

THE EXPERIENCE OF STROKE SURVIVORS IN BANDUNG, INDONESIA

Cecep Eli Kosasih
Faculty of Nursing, Padjadjaran University
Jatinangor, Bandung.

ABSTRAK. Penelitian ini dirancang untuk menggali pengalaman hidup pada penderita stroke di Bandung Indonesia. Tujuan dari penelitian ini adalah (1) menggambarkan makna/arti dan perasaan menjadi seorang penderita stroke, (2) menggambarkan dampak dari stroke pada kehidupan seorang penderita stroke, (3) menggambarkan kebutuhan-kebutuhan seorang penderita stroke. Partisipan dalam penelitian ini berjumlah 10 orang. Tiga jenis alat pengumpulan data yang digunakan yaitu: form data demografik, Barthel index, dan pedoman wawancara. Analisis data menggunakan analisis tema dari van Manen (1990). Hasil penelitian menunjukkan bahwa ada empat tema utama menjadi seorang penderita stroke yaitu: taat perintah dokter, seperti anak kecil, dibawah pengawasan dan bantuan orang lain, percaya kepada Allah. Ada lima tema utama yang berkaitan dengan perasaan menjadi penderita stroke yaitu ketidakpastian akan harapan, terbelenggu di rumah, ketergantungan pada orang lain, tidak berdaya, rendah diri. Dampak stroke bagi penderita adalah tidak bisa aktif lagi, penyesuaian terhadap perubahan emosi, ketidakmampuan melakukan aktivitas sosial, gagal dalam mengemban tanggungjawab, semangat beragama yang meningkat. Tema lain yang berkaitan dengan kebutuhan penderita stroke adalah informasi, pengertian dan perhatian, waktu luang dan pilihan pengobatan. Hasil penelitian akan bermanfaat dalam upaya perbaikan sistem pelayanan kesehatan, pendidikan, administrasi dan penelitian pada area stroke rehabilitas, pencegahan dan peningkatan kesehatan.

Kata Kunci: penderita stroke, arti/makna, perasaan, dampak, dan kebutuhan

ABSTRACT. This study was designed to explore the experience of stroke survivors in Bandung, Indonesia. The objectives of this study were to: (1) describe the meaning and feelings of being a stroke survivor, (2) describe the impact of the stroke on the survivor's life, and (3) describe the needs of stroke survivors. The participants were 10 stroke survivors. Three types of data collection tools were employed: a demographic data form, the Barthel Index, and an interview guide. Data analysis used thematic analysis as suggested by van Manen (1990). The findings demonstrated four main themes of meaning of being stroke survivors: being obedient to the doctor, regressing to childlike status, being under supervision and assistance, and being tested from God (Allah). The findings demonstrated five main themes of feelings of being a stroke survivor:

uncertainty about hope, being bound at home, dependent on someone, powerlessness, and low self-confidence. The impacts of stroke on the survivor's life were identified as: being unable to be active, having to adjust to emotional changes, being unable to undertake social activities, failure to fulfill former responsibility, and enhanced in spiritual life. In addition, three themes were found as stroke survivor's needs: information, understanding and attention, joyful/leisure time, and choices of therapy. The findings will benefit for the improvement of health care system, education, administration, and research in the area of stroke rehabilitation, prevention, and promotion.

Key Words: stroke survivor, meaning, feeling, impact, and need

INTRODUCTION

Stroke, or cerebrovascular accident is the second most common worldwide cause of death, accounting for more than 4.6 million deaths worldwide, of which two-thirds are in developing countries (World Health Organization [WHO], 1997). In ASEAN countries stroke is one of four leading causes of death (Venketasubramanian, 1998). Stroke is a disease that usually carries long-term consequences as well, in terms of both long-term physical disability, and also psychological, social, and spiritual effects (King, Carlson, Shade, Bares, Roth, & Heinemann, 200).

As health care providers, nurses require an understanding of the varieties of lived experiences, which arise from persons telling us their descriptions of a life event experience (Munhall, 1994). In order to build nursing care plans to assist stroke survivors to solve their problems, the lived experience must be explored and revealed, especially in the community. In order to describe the lived experience of stroke survivors, the use of phenomenological study is useful to gain a deep understanding of being a stroke survivor, because this method investigates subjective phenomena in the belief that essential truths about reality are grounded in lived experience (Spiegelberg, 1982).

