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PALLIATIVE COMMUNITY HEALTH NURSING (PCHN) ON IMPROVING FAMILY INDEPENDENCE IN THE CARE OF STROKE PATIENTS

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ABSTRACT
Family caregivers are important partners in the delivery of patient health care. Stroke patients need the help of family caregivers to assist in daily life. The purpose of this study was to explain the effect of PCHN development on increasing family independence in the care of stroke patients at home. The type of research is pre- experimental. The population was families of post-treatment stroke patients registered in Metro City. The sample was taken using purposive sampling technique. A total of 35 people met the inclusion criteria. The independent variable is PCHN. The dependent variable is the level of independence of the family caregiver, collected with an observation sheet of the level of independence of the family caregiver. Data were then analyzed with Wilcoxon Signed Rank Test, $\alpha \leq 0.05$. The test results showed there was a difference in the level of independence of family caregivers of stroke patients before and after PCHN ($p = 0.025$). PCHN can increase the independence of family caregivers in caring for stroke patients at home. Implementation of PCHN through home visits can provide information support related to stroke and home care for families. PCHN can be developed as one of the methods to improve palliative care in the community by community nurses, in order to improve the quality of life of stroke patients. Future research is expected to develop PCHN by involving a multidisciplinary team.

Keywords: family caregiver; independence; palliative care; stroke

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INTRODUCTION

Stroke, also known as cerebrovascular disease, is a neurologic disease that occurs due to impaired blood supply to the brain (Black and Hawk, 2009). There are two types of stroke: hemorrhagic stroke and ischemic stroke. Ischemic stroke is mostly caused by thrombotic or embolic blockage, while hemorrhagic stroke is caused by bleeding due to rupture of blood vessels in a part of the brain. The incidence of stroke increases with age, the higher the age of a person the higher the chance of stroke (Indonesian Stroke Foundation, 2012). However, the number of stroke patients under the age of 45 also continues to increase. WHO predicts that deaths from stroke will increase along with deaths from heart disease and cancer by approximately 6 million in 2010 to 8 million in 2030 (American Heart Association, 2010). According to the Indonesian Stroke Foundation (YASTROKI) (2012), the number of stroke patients in Indonesia is the highest and ranks first in Asia. Stroke is also the number 1 cause of serious disability worldwide. The 2018 Riskesdas results show that the prevalence of non-communicable diseases has increased compared to the 2013 Riskesdas, including cancer, stroke, chronic kidney disease, diabetes mellitus, and hypertension. Stroke prevalence increased from 7 percent to 10.9 percent (Riskesdas, 2018).

If stroke patients are treated properly, it will be able to minimize disability and reduce dependence on others in activities. Nurses have a very large role in providing nursing care and support to stroke patients and their families. The role of nurses starts from the acute stage to the rehabilitation stage, as well as the prevention of complications in stroke patients (National Institute of Neurological Disorder and Stroke, 2008). The role of nurses in the post-rehabilitation stage is not only in terms of preventing complications and reducing risk factors for recurrent stroke, but also identifying the need for home planning that suits the needs of the family, and providing the information needed, and encouraging families to be more effective in carrying out their roles and moving beyond their disabilities. While the main role of nurses towards families of stroke patients is to improve family coping through health counseling (Smeltzer & Bare, 2002).

The patient's own family plays a major role in the recovery stage, so from the beginning of the treatment the family is expected to be involved in the management of stroke patients. Families as caregivers are important partners in the delivery of complex health care services such as during the care of post-stroke patients. According to Wilkinson (2009), with the current trend of chronic diseases, such as stroke, which causes helplessness, the need for long-term care and reduced hospitalization, the presence of families as caregivers in providing care is very meaningful for patient recovery. Informal caregivers (family members or friends) provide care to individuals with various conditions, such as the elderly, dementia and stroke Palliative care is one form of sustainable health care for stroke patients. Palliative care is carried out in an integrated manner to improve the quality of life by alleviating the complaints of stroke patients, providing spiritual and psychosocial support from the diagnosis to the end of life, as well as support for families who feel lost (WHO, 2005). The focus of palliative care is not only on the patient, but also the family. Plenary palliative care includes various settings ranging from hospitals, community care managed by Puskesmas, and home care (Fauzi, 2011).

Many families of stroke patients have to change their role as caregivers to care for family members with stroke. This is due to the acute nature of the illness and little time to adapt. In the acute phase, stroke patients feel disoriented and will inevitably experience enormous dependence on others. The patient's family or family caregiver is the person who always accompanies, accompanies, and is beside the patient for 24 hours. Nurses do always spend time with patients during the patient's care, but still nurses have limited time to accompany and interact with stroke patients (Reinhard et al., 2008). The importance of the role of family caregivers is very helpful for the treatment and healing of stroke patients in terms of physical, emotional, psychological, social, and spiritual aspects. The purpose of this study was to explain the effect of PCHN development on increasing family independence in the care of stroke patients at home.

