new role and the abrupt medical crisis of their family member.<sup>16</sup>

Lack of information not only cause the family to felt frustration, anxiety and fear,<sup>9</sup> but it could also caused injury to the family caregivers such as back pain, muscular injury, muscular aches, and pain.<sup>31</sup> The expression of family caregivers that they were also experiencing back pain after caring to stroke patients. They said that do not know about lifting and handling during patient care (for example: help tilt, sitting, dressing, etc).

A mixed-methods approach to explore the wide spectrum of supportive care needs of acute stroke (10 family caregivers) stated that caregivers were unsatisfied with the information in the early phase of stroke. 90% reported unmet needs in being able to speak to the healthcare team when needed.<sup>9</sup>

#### **Psychosocial domain**

The mean of the item "Getting support from friends and family" was the highest mean score, with 3.39 (SD=0.53). most subjects greatly agreed (53.57%). With regards to their financial situation they felt that finances were very important. 37.5% of

subjects greatly agreed, 8.93% disagreed and 0% greatly disagreed that they had concerns about their financial situation. The subjects said that they felt stressed and needed social support from their family and friends.

The results were similar to the descriptive study<sup>13</sup> in that higher levels of social support are associated with lower levels of caregiver depression and higher levels of well-being and general health, and were capable of independent social problem solving. Psychosocial needs related to the ability to cope with the illness experience and its consequences, including the need for optimal personal control and the need to experience positive self-esteem.<sup>16</sup> What's more, this need is related to family relationships, community acceptance and involvement in relationships.<sup>16</sup> Spousal caregivers were committed to the work of care giving and felt it was their responsibility to care for their affected partners, and in addition they needed to be supported in their care giving work.<sup>26</sup> Some studies reported that the availability of support from family and friends was less than they had initially anticipated.<sup>29,32,33,34</sup>

Not only the physical problems experienced by family while in the hospital with the patient, but also psychological and financial problems. Financial problems really strongly felt by the family. Existing health care system in the hospitals, providing free health insurance for the entire family who cannot afford (poor family),<sup>33</sup> but there are several types of services and treatments that are not covered by insurance, and of course it had to be paid by the patient and family. So, the subjects said that they felt stress and need social support from their family and friends.

#### **Practical domain**

The mean score of practical domain in this study was 15.90 (SD=4.30). More than half of the

subjects needed assistance with transportation, at 35.71%, 50%, and 14.29% for higher, moderate, and lower need level, respectively. Most subjects said that they needed transportation from their home to the hospital as they had no car, so, they had to find public transportation. The subjects had moderate need for making time for themselves, at 62.5%. 73.21% of subjects declared that they had moderate need in preparing their meals. 55.36% of subjects had high need to pay accommodation and transportation.

This result could be explained by the fact that caregivers had problem about finances and transportation. Neurological ward consist of two room level. It is room class 2 and 3, where the patients were in the middle and lower economic level for that room. Most of patients who got the treatment used the insurance from the government (free insurance for poor family). The economic status made the caregivers felt stress and have problem about finances during their hospital stay. They still had to spend money for payment of drugs that were not covered under the free insurance.

Moreover, Ulin General Hospital has policies and regulations about health care system in their hospital. One of the policies is about cost of ambulance services. Ambulance service consists of the medical ambulance service, ambulance 118, general medical ambulance and ambulance bodies. The patient and their family have to pay to the hospital for ambulance services if they would like to use it. Infact, the economic status of the patient and family caregiver could not pay for that services. They tried to search the public transportation that is more cheaper than ambulance. So, most of family caregivers said that they need transportation from their home to the hospital. Another reason is they have no car cause the low of economic status.

This result could be explained by the fact that the caregivers had problems pertaining to finances and transportation.<sup>13,26,31</sup> Another issue for some caregivers whose spouses managed all the finances was accessing funds. Direct assistance was needed in order to accomplish a task or activity and thereby reduce the demand on the person (e.g., homemaking services, financial assistance).<sup>16</sup>

### **Spiritual domain**

The mean score of spiritual domain was 6.09 (SD=1.09). The spiritual domain ranked at the second highest among six domains. The majority of respondents felt moderate need for getting assistance necessary to meet their spiritual beliefs, with 73.21%; followed by those feeling that their needs for getting assistance was at a high level with 16.07%, low need 8.93% and no need 1.79%. Regarding how they got assistance with having their spiritual needs met, most respondents stated a moderate need for assistance, at 78.57%.

