

JDK_2018_Role and function of family

by

Submission date: 21-Jun-2023 01:26PM (UTC+0700)

Submission ID: 2120169953

File name: JDK_2018_Role_and_function_of_family.pdf (463.82K)

Word count: 4618

Character count: 23866

ROLE AND FUNCTION OF FAMILY IN CARE OF PATIENTS WITH STROKE IN COMMUNITY

Agianto^{1,2}, Khanitta Nuntaboot²

¹School of Nursing, Faculty of Medicine, Universitas Lambung Mangkurat, Indonesia

²Faculty of Nursing, Khon Kaen University, Thailand

Correspondence: khanitta@kku.ac.th

ABSTRACT

Background: The increasing of stroke prevalence is high year by year, and Indonesia is the number one for cause of mortality. After three months, stroke survivors require long-term care. A stroke is a lifelong change for both the stroke survivor and the family. Family caregiver is included in multidisciplinary that should provide the patients with stroke because of the unique demands on that population. There is lack of study about stroke care in Indonesia.

Objective: to explore the role and function of family in care of patients with stroke in community, Banjarmasin.

Method: A critical ethnography design used in this study to explore and critically analyze role and function of family in care of patients with stroke in community. There were 15 key informants (family caregivers) in this study using purposive sampling. Content analysis was used to answer the research question.

Result: Daily care activity, spiritual activity, rehabilitation and offering medicine, decision maker, and financial support are the role and function of family in care of patients with stroke in community setting.

Conclusion: Family caregivers are playing an important role in caring for their relatives who have suffered from strokes. They should work together with health workers to help the patient for enhancing the quality of life of patient.

Keywords: Community, Family, Role and function, Stroke Care

INTRODUCTION

The increasing of stroke prevalence is high year by year, and the elderly people are still the most population (1). Stroke is the top four cause of death in the US (275,000 deaths). The same situation in ASEAN countries, Indonesia is the number one for cause of mortality (2, 3, 4, 5). Approximately 328,524 or 23.48% stroke deaths in Indonesia from total deaths (6). According to Indonesia basic health research data, the prevalence of stroke increased from 2007 to 2013 (7, 8). Complication and mortality preventions on stroke are needed a good stroke management in a long-term care.

After three months, stroke survivors (26%) require long-term care. Long-term disabilities are mostly hemiparesis, inability to walk, complete or partial dependence for activities of daily living (ADLs), speech problem, and depression. In addition to the physical, cognitive, and emotional impact of the stroke on the stroke survivor, the stroke affects the lives of the stroke victim's caregiver and family. A stroke is a lifelong change for both the stroke survivor and the family (1). Medical care, rehabilitation, and doing activity daily living are connected to family economy. Low salary and income make the family to find loan from other people such as another family member,

neighbor, or people who have no relation with them. Family will have additional problem because of this. Welfare is very necessary for family as the self-management system of the local communities (9).

Patients with stroke need social activity even they have limitation of activity (10). Family also needs it because they are facing with social burden (11, 12). Moreover, patients and family need social group for their life. The groups will give benefit for them like sharing, counseling, supporting, and encouraging about the experience to provide care patients with stroke during stay at home. Indonesia has group social for stroke, it is called "paguyuban stroke" or stroke alliance (13). This group is not available in every provinces or cities in Indonesia especially in South Kalimantan.

Family has to adapt themselves to take care the patient. They usually get information from nurses when they accompanied patient at hospital, but sometimes the information is not clear and complete. They also got information from TV, newspaper, internet, and their neighbor. Family caregiver has burden when they live with stroke patient. The burdens are about physical, psychological, financial, social, informational, and spiritual (11, 12).

Post stroke is very important to get attention from health personnel and around people including family caregiver. Stroke patients stay in their home or community with their family, spouse or may be alone. The health professional should help this group to prevent secondary stroke (recurrent stroke), to minimize readmission to hospital, prevent complication, decrease number of stroke prevalence, improve their quality of life. Those are not for health professional only, but also for family caregiver who stay long time with patient. The patient needs caregiver to help during chronic phase or long-term care. Caregiver or family in

Indonesia context is a part of multidisciplinary in stroke management (14).

