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about their illness. They search for deeper understanding of the illness for explanations, compare different perspective in term of prevention modalities, health care providers and develop their strategies to manage life. Thus, the experience of stroke patients in the hospital is important to understand how to manage their condition in the hospital. Such experiences serve as the basis for how to manage stroke patients during their stay in the hospital.

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The purpose of this phenomenological study was to explore the stroke patients' lived experiences after they have been discharged from the hospital. The following research questions were addressed:

1. What is the essence of the lived experience of the participants with stroke during hospitalization?
2. What are the themes that emerged from the lived experiences of stroke patients at the hospital?

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Research design applied is interpretative phenomenology. The methodology as described by van Manen (1990) is used to address the aims of this study, and guided the data collection and analysis procedures. There were six activities that comprise of van Manen's methodology in an attempt to research the lived experience (van Manen, 1990).

Participants of the Study

Purposive sampling was used in this study. Criteria for inclusion in this research are patients of stroke who were cared by nurses, can fluently speak, fully consciousness state (fully alert), aged between 19 - 70 years old, experienced the first attack of stroke, has been out of the hospital for 3 months, and is willing to be a participant. The setting of this research is the community of Yogyakarta region. Consent was signed after the study purpose and procedures were explained to each participant. Recruitment of participants continued until no new information emerged from the interview data-based on the spiraling of the interview process. The average time of the interview was 20 to 30 minutes. Participants received IDR 100.000 (equivalent to 8 US dollars) each in appreciation for their participation in this study.

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Data were collected between July 2017 until September 2017. Data collection for the study was through individual face-to-face interviews. Participants were interviewed in Indonesia language at their homes. The open-ended interview guide was developed by the authors of this study based on their knowledge of this area and included questions such as: "Tell me your experiences?", "How do you feel when in the hospital outpatient?", and "What are your experiences of the health care personnel in the hospital? The interview schedule was modified as needed based on participants' responses and the salient literature. Additional questions were used to follow-up the initial question, with the intention of obtaining a comprehensive understanding of patient expected for caring of nurses. All interviews were audiotaped and transcribed verbatim by the researcher. Interviews lasted 20 to 30 minutes, were digitally audio-recorded and transcribed verbatim in Indonesia. Transcripts were stripped off identifying data and replaced with a participant ID number to ensure confidentiality. The transcriptions were also translated into English to involve the foreign co-investigator. Researchers first read each transcript several time to get a sense of the whole. Then, the researcher re-reads each transcript line by line and starts to uncover a tentative notion of the meaning of an experience and labels passages with theme labels.

Data Analysis

Data analysis involves turning to the nature of lived experience, investigating experience as the participants live it, reflecting on the essential themes which characterise the phenomenon, describing the phenomena in the art of writing and rewriting, maintaining a strong and orientated relation to the phenomenon, and balancing the research context by considering the parts and the whole (van Manen, 1990).

RESULTS AND DISCUSSION

Seven participants were recruited and participated in the individual face-to-face interviews.

LIVED EXPERIENCES OF STROKE PATIENTS DURING HOSPITALIZATION

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ABSTRACT

Stroke is the leading cause of disability in the adult population. Their weaknesses assert nurses to give them more attention. The experiences of patients as the part of caring delivery by nurses become important because they have to know their willingness of caring. The aim of this research was to examine and describe the lived experience of stroke patients toward the caring of nurses. This interpretative phenomenology study used individual face-to-face interviews to examine stroke patient experiences. Seven participants were recruited from Yogyakarta community in Indonesia by using purposive sampling technique. The interviews were digitally recorded and transcribed verbatim into written Indonesia. The transcripts were analyzed using van Mannen's (1990) phenomenological method.Results show that there were four major themes that emerged from the findings: (1) The diagnosis of stroke causes various stress responses, (2) The patients' enhanced spirituality, (3) Nurses' caring behavior affects patients' coping, and (4) Patients are able to reflect during the illness.

