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Submission date: 08-Nov-2022 08:13PM (UTC+0800)

Submission ID: 1948149133

File name: C21-2020-IJPHRD-Need_of_Family-1364-1368.pdf (329.83K)

Word count: 3075

Character count: 16340

Needs of Family Caregiver Education for Caring Stroke Patients at Home

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Abstract

Stroke is a major cause of long-term disability. It causes the patient to be family-dependent. Caring stroke patients is a burden for the family caregivers. They must adapt to the patient's condition and be able to handle the patient. Meanwhile, the stroke incidence is unpredictable so the family does not have time to prepare themselves in caring the patient. Thus, the hospital must be able to meet the educational needs of the family in caring stroke patients at home. This study aims to explore the educational needs of family caregivers in caring stroke patients at home. This study applies a qualitative approach and data analysis using Collaizi. This research was conducted through in-depth interviews on fifteen stroke family caregivers at Haji General Hospital, Surabaya. The results of this study indicated that the needs of stroke family caregiver education are: physical education (education about medical rehabilitation training at home, mobilization and transfer of patients, training of handling patients' ADL, signs, symptoms and risk of recurrent stroke); for psychological education and structured discharge planning education.

Keywords: *Stroke family caregiver; education, needs.*

Introduction

The World Health Organization (WHO) defines stroke as rapidly developing clinical signs of focal (global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin. According to the World Stroke Organization, strokes have now become an epidemic in the world. Worldwide, stroke is the second leading cause of death. The current trend shows that the annual number of deaths will increase to 6.7 million in 2015 if no appropriate action are taken. Aside

from being a cause of death, stroke is a major cause of long-term disability.

Disability (physical disability) results in sufferers experiencing difficulties on their daily activities, therefore they need assistance¹. Family support is expected to help patients optimize the rehabilitation phase of patients so that they can improve the quality of life for post-stroke patients^[1]. However, family members carry the burden of continuous treatment for the stroke patients^[2]. Stroke patients and their families often report that they have not been given enough information about strokes and feel unprepared for life after returning from the hospital. The results of a study conducted by Shyu et al (2008)^[3] found that families of stroke patients often felt they were not prepared enough to meet the physical, cognitive, and emotional needs of stroke patients. The patient's family only received little information in caring the patient at home. Nurses provide less information about things that relate to patients' daily needs and how families can overcome problems that arise. Therefore, researchers are interested to explore the educational needs of stroke family caregivers.

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Method

Research Design: The type of this research includes descriptive research with qualitative method, phenomenological approach. This phenomenological approach is to understand, explain and give deep meaning to the educational needs of the family caregiver about post-acute care for stroke patients at Hospital based on their perspective at the time this research was conducted. The study data was collected through in-depth interviews. The researcher also made field notes to comprehensively better ensure the completeness of the data.

Sample: This research was conducted in a hospital of East Java provincial government. Total of 15 stroke family care givers participated in this study. The participants consisted of fourteen women and one male. The age of participants varied from 25 to 68 years. The final education of participants in this study varied from high school to Bachelor's Degree.

Data Analysis: Data analysis was carried out using the Collaizi method. The order of data analysis were performing verbatim transcription, identifying the keywords, categorizing, determining sub-themes, conducting validation to participants and determining the final theme of the study.

Result

One of the effects of stroke is the existence of limitations in carrying out daily activities. This is a burden for the family caregiver, as they have to help the patient's daily activities. Meanwhile, family caregivers have limitations in physical, knowledge and skills. Therefore, providing the family caregiver a proper education is very important. The results of the study found three themes, which were physical, psychological and structured discharge planning education needs.

Physical Education Needs: Education related to the patient's physical condition is the most needed requirement by the family caregiver. The physical education needed by family caregivers including: education about medical rehabilitation training at home, mobilization and transfer of patients, training of handling patients' ADL, signs, symptoms and risk of recurrent stroke.