Multidisciplinary has responsibility in stroke management. Family caregiver also include in multidisciplinary (14). An interdisciplinary team should provide the patients with stroke because of the unique demands on that population (15). In Thailand, the roles of multidisciplinary are different each other, but the purpose is the same, to help the stroke patients and empower the family caregiver of stroke (14). Each professional has different demand, so, they also have difference of role and function to support the system for stroke.

In Indonesia, which are involved in the treatment of stroke patients in community or at home care are nurses and family caregivers. The home visit program in the community for families and patients with stroke is not yet done despite even the incidence of stroke in the community is still high. The health care system in Indonesia is intended for physical health, mental, intelligence, and social. These systems consist of primary, secondary, and tertiary level of health care system. All of them use the referral system (2).

Lack of study about stroke care in Indonesia is happening now. The previous studies are more focused on medical stroke. However, no studies in Indonesia that concern to post stroke in community to prevent recurrent stroke in nursing area. Accordingly, the purpose of this study is to explore the role and function of family in care of patients with stroke in community, Banjarmasin, Indonesia.

METHODS

A critical ethnography design used in this study to explore and critically analyze role and function of family in care of patients with stroke in community,

Indonesia. Ethnography is the study of social interactions, behaviors, and perceptions that occur within groups, teams, organizations, and communities (16, 17).

This study conducted in community level of Banjarmasin that was house hold with stroke patients. The research was started from December 17, 2016 to July 15, 2017. There were 15 key informants (family caregivers) in this study. Purposive sampling was used for selecting potential key informants who met the study's eligibility criteria. Data collected until saturated.

Inclusion criteria were:

- a. Age 18 years old and over.
- b. The family caregivers were currently living and taking care of a family member who has experienced the first occurrence of stroke (all types of stroke) and who needed practical assistance with ADL when discharge from hospital.
- c. Family caregivers had a kinship with stroke survivors.
- d. Family caregivers are able to communicate in Bahasa Indonesia.
- e. Willing to participate in this study.

Key informants with the following characteristics were excluded from the study:

- a. Family caregivers are diagnosed to have terminal illnesses.
- b. Family caregivers have a history of substance abuse.
- c. Family caregivers have a history of major debilitating diseases, such as alcoholism and dementia.

The researcher used field note, recorder, and a structure interview guideline to gather in-depth information in this study. Researcher used three methods for data collection includes participant observation, in-depth interview, and focus group discussion.

- a. Researcher found a gate keeper before enter to the study site. Then, she helped the researcher to identify the key informants as selection criteria. Explanation and information had given to them before sign the informed consent. After that, researcher started to collect the data from participant observation activity that implanted from 17 December 2016 to 28 May 2017 to observe their daily activity to provided stroke patients.
- b. In-depth interview, researcher interviewed the key informant (family and non-family caregivers) using a structured interview guideline. The in-depth interview did about one hour for each key informant and conducted at their own place or home. Types of question that used for interview were general question, specific question and other question which was related to research questions. In depth interview conducted from 28 May – 30 June 2017.
- c. Focus group discussion (FGD) is face to face setting that engages in a series of discussion. Researcher was a moderator or facilitator in this activity to control the flow of discussion. FGD conducted during on 5 July 2017.

Content analysis was used in this study that consists of transcript and coding the data, typology, matrix analysis, thematic analysis, and engaging with and integrating to the related literatures.

Ethical consideration: The study passed the ethical clearance from ethical committee (IRB) of Khon Kaen University, Thailand. The information about the study objective and procedure were provided to the potential informants. They signed the consent from when they were still interested in participating.

Trustworthiness

Credibility addressed the issue of whether there was consistency between the participants' views and the researcher's presentation of them. Credibility had enhanced by the researcher describing and interpreting my experiences as researcher, and also by consulting with participants and allowing them to read and discuss the research findings. The researcher clearly followed the trail that used by the investigator and potentially arrive at the

same or comparable conclusions. The researcher used dependability for each stage of the research to be traceable and clearly documented. Researcher also saw the findings could 'fit' into other contexts or not and also saw the readers can apply the findings to their own experiences or not.