The majority of subjects had a moderate need for spiritual domain; they said that spirituality was important in their life and human life, so, they needed to get the necessary assistance to meet their spiritual beliefs. Their spiritual needs were related to the meaning of and purpose in life.<sup>16</sup> Additionally, spirituality encompasses a man's inner resources; the ultimate concerns around which all other values are focused, the central philosophy of life that guides conduct, and the meaning giving center of human life which influences all individual and social behavior.<sup>15</sup> Some reported studies have examined spirituality in the caregiver which included focus on finding meaning, suffering, optimism, positive affects, and religious benefits. Spirituality gives a caregiver hope and sustenance, and also helps them to express themselves more fully during a difficult time of change.<sup>35,36</sup>

### Supportive care needs level

The level of supportive care needs among stroke caregivers was categorized into three groups, low level (0%, n=0), moderate level (98.21%, n=55), and high level (1.79%, n=1). As a consequence, all stroke caregivers need to see improvements in their supportive care needs in order for them to be at a low level. Another study<sup>13</sup> reported that higher levels of support are associated with lower levels of caregiver problems and higher levels of well-being, general health, and aptness at independent social problem solving. Similarly, an overview of an ongoing longitudinal study (within an 18 month period) reported that support is particularly important at the beginning of care-giving where caregivers can be sufficiently prepared for their role.<sup>27</sup> As mentioned another study reported that the availability of support from family and friends was less than they had initially anticipated.<sup>29,32,33</sup>

### Implications and recommendations

The results of this study can be used as basic information to increase nurses' understanding of the supportive care needs of stroke caregivers. Nurses as caring agents, also need to assess caregiver health and supportive care needs during hospital admittance with the SCANS tools that modified in Indonesia, and provide education or information for stroke caregivers. Beside that, this results can serves as a reminder for nurse educators to take this concept into consideration when designing curriculum and developing teaching content.

The results of this study provide basic information for further study on supportive care needs of stroke patients and their caregivers in Indonesia.

### Conclusion

The conclusions of this study are thus; the overall supportive care needs were at a moderate level (98.21%, n=55). Stroke caregivers need to see improvements as a result of their supportive care needs.

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### References:

1. Murray CJL, Lopez AD. Mortality by cause for eight regions of the world: Global burden of disease study. *Lancet* 1997; 349: 1269-76.
2. Hinkle JL, Guanci MM. Acute ischemic stroke review. *J. Neurosci Nurs* 2007; 39: 285-93.
3. Venketasubramanian N. The epidemiology of stroke in ASEAN countries – a review. *Neuro J. Southeast Asia* 1998; 3: 9-14.
4. Depkes RI. Delapan dari 1000 orang di Indonesia terkena stroke. Retrieved November 8, 2011, from <http://www.depkes.go.id/index.php/berita/pressrelease/1703-8-dari-1000-orang-di-indonesia-terkena-stroke.html>.