There have been few studies on the lived experience of stroke survivors at home, especially in an Indonesian setting. Although many studies related to stroke have been done in Thailand (Hirunchunha,1998; Chantawatchai,1999). Thus, study on the lived experience of stroke survivors was conducted in Bandung, Indonesia, to gain insight and understanding of what the experience is like for Indonesian, Muslim stroke victims, within their culture and religion.

METHODS

Hermeneutic phenomenological study was conducted to explore the lived experience of the stroke survivors who were the participants of the study. The population of this study was patients who had survived a stroke. Ten stroke survivors recruit as participants in the study who had discharged from the hospital after preliminary treatment, and were living at home with family members in Bandung, West Java Province, Indonesia. Instruments of the study

consisted of (1) a demographic data; (2) an interview guide; (3) an "Activities of Daily Living" (ADL) assessment, using the Barthel index, and (4) field notes and tape-recordings. The interview guidelines were pilot-tested with two stroke survivors to check for appropriateness and clarity. The instruments were tested for validity by three nursing experts from the Faculty of Nursing, Prince of Songkla University, two phenomenological nurse experts and one expert in caring for stroke patients.

ETHICAL CONSIDERATIONS

The researcher first gave information verbally to the participants concerning the purpose of the study, the planned procedures for gathering data, and the possible benefits and risks to the participants. The participants were clearly informed of their freedom to participate or not participate in the study and also informed, if agreeing to participate, that they were free to withdraw from the study at any time for any reason. The researcher assured the participants that their anonymity would be strictly protected, and that all transcripts would be confidential and protected. Each participant then signed or verbally agreed to the consent form before data collection was performed. Moreover, before data collection began, the research proposal was approved by the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University.

PROCEDURES

The researcher asked for permission to collect data from the Dean of the Faculty of Medicine, University of Padjadjaran, and from the head nurse of the outpatient department of the neurological clinic of Dr. Hasan Sadikin. The participants were asked to sign or give verbal consent if they agreed. The researcher conducted the study using an in-depth interview method at the stroke survivor's home with their family members. Each interview was of about 30–60 minutes in duration, and was audiotaped and transcribed. Data analysis in this study used thematic analysis as suggested by van Manen (1990). All steps were performed in order to keep close to the meaning of the original data from the participants.

RESULTS

A. Meaning of Being a Stroke Survivor

1. Being Obedient to the Doctor

The participants believed in what the doctor said, for example in what medicine they used, the diet and exercise programs, and regular check-ups at the hospital. As one participant expressed:

We have to obey the doctor, and consume medicine 3 times a day. I just follow the doctor's instructions. That is the reason why I check up

*regularly to the hospital monthly and get 5 kinds of medicines.
(Participant 01)*

2. Regression to childlike status

The participants felt that during their time as a stroke survivor they could not do many activities such as moving, speaking, and/or performing their jobs freely, and what abilities they did have were reduced. These disabilities caused the participants to have negative perceptions. As one participant stated:

*Before the stroke I usually worked at home and I did everything as a mother. But after the stroke everything was lost. I was like a child so I was forced to depend on someone else to do what I wished.
(Participant 06)*

3. Being under supervision and assistance

They had to be assisted because the caregivers worried about them getting in an accident. This decreasing ability to perform the normal activities of daily living also reduced their ability to join in social activities. As one participant stated:

I think, being a stroke survivor is so bad an experience. I cannot perform what I want to do freely. I depend on someone else, and I have to ask other if I need something. (Participant 10)

4. Being Tested From God (Allah)

They realized that during their lives they might have sinned or made mistakes, and everything that happened in their lives was a test from God, to see if they could pass the test or not. As one participant stated:

A human being has limitations, and then God gives a test through disease to see if the human being can pass or not.... Generally, as long as I live in this world, I have to do good deeds. Maybe if I didn't get this disease I would forget to be a good person. (Participant 02)

B. The Feelings of Being a Stroke Survivor

1. Uncertainty about Hope

Five participants perceived that they still had at least some hope that they would be able to deal with the disability. However, the other five participants felt that they had little or no hope of getting better again, as they did not know when they would recover from the stroke and the effects of the aftermath of stroke were still heavy on them. As one participant stated:

According to my religion we have to maintain intense effort, intention and discipline in order to keep healthy. We have to keep being patient and grateful to Allah in accepting all Allah's treatment. And to be sure of Allah's help and not lose your hope. (Participant 01)

2. Being Bound at Home

The participants felt that they became restricted like a prisoner because they had no independence to do things on their own. As one participant stated:

After discharged I still had disabilities such as difficult to move, difficult to speak, sometimes I had a headache. Also my activities were changed, as most days I spend sitting on a chair. The stroke was so difficult for me, I could not go anywhere I just stayed at home. (Participant 10)

3. Dependence on Someone

The participants had to accept such things as disability to walk, or only a little with help, and difficulties to move and work. Therefore, they depended on the caregiver to meet their need and wants. As one participant expressed:

Before the stroke, I was just a housewife who took care of my family, and my husband was the main breadwinner. Nowadays, I cannot walk properly, it is difficult to move my hand and my leg, difficult to work, and I am dependent on another. It is terrible for me. (Participant 05)

4. Powerlessness

Mostly the participants suffered weakness or paralysis in various parts of their body. The disabilities that usually remained for a long time were a negative influence on their feelings. As one participant stated:

For me being a stroke survivor was terrible because it made me powerless, I could not do the activities of daily living, it was difficult to walk and difficult to participate in social activities. (Participant 05)

5. Lost Self-Confidence

After the stroke, they had many obstacles in performing normal tasks because of their disability and this caused a declining self-confidence. As one participant stated:

The most prominent effect was the loss of confidence to express an opinion verbally. It causes miscommunication with others.... Sometimes I doubt when I say something to someone whether he/she understands what I said...(Participant 02)

C. The Impact of Stroke on the Stroke Survivor's Life

1. Being Unable to be Active

Seven participants reported that they had many difficulties in such things as walking, limitations in moving their body or in coordination of different parts of the body, and paralysis. They reported that they could not go anywhere, and these problems led the participants to stay at home rather than work or go outside. After their stroke, they also could not communicate effectively, especially those participants who had been teachers. As one participant expressed:

I had many difficulties therefore I could not go to anywhere, I could not do anything, it was very bad. (Participant 06)

2. Having to Adjust to the Emotional Changes

After the stroke, and they mostly had to stay at home, as they could no longer perform their normal task properly. This sudden major change in their daily life naturally affected their emotional stability and forced the participants to adjust their emotional outlook. Some participants felt pessimistic about being able to face their new problems, and to solve these problems they asked the God for help. As one participant expressed:

Sometimes I felt pessimistic about my ability to face the illness. Then, I had to do much reflection to my self. I believed that the God gave the illness and also the drugs to cure it. (Participant 04)

3. Being Unable to Undertake Social Tasks

The participants could not go to work and could not conduct activities in social organizations, or other social activities among their neighbors such as social services, involvement in neighborhood committees, or involvement in religious practices. As one participant expressed:

Before I had the stroke, I did many activities such as working at my office, teaching the people every morning, and so on. Now I just teach people, but not everyday... Also my social activities in my organizations are much more limited. (Participant 04)

4. Failure to Fulfill their Former Responsibilities

After stroke, they could not fulfill their responsibility such as go to work or accomplish their jobs, giving an Islamic speech, carry out their responsibilities as a wife, or fulfill their duties as a parent. The loss most often described by patients was loss of their mobility. As one participant expressed:

... But after I had the stroke I could not go to school and work at my shop... Since I was sick I could not take care of my children such as bring and pick up my children from school on the motorcycle...(Participant 03)

5. Enhanced Spiritual lives

The participants believed that through praying to God they could cope with their problem, which also indicated that they still had hope of being recovered.