RESULT AND DISCUSSION

Characteristic of family caregivers of this study consist of gender, age, religion, marital status, and level of education. Those are shown on table 1 below:

Table 1. Demographic characteristic of family caregivers (n=15)

Demographic characteristic	Frequency	Percentage (%)
Gender:		
Male	4	26.67
Female	11	73.33
Age (Min=19 Max=73 Mean=39.86)		
18 – 29	3	20
30 – 39	5	33.33
40 – 49	4	26.67
≥ 50	3	20
Religion:		
Islam	15	100
Christian	0	0
Marital status:		
Married	12	80
Widowed	1	6.67
Single	2	13.33
Level of education:		
Elementary school	3	20
Junior high school	2	13.33
Senior high school	6	40
University	1	6.67
No education	3	20

There are many family members who are involved in this caring such as son, daughter, son-in-law, daughter-in-law, grand-son, grand-daughter, brother, sister, uncle, and aunt. Particularly daughters experienced more stress than sons (18). Family is very important in Indonesia and it is very common for extended families, including grandparents, aunts, uncles and cousins, to live together in one place;

however, as with many cultures, the nuclear family is becoming more popular in contemporary urban areas. That said, elders and unmarried siblings will often reside with their families, even in modern culture (19). Traditional aged care was seen as the responsibility of the family; however, the demands on modern families can make caring for an elderly loved one difficult (19).

There are four themes for role and function of family in care of patients with stroke in community, Indonesia.

Daily care activity

Stroke patients are doing their daily activity even they have disability. There are many people who help them to do that especially the family members as the caregiver (14). Family caregivers have big roles in nursing care of stroke in community and at home (20). They stay for long time with patients and have their own responsibilities every day. There are many roles and functions of family caregivers including sweeping and cleaning the house, cooking and offering the food, washing the clothes, preparing and buying the medicine to pharmacist, primary health care (Puskemas), or hospital. Helping the patient's personal hygiene is one of roles of family caregiver in Indonesia. Family also helps the patients every day for bathing, shampooing, oral hygiene, toileting, grooming, and nailing.

"He helps for cleaning the house too, sweeping, washing clothes, and cooking. For bathing, he can be alone. As usual his response after the activity, he had tired. Then he takes a rest. Strong activity" (Caregiver: Mrs. SB, 38 years old, May 30, 2017)

"For home activity, surely I cook. My husband (stroke patient) usually has been washing dishes, washing clothes, bathing children. So, I just get relax at home again. If we are lazy to cook, we buy meal at outside." (Caregiver: Mrs. SA, 33 years old, June 8, 2017)

"Daily routine care is our responsibility and this is our

obligatory to help stroke patient at home. As a part of family member, we should do these such as helping him/her for personal hygiene, sweeping the floor, cooking and offering the food, washing the clothes, and buying medicine to pharmacist. If he/she needs to go to Puskesmas or hospital, we bring him/her by motor bike or becak." (FGD: Caregiver group)

I am a wife that usually I just stay at home for cooking, sweeping the floor, washing the clothes, and also care my children. But now I have to do my husband's roles for working to earn money at outside. I should do that because the situation pushed me to do that. Not only that, changed the broken lamp and other hard activities at home were done by me too." (Caregiver: Mrs. AG, 31 years old, May 30, 2017)

Stroke patient who stays in nuclear family which consists of father, mother, and child or children is totally different with stroke patient with extended family type. The situation and problem for each type of family are various. The nuclear family that has stroke patient will face the big problem such as financing problem, psychological problem (12), changing or roles, and home activity including cleaning the house, ironing the clothes, helping the spouse to do home activities.

Spiritual activity

Even stroke patients have limitation to do activities or moving, they still try to do take a prayer, or we called "sholat" for 5 times a day. They believe that the relationship between the God and human will be good if they have "sholat". When they take a prayer, they make wishes to the

God, including recovery of sickness. Sholat is one of muslim's obligation that have to do by muslim in the world.