***Keywords**: Patient stroke, caring for nurses, phenomenology*

INTRODUCTION

The number of stroke patients ranked first in Asia and well-known as the highest cause of death in Indonesia. The number of stroke patients in Indonesia according to the Center for Data and Information Ministry of the Republic of Indonesia (2013) was 1,236,825 cases. The percentage of patients who died at the first stroke was 18% to 37% and 62% for recurrent stroke. International Classification of Disease data, taken from the National Vital Statistics Reports of the United States for 2011, showed an average stroke death rate of 41.4% of 100,000 sufferers. The prevalence of stroke in Indonesia reached 8.3 of 1000 populations, this prevalence rate increases with increasing age (Souza, 2013). In the UK, stroke is the largest single cause of disability with an annual cost to society of approximately £8.9 billion, around half of this cost representing direct care of the patients (Hole, Stubbs, Roskell, & Soundy, 2014).

Stroke is the leading cause of disability in the adult population (Adamson, Beswick, & Ebrahim, 2004). Approximately 75% of patients that experienced stroke are left with some degree of disability, including physical and or cognitive challenges, while fifteen percent will succumb to the event (HSF, 2008). A stroke is a sudden and traumatic event that can possibly have long-lasting physical, emotional, an social consequences. The stroke patients may hav many problems in their life, for example, difficult in returning to work, loss of employment an related financial difficulties, marital difficulties an responsibility for family activities such as raisin young children and or caring for older family membe (Kersten, Low, Ashburn, George, & McLellan, 200 Stone, 2005; Teasell et al., 2000; Vestling, Ramel, Iwarsson, 2005).

Sociologists and anthropologists hav documented that the occurrence of a chronic illne such as stroke often leads to a loss of independence an biographical disruption, in which people experienc chaos and discontinuity in their lives and sense self (Lewinter, 2009). Adjustment to acceptance chronic illness demands to reorder temporal aspec of one's daily life and reintegrating one's sense of se The experience of time is recognized as an importa feature of transitions and the adjustment proces Little is known about how a stroke patient manag changes in the experience of time during the healt to sick condition at the hospital.

Though, Nunstedt, Rudolfsson, Alsen, a Pennbrant (2017) discussed that patients with lon term illness show variations in the degrees of th

reflection about their illness. They search for deeper understanding of the illness for explanations, compare different perspective in term of prevention modalities, trust health care providers and develop their strategies to manage life. Thus, the experience of stroke patients in the hospital is important to understand how to manage their condition in the hospital. Such experiences serve as the basis for how to manage stroke patients during their stay in the hospital.

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RESULTS AND DISCUSSION

Seven participants were recruited and participated in the individual face-to-face interviews

Seven of the participants were originally from Yogyakarta, Indonesia. The mean age of the participants was 54 years. Most of them were married and employed. Five of the participants had senior high school degree, and two of the participants had a university degree. Their religions were Islam, Christian, and Catholic. Types of stroke were hemorrhage stroke and non-hemorrhage stroke.

The following major themes emerged from the findings: (1) The diagnosis of stroke causes various stress responses, (2) The patients' enhanced spirituality, (3) Nurses' caring behavior affects patients' coping, and (4) Patients are able to reflect during the illness.

The diagnosis of stroke causes various stress responses. Patient in this study described various stress responses to stroke diagnosis. The stress responses were shock, sadness, despair, and resignation. The greatest among them was shocked because they felt that they have never hurt anyone. They also felt surprised because they did not know the early symptoms of stroke.

"The body feels like a cold, and then I am sunbathing, but suddenly my feet are difficult to move, I do not know if I get stroke and then I go to Puskesmas." (P7)

The diagnosis of stroke also causes anxiety. Such concerns are anxiety to be a burden to others, anxiety about the consequences of illness, and worry about uncertainty in life. Yogyakarta is a strong area of Javanese tradition. In Javanese tradition, parents will stay with their children when they are getting older. The condition of stroke survivor is usually flawed, and it ends up causing anxiety that they will be a burden for their children.

"I'm afraid how if later I cannot walk and I would be the burden of the family." (P6)

"I am sad, not because of the fear of dying or because of my condition at that time but I am afraid to trouble my children." (P4).

Concerns about the consequences of illnesses are the discomforts of hospitalization, fear of disability, fear of death, concerns of not being able to take care of home, worrying about medical expenses, wo about themselves. Some participants said t hospital is a scary place and the hospital atmos needs to be changed into a comfortable plac home.