The participants reported that after performing the religious practices they felt more comfortable in their mind, with feelings of calmness and peace. As one participant stated:

We always have to pray and make requests to Allah (the God) as much as possible.... for our recovery, particularly in doing "sholat" (the 5 obligatory dairy prayers for Muslims). We have to be patient and say or grace to Allah in accepting all of Allah's treatment and to be sure of Allah's help and not lose hope. (Participant 01)

D. The Needs of Being a Stroke Survivor

1. Information

The participants wanted more detailed information related to the stroke such as how to prevent a recurrence, medications, diet regulation, and exercise, especially for use after they returned home. As one participant expressed:

I only want to be healthy. I needed information about the stroke such as how to prevent a second stroke, the food that I have to eat and the food that I have to avoid, and how to exercise. (Participant 03)

2. Understanding and Attention

The participants needed understanding and attention from the people around them, usually their spouses and/or their children. As one participant expressed:

As a stroke survivor I need understanding from my husband and my children that I cannot perform all of the duties of a housewife due to my disability. (Participant 06)

3. Joyful/Leisure Time

The participants felt that happy or leisure time was necessary to relieve the boredom or stress that built up during the day due to their problems. As one participants expressed:

One need I have is just happy time for myself, such as reading a book by myself to enhance my knowledge about my religion. (Participant 04)

4. Choices of Therapy

Most of the participants in the study tried to improve their condition not only from the medications the doctors gave them, but also from available alternative therapies. As one participant stated:

The effort to cure the illness included medicines and alternative medicines. I always went to the hospital every month to check my body. Also I found alternative medicines and I have some drugs and get massages. (Participant 04)

DISCUSSION

The details of experiences of being a stroke survivor are discussed below.

1. Meaning of Being a Stroke Survivor

Obedying the doctor's instructions was a central aspect of their lives following their discharge from the hospital. They preferred to obey the doctor, especially in regard to taking their medicines, because the participants trusted their doctors more than other health providers. The patients look the doctor as superior position and they believed that the doctor had well knowledge to cure the disease. Therefore whatever the doctor said they would follow it. The relationship between the doctors and the patients is based on paternalism and trust, and it is believed that doctors are able to cure illnesses (Guwandi, 2001). They all reported that their physical ability had declined to childlike status. It is well understood that stroke can lead to neurological problems or deficits (LeMone & Burke, 2000). This decreased ability to perform the normal activities of daily living also reduced their ability to join in social activities (Gresham, Fitzpatrick, Wolf, McNamara, Kannel, & Dawber, 1975). Therefore, most of stroke survivors need to be assisted and under supervision by another. All the participants stated that their illness was a test from the God. It developed when they belief all the calamity that came to them as test from God. According to Islamic faith, God will test the individual until the end of live. Spirituality involved a belief in a higher power, spirit guide, God, or Allah, and that God gave an illness as a test of patience (Fryback, 1993).

2. Feeling of Being a Stroke Survivor

The feeling of uncertainty emerged because some of the stroke survivors still hoped for a better quality of life in the future while others reported that they were still uncertain about recovering from their stroke. This finding is similar with a study found that stroke patients had feelings of uncertainty about the future, particularly in most individuals who had been unprepared for their stroke (Burton, 2000). They also felt like a prisoner due to they had many limitations on their life, even when going to the rest room they were supervised by someone. Feeling bound at home was expressed most of the participants. It was due to inability to move freely. Feeling of isolation was common among the stroke patients (Haggstrom, Axelsson, & Norberg, 1994). It is also consistent with the study found that the stroke survivors had common feeling of being isolated or stuck in a cage (Burton, 2000). They also had feeling of dependence on someone. This feeling is the consequences of impact of stroke that lead the participants' incompetents to do by themselves. Moreover, lead them to feeling of powerlessness. A study found that slower recovery times than might have been expected were often associated with feelings of despondency and frustration, and spending too much time reflecting on the victim's pre-stroke life (Burton, 2000).

The stroke survivors felt ashamed to try to have relationships with people around them. This feeling was strongest during the beginning phase of the recovery, as the patients encountered for the first time the meaning and extent of their many disabilities. A study found that many stroke patients were uncomfortable with their newly disabled state and were either ashamed or did not wish to burden their friends, relatives or former acquaintances with their post-stroke selves (Dowswell, Lawler, Dowswell, Young, Forster, and Hearn, 2000).