"As muslim we always take a prayer 5 times a day. That is our obligation as muslim. We believe in this way as our communication with Allah, we feel in peace and Allah will give what we need. Sure, we help our family who is sick if he/she would have sholat. It does not matter for us. They can sholat with sitting on the chair or on the bed." (FGD: Caregiver group)

For "sholat", the patients should clean some part of their body with water or "wudhu". They also have to clean the place of sholat and use the polite dress or "mukena" for woman as well as using "sajadah" (a kind of carpet that put on the floor). In the beginning, person with stroke cannot do those by themselves. They need someone to help them. Family caregiver is someone who can help them for those. The same condition with family caregivers, they should take a prayer 5 times a day to praise Allah and hope something in their live. Muslims turn to the Kaaba (House Built to Worship One GOD) to pray 5 times a day, when the direction is known, although they can pray in any position or direction if dictated by circumstances. There are no symbols or signs that represent Islam except the Holy Qur'an. Among the main obligations of the sick people are the prayers. Lots of Muslims who sometimes do not pray with the excuse of illness or force themselves to perform the prayers in the ordinary manner that healthy people do. Actually they should pray with their condition ways (21).

Some of patients take a prayer 5 times a day. Another patients do not

do with reasons have difficulty to do. The family caregivers still do their prayer every day. For the patients who take prayer, get helping from family caregiver. Particularly for "wudhu" (clean the some part of bodies with water, wear the sholat costume, and prepare the "sajadah" (carpet for praying). (Participant observation from 23 December 2016 – 17 March 2017)

"... I should help her (stroke patient) to "sholat" 5 times a day. She needs my helping to go to bathing room to take "wudhu" then helping to use "mukena" and preparing "sajadah". I also have "do'a" to Allah for our health in our family." (Caregiver: Mrs. AN, 73 years old, June 19, 2017)

"Not all stroke patients would take a prayer. But some of them would have it. We tried to help them for praying. They cannot stand very well, so they can sit on the chair or on "sajadah" which is on the floor or bed. If they cannot go to bath room, kitchen, or rest room for "wudhu", they can do "tayyamum". This is our believe in Islam to have to take a prayer 5 times a day about 5-10 minutes per each praying." (FGD: Caregiver group)

Religious beliefs and customs can play an important part of daily activities including prayer and food preparation, particularly during times of religious significance observed by the various faiths (19). **Personal beliefs due to religion and culture played major roles throughout the caregiving process** (20).

Rehabilitation and offer medicine

Family also helps the patient to do active and passive rehabilitation at home. Trying to bring the patient to health care facility is one of their roles when the patient needs to check up the condition to doctor or health workers.

Family caregivers help the patient every day at home for daily activity such as personal hygiene, doing rehabilitation at home with simple exercise, and also brought the patient to check up to health care facilities such Puskesmas, hospital, and private clinic for neurology. (Participant observation from 5 January – 13 May 2017)

“...my wife is taking care me every day. We stay together and our children have to work from morning to evening. Other families usually come on weekend or holiday. They help me to clean the house including sweeping, washing the clothes, cooking, preparing and offering the medicine.” (Patient: AD, 36 years old, June 1, 2017)

Rehabilitation is a technique to care in which person with disability and chronic disease are “made able” again (22). The purpose of rehabilitation is to repair of the function, and the patient will be soon as independent person (14). Early rehabilitation is critical to making optimal recovery and should be initiated as early as possible, preferably within 24 to 48 hours of the stroke. An individualized rehabilitation plan includes phased interventions along with periodic evaluation of progress toward meeting individual goals. It also includes interventions to prevent a recurrent stroke. Phased interventions relate to implementing

deficit specific interventions along a continuum from simple to complex actions. Usually interdisciplinary collaboration is needed for optimal outcomes (14).