METHOD

This research is a type of pre-experimental research. The population was family caregivers of stroke patients after treatment in Metro City. The sample was selected from the population using purposive sampling technique, with inclusion criteria: 1) the family caregiver is one of the closest people (can be father, mother, husband, wife, and child) who lives with and is actively involved in the care of cancer patients at home; and 2) the family caregiver can read and write. The sample obtained from these criteria was 35 people. The independent variable in this study is Palliative Community Health Nursing, which is a 3x30-minute home visit package by community nurses, focusing on promotive and preventive activities that can be carried out independently by families of cancer patients at home. Meanwhile, the dependent

variable in this study was the level of independence of family caregivers in caring for stroke patients at home, which was assessed by the observation sheet for the level of family independence from the Indonesian Ministry of Health (2006). The data were then analyzed using the Wilcoxon Signed Rank Test with $\alpha \leq 0.05$ to determine whether there was a difference in the level of family independence before and after the intervention.

RESULTS

The results of the analysis of respondent data show that more than half of the respondents are female, as many as 24 people (68.57%) and most are in the late adult age group (36-45 years) as many as 28 people. Based on Table 1, it can be seen that most respondents were at family independence level II before the implementation of PCHN, as many as 28 people (80%). Meanwhile, after the intervention, it is known that most respondents are at family independence level III, as many as 32 people (91.42%). However, there were three respondents who did not experience an increase in the level of independence in the care of stroke patients at home after the intervention. The results of the Wilcoxon Signed Rank Test showed $p = 0.025$, which means there is a significant difference in the level of family independence before and after the implementation of PCHN. Based on the analysis of family independence observation results, it is known that before the implementation of PCHN, all respondents (35 people, 100%) were able to accept health workers and receive health services in accordance with the nursing plan. While after the implementation of PCHN, all respondents (35 people, 100%) were able to accept officers, receive health services according to the nursing plan, know and can express their health problems correctly, and utilize health care facilities as recommended. And there are 10 respondents who are able in all aspects of independence, including being able to take active health improvement (promotive) actions.

Table 1.
Family Independence Level before and after PCHN implementation

Number of Responden	Before	After
28	2	3
3	2	2
4	3	4

Table 2.
Family Independence Level

Independence Level	Pre Test		Post Test	
	f	%	f	%
Receiving officers	35	100	35	100
Receive health services according to the nursing plan	35	100	35	100
Know and can correctly express their health problems	15	42.85	35	100
Utilize health care facilities as recommended	15	71.42	35	100
Perform simple nursing actions as recommended	9	25.71	26	74.28
Take active preventive measures	2	5.71	15	42.85

DISCUSSION

After the patient's condition has stabilized and the acute phase has passed, the patient enters the third phase, the recovery phase. Stroke patients require comprehensive treatment, including recovery and rehabilitation efforts in the long term, even throughout the rest of the patient's life. The family plays a major role in this recovery phase, so from the beginning of the treatment the family is expected to be involved in the patient's treatment. Discharge

planning is carried out by doctors, nurses and other members of the stroke team, involving stroke patients and families if possible. The discharge planning process begins when the patient is admitted to the hospital, including education to the patient and family. Health education materials include the following: Care giver personnel who care at home, especially in the first three months after stroke, preparation of bedrooms, beds, bedside tables, chairs and wheelchairs, bathrooms, patient clothing, as well as medical devices and non-medical devices according to patient needs. During home care, the family plays an important role in efforts to improve the patient's ability to be independent, increase the patient's self-confidence, minimize disability to be as light as possible, and prevent stroke reoccurrence.

Families and patients can use resources in the community to help post-stroke patients adapt to their situation, such as participating in stroke clubs organized by the Indonesian Stroke Foundation or YASTROKI. Possible health problems experienced by post-stroke patients at home include: paralysis / weakness of half of the body or hemiparese, impaired sensibility or the patient experiences numbness or numbness, impaired sitting or standing balance, speech disorders and communication disorders, swallowing disorders, visual disturbances, urination disorders or incontinence, defecation disorders or constipation, difficulty wearing clothes, memory disorders or memory, personality and emotional changes.