1. Medical rehabilitation training at home: The majority of informants mentioned that they needed education about medical rehabilitation, i.e. how

to do the proper therapy on the legs, arms and communication for the patient. The excerpts from the interview are as follows:

"I want to get some information on how to practice lifting hands, they are heavy, right? So, how?" [Ik2, child]

"So, you know, it feels stiff to stand up. What do I have to do to make it easier to walk?" [Ik5, child]

"How to recover the way (the patient) talk? Is there a cure or exerciseto be back like normal?" [Ik11, wife]

2. Mobilization and transfer of patients:

Mobilization is assumed to be one of the things that health workers need to provide. Some informants said that they wanted to know how to practice walking and using a cane during walking exercises. The result of the interviews were as follows:

"My husband can already take a step, but I'm still afraid if he ask me to train him to walk. He uses a walking stick, so how to use it?" [Ik7, wife]

"She asked for a walk using a wheelchair later at home. I'm afraid she would fall when I put her on the wheelchair. I want someone to teach me how." [Ik9, husband]

"Usually, I just tilt (the patient) to the right because the left hand hurts. Of course I'm afraid when doing it. I want to be taught on how to tilt the body" [Ik4, child]

3. Training and handling of patient's ADL:

Some informants complained about how to help assist patient's ADL. This is because patients were unable to carry out their own activities. An education about ADL assistance needed were how to help patients wearing clothes, how to bathe and how to feed the patients without making them choke.

"It's hard to help him wearing clothes because his hand can't move. What is the proper way to do it? Can I pull his hand? Because I'm afraid to do it and leaving him naked is quite impossible." [Ik8, wife]

"When I bathe him, it confuses me. It's too heavy to lift the hand, but is it okay to wipe (the hand)? I want to learn the right way to wipe the hand, how to tilt the body, and what if bathing him once a week? I want to ask about the treatment. I still find it difficult." [Ik7, wife]

"The patient sometimes choke when eating. Why is it? [...] how to avoid that?" [Ik2, child]

One participant stated that it is essential to provide the education on feeding the patients properly using nasogastric tube, the side effects, recommended lying positions during feeding, how to regulate food menus, and how to prepare food for feeding through a nasogastric tube, as expressed by one participant the following :

"How to feed (the patient) in lying position. Is it okay to feed (the patient) with this position? And if (the patient) must sit, how is the right way to sit? And then what is the side effect? I just want to know." [Ik3, child]

"How to put on diapers? Because it's hard to lift the body. I'll be doing it by myself at home later." [Ik13, child]

4. Signs, symptoms and efforts to prevent the risk of recurrent stroke. The majority of informants stated that they wanted to know how to prevent recurrent stroke.

"I once heard the stories of those people, they said don't let (the patient) fall down, or else it will worsen the condition. It's so scary. Is that true? If so, they should've told us so we would be careful" [Ik1, Wife]

"The doctor explained yesterday, said there was a golden period or something. So if (the patient) have another stroke, we must help in hours. How do you do it? This would freak me out. I would like to ask this again to the doctor again because it is quite important." [Ik2, child]

Psychological Education Needs: Educational needs about how to deal with patients' psychological changes are also important for the informants. They complained that they were their confused about the patient's psychological changes and how to deal with their condition who became easy to get angry, be offended, and be sad. They sometimes became emotional when dealing with angry patients. Some interview quotes were as follows:

I am so confused, why does my husband become quiet, sometimes he suddenly cries, he wasn't like that before. He just wants to talk to his child. What should I do? Who can explain this to me? [IK1, wife]

"Father gets angry easily now. When his children visit him, it seems like he wants to start a fight with them [...] How do I make him calm? That's what I want to know." [Ik2, child]

When my father gets angry, sometimes I'm so exasperated, I feel like pinching him. But sometimes I feel sorry for him too. What is the solution when it comes like this? I myself am also tired of taking care of everything [...] I want to learn how to handle this kind of situation [Ik4, child]

Moreover, education on how to motivate and encourage patients is also needed for by the caregivers. According to them, some patients feel sad and despair in experiencing their condition. The excerpt of the interview is as follows:

For me, I want to know how to get back the patient's spirit to live again. It's sad when he can only cry and doesn't want to do anything [Ik6, wife]

I don't know what to do. Please teach me to make the patient to stay motivated [I4, child]

Structured Discharge Planning Needs: The discharge planning given to the family caregivers has not been structured so far. All informants stated that the provision of education by the PPA (professional caregivers) related to planning the return of stroke patients was very important. The majority of informants stated that education is needed as their guide in caring their affected family members at home. This was revealed by several participants:

"Yes, I want to be told that at home, about what to do for the (muscles and joints) exercise, and what's not, so I can take care of my parent" (Ik14, child)