"Who is happy in the hospital, there are a scary tools." (P5)

Anxiety about the consequences of the di they also experienced are hospitalization, d disability, unable to perform his role, m expenses, and himself.

"I am very sad, and my child is still secon School. I usually do all the activity now I'm laying sick in my hospital, always screaming crying especially with the Indonesian Nat Health Insurance System where a week afte condition is stable I have to go home even w cannot move."

The loss is a subjective experience know an individual. It can be threatened or perceived. loss produces a grieving process. One's difficul resolving the loss depends on the significance o lost object. Loss and grieving manifest respo According to Kubler-Ross (1969), stage of grievin denial/shock, anger/hostility, bargaining, depres and acceptance. Most of the stroke pat experience these stages, and the difference is in long each stage is encountered.

Patients' enhanced spirituality

The stroke patients shared their spir experiences during their hospitalization. Trust in gives strength to heal and go through the pain wit sincerity. Their experience proves that self-close to the Almighty God gives submission to live the of their lives. They realize without resignation it be difficult to go through the condition because will continue to feel anxiety that makes them m depressed.

"Nurses ... they're good. But there is one n I like. I forgot her name. Every time he come invites me to pray, it is difficult for me to spea that time but he leads the prayer. I think the person needs to be brought closer to God s

can surrender. If you have not surrendered yet... it is difficult to recover because his thought is everywhere so it can add depression."

Depression is a further complication of stroke that will increase morbidity and mortality in post-stroke patients (Amien, 2011). Stroke patients feel happy when there are nurses who invite them to pray. They feel that by getting closer to God, it is faster to heal.

Stroke patients experience a lot of worries and losses such as job loss, social relationships, body functions, and self-confidence, so they are easily irritable and stressed. They have shared that getting closer, believing in the power of God, and surrender will make their lives better. The grieving response is normal, occurs in a predetermined sequence, and is self-limited. From the results of observations made, patients who believe in God's power goes through faster in the stage of acceptance.

Nurses caring behavior affects patients' coping

Most of them shared nurse's behavior is good. The stroke patient defines a good nurse's behavior as a dexterous act in performing nursing actions, rapid response as needed, nurses are friendly enough, nurses motivate clients to recover, the reward for client advancement, nurses invite to pray, happy with the presence of nurses. But stroke patients also have experiences that nurses coming to see patients if there is action to be done, rarely greeting patients, nurses rarely talk to patients, nurses lack understanding about stroke patients' Activities of Daily Living (ADL) needs, less smiling nurses, there are nurses who are rude, less caring, less patient, lacking a sense of humour, still acting like a robot, and do not provide the patient with the necessary information.

"They come when doing such actions as injecting, dripping infusion, giving medicine. They are very agile when doing nursing actions, injecting and so forth in accordance with a predetermined schedule but they rarely come to my room just to say hello or have a chat with me. "(P1)

The stroke patient explained that positive reinforcement from nurses could motivate them. Positive reinforcement makes stroke patients motivated to rise, have hopes and that there is still hope for a better life.

> "Nothing ... they are all good, they are always trying to encourage me to get well soon, I make a little progress, but they give praise, that's what keeps me excited so that on the 7th day I can lift my legs .... alhamdullilah ... It is a miracle, isn't it?"(P3)

Caring involves trusting the other to grow in its own time and in its way. In caring for another person, he or she must trust him or herself that they can learn from their mistakes. Caring is responsive to the growth of others, and caring also involves continuous learning about others. She/he who cares is genuinely humble in being ready and willing to learn more about others and himself, and what caring involves. Hope, as an expression of a present alive with possibilities, shares energies and activates our power. If the patient loses hope, somehow patient lose the vitality that keeps life moving. The patient loses that quality that helps them to go on in spite of all. Courage is also present in going into the unknown, taking the risk, and trusting. Courage is not blind: it is informed by insight from past experiences, and it is open and sensitive to the present. The greater the sense of going into the unknown, the more courage is called for in caring.