3. The Impact of the Stroke on the Stroke Survivor's Life

The participants perceived that being unable to be active included being unable to participate in the many normal activities of daily living, memory impairment, and sexual dissatisfaction. A stroke may cause weakness, paralysis, and/or spasticity, leading to the physical limitations faced by stroke survivors in conducting the normal activities of daily living (LeMone & Burke, 2000). Stroke patients described their inability to communicate as extremely depressing and frustrating (Mumma, 1986). Other contributory factors to limitation of activities of daily living were fatigue and weakness (Glader, Stegmayr, and Asplund, 2002). The cognitive function was also noticeably disrupted in many participants. Loss of memory was seen as a major problem resulting from the stroke, including an inability to remember new information. The stroke patients reported cognitive impairment, problems with lower limbs, and speech difficulties as the most common residual impairments (Geddes, Fear, Tennant, Pickering, Hillman, and Chamberlain, 1996). Sexual problems were also of concern among the participants, as following the stroke they found a decrease in their sexual desire and ability to satisfy their spouse (Kimura, Murata, Shimoda, & Roninson, 2001).

The psychological impact of their stroke was also influenced by the physical problems. The stroke survivor had to adjust of their condition. The adjustment process of stroke victims was gradual and prolonged (Kirkervold, 2002). Religion also had a considerable influence on acceptance of a stroke, as religious beliefs and spiritual practice act as a coping mechanism to assist with the psychological problems new stroke victims face (Ellison, & Levin, 1998).

After their stroke some participants were unable to perform such activities because of their many new physical limitations, including difficulty in verbal communications (Ahlsio, Britton, Murray, & Theorell, 1984). They also failed to fulfill former responsibility. Stroke patients had three major categories of loss: activities, abilities, and independence (Mumma, 1986). Being grown in spiritual life emerged from the interviews as a central theme of most participants. They found calmness, peace and psychological satisfaction by remembering God. Most participants performed prayer to Allah (the God) for healing.

4. The Needs of a Stroke Survivor

Thus 'information' was a central need for them – information about how to manage their medication, exercise properly, manage their diet, and prevent a

recurrence of the stroke. This finding is consistent with a study found that information needs covered all data concerning the illness, its treatment and recovery (Lui, & Mackenzie, 1999). Understanding and attention also recognized by the participants as important need. During stroke recovery, the major psychological support valued by the informants included giving them reassurance and a sense of security, offering verbal encouragement, listening to their worries, showing a caring attitude and respecting them as individuals (Lui, & Mackenzie, 1999). The participants tried to maintain or improve their health by having strong determination and also by using a combination of medicine, both modern medicine and alternative and complementary therapies such as (in this study) herbal therapy and massage therapy, which they perceived will benefit them. Other studies have also found similar behavior, that is, stroke survivors seeking alternative or complementary therapies such as herbal therapy, massage therapy, acupuncture (Moon, Whang, Park, Kim, Bae, Cho. 2003).

CONCLUSIONS AND RECOMMENDATIONS

There are four aspects of the lived experience of stroke survivor. Meaning of being a stroke survivor; being obedient to the doctor, regression to childlike status, being under supervision and assistance, being tested from God (Allah). The feeling of being a stroke survivor; uncertainty about hope, being bound at home, dependence on someone, powerlessness, lost of self-confidence. The impact of stroke survivor's life; being unable to be active, having to adjust to the emotional change, being unable to undertake social tasks, failed to fulfill their former responsibilities, enhanced in spiritual lives. The need of being a stroke survivor; information, understanding and attention, joyful/leisure time, choices of therapy.

Overall, the stroke survivors have a several meaning of life that is different with other. They undergo a difficulty lives such as physically, psychologically / mentally. They also have a need to solve the problems. However, some of them still can handle the problems and enhancing their spiritual life.

The findings can be used to help health care provider to understand how the survivors construct their views, how they think, act and reflect on their life, and how they feel about the stroke. The findings are beneficial for health care system (rehabilitation, prevention, and promotion). Nurse educators should emphasize the importance of understanding the meaning of being a stroke survivor when caring for these patients. These findings also provide data for nursing administrators to better manage the care of stroke survivors to offer a better quality of life for the stroke survivors in the community. This study provides some basic information on the social & psychological experience of stroke survivors at home. The results of this study can be used as support evidence or guidelines for developing some programs to enhance and promote

the health of stroke survivors, and to support previous reference for others studying the experiences of stroke survivors.