The level of family independence before the implementation of PCHN was mostly at level II. This shows that all families have been able to accept the arrival of health workers, and receive services during visits well. Based on the results of research by Steele and Fitch (1996), families of post-treatment stroke patients really need support from health workers while providing care at home, so that families can provide proper care and are not physically and emotionally disturbed. The nurse's visit to the house is perceived as a concern for the family, so that the family openly accepts the nurse. The ongoing care of cancer patients that lasts for a long time makes nurses and families generally already know each other and have a good relationship. Therefore, there was no resistance from the family to the visits and services provided by nurses at home. The majority of respondents had utilized health services, namely health centers or hospitals to undergo cancer treatment. Once an individual is diagnosed with stroke, that is when the individual begins to relate to health care facilities.

For patients who use social health insurance, they must also first request a referral from the puskesmas. Therefore, the utilization of health care facilities by stroke patients and their families is quite good. Based on the results of the analysis, only some respondents were able to reveal the health problems faced. According to Depkes RI (2007), proper family knowledge about stroke affects their skills in providing care to patients while at home, to prevent recurrence and improve their quality of life. However, respondents only knew that one of their family members had suffered a stroke. When asked to explain further about stroke management and how to modify the right environment for the care of stroke patients at home, it was found that most of their understanding was still low. After PCHN, the level of family independence in stroke care has increased, namely 1 family that has been able to reach level IV, 5 families reach level III, and only 2 families are still at level II. In families that have reached level IV family independence, the family has been able to carry out nursing actions as recommended, able to carry out stroke prevention in the family, and even able to make active health promotion efforts. These respondents have participated as stroke-aware cadres that have been formed in the home environment.

On the other hand, there were families who did not experience an increase in the level of independence after the implementation of PCHN. This is because the respondents are elderly (> 60 years old), so they are less able to receive information provided by the nurse. Respondents may need more frequent and intensive visits from nurses to increase their independence in caring for stroke patients at home. Palliative care is a form of integrated health care to improve quality of life by alleviating complaints, providing spiritual and psychosocial support from the diagnosis until the end of life (WHO, 2005). Meanwhile, Community Health Nursing or known as community health care is a form of care that emphasizes high-risk groups in the community aimed at increasing independence in overcoming health problems through increasing knowledge, skills, guiding individuals, families, and community groups (Depkes RI, 2006). PCHN is a package of community health care services provided to patients and families of stroke patients at home that focuses on promotive and preventive activities. The process of implementing PCHN in this study began with a family assessment using the health assessment format for families with stroke.

The assessment identified family tasks in health consisting of the ability to recognize stroke problems, make health decisions, provide care to stroke patients at home, modify the physical and psychological environment conducive to health improvement, and utilize the nearest health facilities. The form of PCHN intervention is an effort to overcome the family's inability to carry out these tasks. PCHN is a home visit package implemented by community nurses for post-treatment stroke patients who live with their families at home. Through PCHN, community nurses provide counseling on nutrition in stroke patients, stroke prevention, as well as motivation to continue to utilize health services at puskesmas and hospitals for treatment and referral. This is in accordance with what Friedman (1998) wrote that the purpose of counseling in the family is to provide information, so as to be able to make appropriate decisions in relation to health and illness, help to participate effectively in care and healing, help adapt to the reality of the disease and its treatment, and help to experience a sense of satisfaction with their own efforts that support health improvement. Health education is a process of learning from individuals, groups, communities from not knowing health values to knowing, from not being able to overcome health problems to being able to. Knowledge is the result of knowing and occurs after people perceive a certain object. Sensing occurs through the five human senses, namely: sight, hearing, smell, taste and touch. Most human knowledge is gained through the eyes and ears.

Cognitive knowledge is a very important domain in shaping a person's actions (Notoatmodjo, 2003). This PCHN research is able to increase family independence in stroke care at home because the application of PCHN views the family as a client. There is a strong relationship between the family and the health status of its members. The family plays a very important role in every aspect of the care of individual family members from recognizing or detecting health problems, making appropriate decisions for care, carrying out care, creating a healthy environment to bringing to health services. The implementation of PCHN through home visits can provide an opportunity for families to obtain health information related to cancer and home care, thus improving the family's ability to recognize cancer. Through PCHN, families are increasingly able to carry out home care actions related to preparing healthy food and carrying out activities to improve body health. In the end, families are also able to take preventive measures to avoid cancer in other family members, and always go to health services for treatment and referral.

CONCLUSION

The research showed there was a difference in the level of independence of family caregivers of stroke patients before and after Palliative Community Health Nursing (PCHN). PCHN increase the independence of family caregivers in caring for stroke patients at home. Implementation of PCHN through home care and home visits can provide information support related to stroke and home care for families. PCHN can be developed as one of the methods to improve palliative care in the community by community nurses, in order to improve quality of life of stroke patients and their family caregiver.

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