Nursing as a discipline encompasses the knowledge in the extant framework and theories that are embedded in the totality and simultaneity paradigms (Parse, 1987). These theories and frameworks explicate the nature of nursing's major phenomenon of concern, the human-universe-health process. The totality view is of the human as body-mind-spirit, and the simultaneity view is of the human as unitary. The body-mind-spirit perspective is particulate with a focus on the bio-psycho-social-spiritual part of the whole human as the human interacts with and adapts to the environment.

Caring is the central focus of nursing as a profession and discipline. Caring is an inter-subjective human process expressing respect for the mystery of being-in-the-world, reflected in the three spheres of mind-body-soul (Watson, 2012). Mayeroff (1971) defined caring as helping another grow and actualize himself, is a process, a way of relating someone that involves development, in the same way, that friendship can only emerge in the time through mutual trust and

relationships and transformation of the relationship. Nurses cannot work without caring because nursing is a discipline and profession. This study found nurses have not shown caring behavior. It means nurses have not known yet that nursing is a discipline and profession. Therefore they should show a caring attitude in every nursing activity.

Patients are able to reflect during the illness

This study also has shown that the stroke patients' behavior during hospital illness understood that nurses have heavy workloads so they should be more independent. Stroke patients trying to meet their own needs are not dependent on the nurse.

> "Nurses always come on time when I call, but sometimes they have a rough speech. I got angry, but then I realized maybe because of their heavy workload, so they become irritable. It's impossible to take care of me the way I want, and they have lots of patients. " (P2)

> "They rarely visit me because they have many patients. I need to be able to understand that and try to do what I can do myself not depending on them. " (P3)

They also have reflection during care in the hospital. Their reflections on how their lifestyle was before the illness, how they got sick and finally they tried to resign themselves to the current illness.

> "Early in the morning, I woke up my lips not symmetrically my legs cannot pay it attaches. Well ... surely this is a stroke because I am also taking care of a stroke-hit mother. I like to smoke and drink coffee. This is the result. I surrender just people live that there is His setting. I continue to hope and pray" (P5)

Orem (2001) defined self-care as the practice of activities that individuals initiate and perform on their behalf in maintaining life, health, and wellbeing. Orem said that patient needs requirement to self-care, the nurse has to know about self-care agency. Self-care agency is, therefore, the mature or maturing individual's capability for deliberate action to care for himself. Nursing is legitimate or needed when the individual's self-care capabilities and care demands are equal to, less than, or more than at a point time. Nurses should first assess the patient's ability care for himself, in the acute period, stroke patie are expected to have total rest. Although the patie wants to be consciously independent, nurses have think about the benefit of the patient's recovery.

Nunstedt, Rudolfsson, Alsen, and Pennbra (2017) concluded that patients whose illness has mo existential threat are more likely to reflect about th illness and the treatment methods. Thus, the illne condition is an opportunity for nurses to provide experience that provides a deeper understanding their illness.

Nurses should have consciousness in the cari moment, which in turn affects the field of the who (Watson, 1992). The caring moment is the most evide within the transpersonal Caritas energetic field mod in that one's consciousness, intentionality, energe hearth-centered presence radiating a field beyo the two people or situation, affecting the larger fie Thus, nurses can become more aware, more awak more conscious of manifesting a Caritas field of lo and healing for self and others, helping to transfo the system.

CONCLUSION

The following major themes emerged fro the findings: (1) The diagnosis of stroke caus various stress responses, (2) The patients' enhance spirituality, (3) Nurses' caring behavior affects patient coping, and (4) Patients are able to reflect during th illness.

Patients with stroke provide a positiv perspective on the experience despite the chron illness that they have. The experience of stroke an hospitalization has provided the patients an encount with themselves and others that contributed to th positive perspective. Patients feel that the nurse good, but after they explain more deeply, they fin that there are some nurses who are not good becaus being good only describes the physical presence of th nurse. The good condition they describe has not y described the true meaning of caring, which shou involve the nurse being in a caring relationship wit the patient by considering the needs of the patie holistically.

RECOMMENDATION

It is recommended to generalize such strategies to improve the quality of nurse's caring because stroke patients experience many stressors that make them feel helpless. The appropriate nursing care approach is needed to address the problem.

Acknowledgment

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