REFERENCES

- Ahlsio, B., Britton, M., Murray, V., & Theorell, T. Disablement and quality of life after stroke. *Stroke*. 1984; 15, 886-90.
- Burton, C. R Living with stroke: a phenomenological study. *Journal of advanced nursing*. 2000; 32, 301-309.
- Chantawatchai, A. Functional abilities in activity of daily living and related factors among stroke patients 3 months after onset. Mahidol University Thailand. Master Thesis. 1999.
- Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., and Hearn, J. Investigating recovery from stroke: a qualitative study. *Journal of Clinical Nursing*. 2000; 9, 507-515.
- Ellison, C. G., & Levin, J.S. The religion-health connection: Evidence, theory, and future directions. *Health Education & Behavior*. 1998; 25, 700-720.
- Fryback, P., B. Health for people with a terminal diagnosis. *Nursing Sciences Q*. 19936 (3), 147.
- Geddes, J. M. L., Fear, J., Tennant, A., Pickering, A., Hillman, M., Chamberlain, M. Prevalence of self reported stroke in a population in northern England. *Journal. Epidemiological Community Health*. 1996; 50, 140-143.
- Glader, E. L., Stegmayr, B., Asplund, K. Poststroke fatigue: a 2-year follow-up study of stroke patients in Sweden. *Stroke*. 2002; 33, 1327-1333.
- Gresham, G. E., Fitzpatrick, T. E., Wolf, P. A., McNamara, P. M., Kannel, W. B., & Dawber, T. R. Residual disability in survivors of stroke-the Framingham study. *New England Journal of Medicine*. 1975; 293, 954-956.
- Guwandi, J. Pembuktian Terbalik. Retrieved [April 9, 2001] from Kompas Cyber Media. <http://www.kompas.com>
- Haggstrom, T., Axelsson, K., & Norberg, A. The experience of living with stroke sequelae illuminated by means of stories and metaphors. *Qualitative health research*. 1994; 4, 321-337.
- Hirunchunha, S. Development of a care model for the caregivers of stroke patients at home. Mahidol University Thailand. Ph.D. Dissertation. 1998.
- Kimura, M., Murata, Y., Shimoda, K., & Roninson, R. G. Sexual dysfunction following stroke. *Compr Psychiatry*. 2001; 42, 217-222.

The Lived Experience of Stroke Survivors in Bandung, Indonesia (Cecep Eli Kosasih)

- King, R. B., Carlson, C. E., Shade, Z. Y., Bares, K. K., Roth, E. J., & Heinemann, A. W. Transition to home care after stroke: depression, physical health, and adaptive processes in support persons. *Research in Nursing and Health*. 2001; 24, 307-323.
- Kirkervold, M. The unfolding illness trajectory of stroke. *Disabil Rehabil*. 2002; 20, 887-889.
- LeMone, P., & Burke, K. M. *Medical-Surgical Nursing: Critical Thinking in Client Care* (2nd ed.). New Jersey: Prentice Hall Health. 2000.
- Lui, M. H. L. & Mackenzie, A. E. Chinese elderly patients' perceptions of their rehabilitation needs following a stroke. *Journal of Advanced Nursing*. 1999; 30, 391-400.
- Moon SK, Whang Y. K, Park S. U, Ko C. N, Kim Y. S, Bae H. S, Cho K. H. Antispastic effect of electroacupuncture and moxibustion in stroke patients. *Am J Chin Medicines*. 2003; 31, 467-474
- Mumma, C. M. Perceived losses following stroke. *Rehabilitation nursing*. 1986; 11, 19-24.
- Munhall, P. *Revisioning phenomenology: nursing and health science research*. New York: National League for Nursing Press. 1994.
- Robinson & Smith, G. Prayer after stroke: its relationship to quality of life. *Journal of Holistic Nursing*. 2002; 20, 352 –366.
- Spiegelberg, H. *The phenomenological movement: A historical introduction*. (3rd revised & enlarged edition) The Hague: Martinus Nijhoff Publishers. 1982.
- Venkatasubramanian, N. The epidemiology of stroke in ASEAN countries-A review. *Neurol J Southeast Asia*, 1998; 3, 9-14.
- World Health Organization [WHO]. *World Health Report*. 1997. Retrieved February, 2003, from [http:// www.who.int/ whr2001/2001/ archives/1997/ exsum97e.htm](http://www.who.int/whr2001/2001/archives/1997/exsum97e.htm)