6. Burke KM, Lemone P, Mohn-Brown EL, Eby L. Medical-surgical nursing. 2nd ed. New Jersey: Pearson; 2007.
7. Kuptniratsaikul V, Kovindha A, Suethanapornkul S, Manimmanakorn N, Archongka Y. Complications during the rehabilitation period in Thai patients with stroke. *Am. J Phys Med & Rehabil* 2008; 88 (2): 92-9.
8. Schofield H, Bloch S, Herrman H, Murphy B, et al. Family caregivers disability, illness and ageing. Australia: Allen & Unwin; 1998.
9. Dorsey MK, Vaca KJ. The stroke patient and assessment of caregiver needs. *J Vasc Nurs* 1998; 16: 62 -7.
10. MacIsaac L, Harrison M B, Buchanan D, Hopman WM. Supportive care needs after an acute stroke: a descriptive enquiry of caregivers perspective. *J. Neurosci Nurs* 2011; 43 (3): 132-40.
11. Thompson TC, Pierce LL, Steiner V, Govoni AL, Hicks B, Griedemann M. What happened to normal? Learning the role of caregiver. *On-Line J Nurs Informatics* 2004; 8(2): 13.
12. Dewit SC. Medical-surgical nursing concepts & practice. St Louis, Missouri: Saunders Elsevier; 2009.
13. Phipps WJ, Monahan FD, Sands JK, Marek JF, Neighbors M. Medical-surgical nursing health and illness perspectives. USA: Seventh edition. Mosby; 2003.
14. Grant JS, Elliot TR, Weaver M, Glandon GL, Raper JL, Giger JN. Social support, social problem solving abilities and adjustment of family caregivers of stroke survivors. *Arch Phys Med Rehabil* 2006; 87: 343-50.
15. Grant JS, Glandon GL, Elliot TR, Giger JN, Weaver M. Caregiving problems and feelings experienced by family caregivers of stroke survivors the first month after discharge. *Int J. Rehabil Res* 2004; 27 (2): 105-11.
16. Theis SL, Biordi DL, Coeling H, Nalepka C, Miller B. Spirituality in caregiving and care receiving. *Holistic Nurs Pract* 2003; 17 (1): 48-55.
17. Fitch MI, Porter HB, Page BD. Supportive care framework: a foundation for person-centered care. Ontario: CANO/ACIO; 2009.
18. O'Connell B, Baker L. Managing as carers of stroke survivors: strategies from the field. *Int J. Nurs Pract* 2004; 10: 121-6.
19. Vadivelu S. The unmet supportive care needs of patients with newly diagnosed advanced colon cancer. Master thesis in nursing 2012; McMaster University.
20. Sanders SL, Bantum EO, Owen JE, Thornton AA, Stanton AL. Supportive care needs in patients with lung cancer. *Psycho-Oncol* 2010; 19: 480 - 9.
21. Kerr LMJ, Harrison MB, Medves J, Tranmer J. Supportive care needs of parents of children with cancer: Transition from diagnosis to treatment [On-line]. *Oncol Nurs Forum* 2004; 31 (6): 116-26.
22. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, et al. The unmet supportive care needs of patients with cancer. Supportive care review group. *Cancer* 2000; 88 (1): 226-37.
23. Veenendaal HV, Grinspun DR, Adriaanse HP. Educational needs of stroke survivors and their family members, as perceived by themselves and by health professionals. *Patient Edu Couns* 1996; 28: 265-76.

24. Binder LM. Emotional problems after stroke. *Stroke J Am Heart Assoc* 1984; 15: 174-7.
25. Lemeshow S, Hosmer Jr DW, Klar J, Lwanga SK. Adequacy of sample size in health studies. USA: World Health Organization; 1990.
26. Chow SKY, Wong FKY, Poon CYF. Coping and caring: support for family caregivers of stroke survivors. *Journal Compilation* 2007: 133 – 143.
27. Coombs UE. Spousal caregiving for stroke survivors. *J Neurosci Nurs* 2007; 39 (2): 112-9.
28. Brereton L, Dip N, Nola M. You do know he's had a stroke, don't you? Preparation for family caregiving – The neglected dimension. *J Clin Nurs* 2000; 9 (4): 498-506.
29. King RB, Ainsworth CR, Ronen M, Hartke RJ. Stroke caregivers: pressing problems reported during the first months of caregiving. *J Neurosci Nurs* 2010; 42 (6): 302-11.
30. Sit JWH, Wong TKS, Clinton M, Li LSW, Fong VM. Stroke care in the home: The impact of social support on the general health of family caregivers. *Neurology* 2004; 13: 810-24.
31. O'Connell B, Baker L, Prosses A. The educational needs of caregivers of stroke survivors in acute and community settings. *J Neurosci Nurs* 2003; 35 (1): 21-8.
32. Hinojosa, M. S., & Rittman, M. Association between health education needs and stroke caregiver injury. *J Aging Health* 2009; 21: 1040-58.
33. Bakas T, Austin J, Okonkwo K, Lewis R, Chadwick L. Needs, concerns, strategies, and advice of stroke caregivers the first six months after discharge. *J Neurosci Nurs* 2002; 34 (5): 242-52.
34. Hartke RJ, King RB. Analysis of problem types and difficulty among older stroke caregivers. *Top Stroke Rehabil* 2002; 9 (1): 16-33.
35. Pemerintah Kalimantan Selatan. Peraturan daerah Kalimantan Selatan No.3 tahun 2011 tentang pola tarif pelayanan kesehatan pada Rumah Sakit Umum Daerah Ulin Banjarmasin 2011. Retrieved June 25, 2013, from <http://www.djpp.kemham.go.id/index.php/component/content/article/2329>
36. Pierce LL, Steiner V, Havens H, Tormoehlen K. Spirituality expressed by caregivers of stroke survivors. *West J Nurs Res.* 2008; 30 (5): 606-19.