Decision maker

In Indonesia culture particularly in Banjar culture, head of family is a male who has big role for decision making. The family members just follow him for the decision. This is contrast role and function in a family. It will change for the role and function if the head of family has sick such as stroke. The spouse means a wife as well as a family member will take the position as head of family. It will change the role and function between head of family and family members. These role and function of male, female, head of family and family members are showed below:

“even my husband is getting sick, he is still responsible for decision making. We all respect him for that. We are as family member followed him if we were facing the problem in this house.” (Caregiver: Mrs. SA, 33 years old, June 8, 2017)

Caregivers or carers are people who provide care to family members, life partners or friends whose are sick, elderly or disabled, without paid (23). Caregivers need assistance to make decisions about the next phases of care for stroke patients (24). Caregivers perform a major role in the nursing system and health care arena. They may work in close association with physicians, nurses, and other health care providers (20).

Financial support

Financial is the most problem in family with stroke (11, 12). It is caused by their condition is at low income and low

economy level. They do not have enough money to support their live. If the head of family or husband had stroke, means that the money resource at that family is none. The patient cannot earn money and have to stay at home for long time and need dependent activities at the beginning of stroke attack. Then, the spouse will change the roles and should go for working and get money to support their needs. Stroke events make the poor family in a bad level. They lose the job, and get the lower income ³an before since they had stroke. The most Indonesian families are close and work hard to help each other. People have a responsibility to their families and especially to their elders. Indonesians are expected to respect the experience of their elders and follow their advice. They are also expected to look after their parents in old age (19).

The family stays at small house, slum area, and low economic level. Most of them earn money as labors. The salary as labor is not much, but they have to support their daily needs. This condition is one of reason why they did not bring the stroke patient to health care service. (Participant observation from 22 December 2016 – 2 April 2017)

“Brother-in-law paid all hospitalization. It is about 6 million rupiahs. He admitted my husband to the hospital even I already told him that I had no money at all, but he said that he would pay everything during hospitalization. After admit in the hospital, my husband was better and can work as usual for 7 months. Then, he got recurrent stroke.” (Caregiver: Mrs. AG, 31 years old, May 30, 2017)

“...it was heavy, no job, no saving of money, need much money, getting massage for many time, it's really hard for me. But Alhamdulillah after I follow the ways, I can adapt and enjoy.” (Caregiver: Mrs. GS, 57 years old, June 3, 2017)

Good relationship in Indonesia culture is still tight and keeps each other in the family. They think that culture is having in whole family in Indonesia which is as one of responsibilities to people who is sick. In Indonesia, the family is a key element in caring for the ill family member. It is a tradition and considered an obligation to take care family member who is sick, at home as well as during hospitalization (25). So, it is rarely we are facing the paid caregiver in a family. We will find it if the economic status of family is good enough or high level.

CONCLUSION ⁴

However, family caregivers are playing an important role in caring for their relatives who have suffered from strokes. The patients also have problem to do their activities such as daily care, personal hygiene, spiritual activity, rehabilitation, offering the medicine, financing support and decision maker when they are facing the problem. For those who contributed and involved in stroke management in community are many people, not only health workers (physicians and nurses), but also family caregiver as the main person who stay long time with stroke patient. They should work together to help the patient for enhancing the quality of life of patient. Role and functions of each person including family plays necessary in stroke management in community.

ACKNOWLEDGEMENT

Researchers would like to thank to Faculty of Nursing, Khon Kaen University for providing the scholarship of this research.