"Yes, about taking care of the sick, for example, taking care of the diet, bathing, the exercise for walk" (Ik 13, child)

Discussion

Family caregiver requires education from caregiving professionals so that they are able to treat patients properly at home. The required information is related to physical education needs (medical rehabilitation training at home training, mobilization and transfer of patients, handling patients' ADL and early symptoms of stroke). Whereas the need for psychological education is related to the patients' psychological changes and how to handle them. All informants stated that they needed education about how to perform medical rehabilitation at home. Changes in patients' neurological deficits caused them to experience limitations and became dependent on the family caregiver. In order to avoid the long term impact

of the neurological deficit, the family caregiver must learn about the rehabilitation techniques [4].

Organ dysfunction in stroke patients causes them to depend on the family caregiver to carry out daily activities. In handling ADL (Activity Daily Living), the family must have the skills so that the patient's ADL can be handled properly and to minimize the occurrence of complications. For example, bathing the patient must be done as clean as possible to avoid the risk of decubitus, improper feeding can increase the risk of pneumonia and improper way of wearing clothes will make it difficult for the process. Safe transfer techniques are important to prevent injury. Therefore families need to get education about safety and prevention of falling down.

The majority of informants also needed education regarding explanations about the introduction of stroke symptoms and prevention of complications. This is important to provide proper and fast handling and prevent recurrent strokes. Not only that, an education about how to manage risk factors such as hypertension, heart disease, diabetes, high cholesterol, and smoking is important to prevent recurrent stroke [4].

Based on the results of the study, psychological education is also a necessity for stroke patients. This is due to the fact that stroke patients generally experience dysfunction of mental and psychological activity that is manifested by emotional lability that shows the reaction easily or inappropriately [5]. Moreover, stroke patients usually show loss of self-control, so they tend to become easily angry and offended.

Hospitals need to assess the needs of education for the family caregiver. By doing so, the education provided will be in accordance with their needs. Education needs to be given in the form of knowledge and skills improvement to obtain the ideal result.

Discharge planning is a component of an ongoing treatment system for clients and helps families to find a way to solve the problems [4]. Discharge planning aims to help patients and families achieve optimal levels of health. Discharge planning starts on the day the patient is hospitalized, followed by scheduled update according to the patient's condition. The results of the study showed that the return planning was not structured. Most participants said they had been given an explanation of how to treat stroke patients. However, it seems not quite enough because the informants do not directly practice the procedure. Moreover, there was no evaluation to

see the extent to which the informants understood the education provided. This was expressed by most participants, where they said that nurses had told them what to do, but were limited to giving information and without providing explanations on how to perform correctly. Meanwhile, some of other participants said they knew various ways to do treatment, by seeing nurses working.

The role of nurses besides providing nursing care directly, they also provide information, education and skills needed by the family caregiver. In providing the information, education and skills, their goal is to aim for families to understand about stroke and to know the proper treatment [6]. Good knowledge, attitudes and behavior of the family will encourage patient gradually become independent. Health treatment at home as part of the nursing process at the hospital. Medical surgical specialist nurses have a great role in appropriate discharge planning to the patient's condition [7]. Warhola (1980) [8] mentioned that specialist nurses play a role to planning and coordinating nursing care according to the needs of patients and families. As the executors of nursing care, specialist nurses provide and evaluate nursing care. Structured discharge planning application is very necessary to make family caregivers be independent. In order do Structured discharge planning, it is necessary to have social support from various parties such as nurses, hospital management and family caregivers. The existence of social support from various parties will make the program run smoothly [9].

Conclusion

The results of this study indicated that the family caregiver requires education from caregiving professionals for caring stroke patients at home. This education is their provision in caring patients at home. Assessment on educational needs is important in order to meet the educational needs of stroke family caregivers. Education is given in accordance with the needs of the results of the assessment in the form of knowledge and skills. To see the extent to which family caregivers can learn about the education provided, an evaluation is needed. Hospitals are expected to be able to meet the educational needs for stroke family caregivers so that they are ready to for caring patients at home.

Conflict of Interest: The researcher stated that there was no conflict of interest in this study

Source of Funding: This work has been fully

supported by Faculty of Public Health, Universitas Airlangga.

Ethical Clearance: Ethics approval was received from Ethics Committee of RSU Haji Surabaya.

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