REFERENCES

1. Lewis SL, Dirksen SR, Heitkemper MM, Bucher L. *Medical-Surgical Nursing: Assessment and management of clinical problems*. Volume 2. 9th Ed. Canada: Elsevier; 2014.
2. Kemenkes RI. *Buku saku FAQ (Frequently Asked Questions) BPJS Kesehatan*. Jakarta: Kemenkes RI; 2013.
3. Park J. (2017). *Acute Ischemic Stroke*. USA: Springer Link.
4. Cheung RTF. (2014). A Systematic approach to the definition of stroke. *Austin J Cerebrovasc Dis & Stroke*, 1 (5): 1024.
5. Aditama TY. *stroke is the leading of death in Indonesia*. Health research and development of Ministry of Health. Retrieved from August 20th, 2015 from <http://www.litbang.depkes.go.id/node/639>; 2015
6. WHO. *World health rankings life longer live better*. Retrieved June 17, 2016, from: <http://www.worldlifeexpectancy.com/in-donesia-stroke>; 2014.
7. Indonesia Basic Health Research. **Basic health research**. Jakarta: Health Ministry of the Republic of Indonesia; 2007.
8. _____. *Basic health research*. Jakarta: Health Ministry of the Republic of Indonesia; 2013.
9. Nuntaboot K. Nurses of the community, by the community, and for the community in Thailand. *Regional Health Forum*, 10 (1): 11-28; 2006.
10. MacIsaac L, Harrison MB, Buchanan D, Hopman WM. Supportive care needs after an acute stroke: a descriptive enquiry of caregivers perspective. *Journal of Neuroscience Nursing* 2011, 43 (3): 132-140.
11. Agianto & Nuntaboot K. The supportive care needs of stroke caregiver during hospital stay at Ulin General Hospital South Kalimantan Indonesia. *Journal of Nursing Science & Health* 2013; 36 (3): 1-8.
12. Agianto & Setiawan H. Supportive care needs of stroke caregiver at Neurological clinic in Banjarmasin, Indonesia. *Dunia Keperawatan* 2017, 5 (2): 107-114.
13. Kompas. Klinik Stroke Nusantara atasi dan cegah stroke. *Kompas*. Retrieved October 6, 2015, from <http://nasional.kompas.com/read/2008/01/11/01184998/klinik.stroke.nusantara.atasi.dan.cegah.stroke>; 2008.
14. Hickey JV & Livesay SL. *The continuum of stroke care: An interprofessional approach to evidence-based care*. Philadelphia: Wolters Kluwer; 2016.
15. Corrigan ML, et al. *Handbook of clinical nutrition and stroke, nutrition and health*. New York: Springer; 2013.
16. Atkinson P, Hammersley M. *Ethnography: Principles in Practice*. 3rd Ed. New York: Routledge.
17. Reeves S., Kuper A., & Hodges B.D. (2008). Qualitative research methodologies: ethnography. *BMJ* 2007; 337: 1-3.
18. Huizinga GA, et al. Stress response symptoms in adolescent and young adult children of parents diagnosed with cancer. *Eur J Cancer* 2005; 41(2): 288-295.
19. Moffatt, A. *Indonesian Culture Profile*. Australia: Diversi care; 2012.
20. Subgranon, R. *Caregiving process of Thai caregivers to elderly stroke*

- relatives: A grounded theory approach*. Dissertation. University of Utah; 1999.
21. Syamhudi K. *Sholat orang yang sakit*. Retrieved from August 15, 2017, from <https://almanhaj.or.id/2587-shalat-orang-yang-sakit.html>; 2009.
 22. Pryor, J. Rehabilitative nursing: A core nursing function across all settings. *Collegian* 2002; 9 (2): 11-15.
 23. World Federation of Mental Health [WFMH]. *Caring for the caregiver: Why your mental health matters when you are caring for others*. Woodbridge VA: WFMH. Retrieved from www.wfmh.org; 2010.
 24. Phipps WJ, Monahan FD, Sands JK, Marek JF, Neighbors M. *Medical-surgical nursing health and illness perspectives*. 7th Ed. USA: Mosby; 2003.
 25. Effendy C, et al. Family caregivers' involvement in caring for a hospitalized patient with cancer and their quality of life in a country with strong family bonds. *Psycho-oncology* 2015; 24: 585-591.

JDK_2018_Role and function of family

ORIGINALITY REPORT

9%

SIMILARITY INDEX

9%

INTERNET SOURCES

2%

PUBLICATIONS

8%

STUDENT PAPERS

PRIMARY SOURCES

1

[docplayer.net](#)

Internet Source

2%

2

[nursekey.com](#)

Internet Source

2%

3

[14a03gp.wordpress.com](#)

Internet Source

2%

4

[cdmbuntu.lib.utah.edu](#)

Internet Source

2%

5

[digital_collect.lib.buu.ac.th](#)

Internet Source

2%

Exclude quotes On

Exclude matches < 2%

Exclude bibliography On