CHAPTER 3

RESEARCH METHODS

Design of the Study

This hermeneutic phenomenological study was conducted to explore the lived experience of the stroke survivors in Bandung, Indonesia.

Population

The population of this study was patients who have been survived from stroke, discharged from the hospital, and were living at home with family members in Bandung, West Java Province, Indonesia.

Participants

Participants in this study were drawn from accessible population through purposive sampling. They were a group of patients who had survived a stroke. Further specific inclusion criteria in the study were as follows:

- 1) A patient who had had a stroke, as diagnosed by a physician, and who had survived but was living with some degree of disability.
- 2) Age of the participant more than 18 years.
- 3) They had had the stroke at least three months prior to the beginning of the data collection, and they could recall their experiences during and following the stroke.
- 4) Mental state conscious and able to communicate.
- 5) Willing to participate in this study.

Sample Size

Sample sizes in qualitative research tend to be small because of the large volume of verbal data that must be analyzed, and also because this type of design tends to emphasize intensive and prolonged contact with the subjects (Sandelowski, 1986 Cited in Lobiondo-wood & Haber, 1994). Qualitative methods seek to represent the situation being studied holistically, and to provide contextual knowledge of the phenomenon being studied. Sample sizes must also be decided on with consideration of informational needs, and a central guiding principle in sampling is data saturation (Polit, Beck, & Hungler, 2001). Therefore, the sample size selected for this study was based on the data saturation that the researcher collected, recruiting new study participants and interviewing them until the researcher felt a state of data saturation was reached which no new information was obtained and redundancy was achieved. In this study ten stroke survivors were recruited as participants. The participants were selected among stroke patients who visited to outpatient department of Hasan Sadikin hospital according to the rich experience that they had following the stroke.

Instruments

Instruments of the study consisted of (1) a demographic data form collecting information such as age, gender, marital status, occupation, level of education, medical diagnosis, duration having this diagnosis, and situation characteristics; (2) an interview guide for exploring the lived experience of stroke survivors which the researcher developed based on the literature review; (3) an "Activities of Daily Living" (ADL) assessment form was used to explore the ability of the study subjects to performing ADLs; in this study, the Barthel index (Mahoney & Barthel, 1965) was

used to evaluate the ADL of the subjects; and (4) field notes and tape-recordings were used in this study to obtain information from the participants.

The interview guidelines were pilot-tested with two stroke survivors to check for appropriateness and clarity. The instruments were tested for validity by three nurse experts from the Faculty of Nursing, Prince of Songkla University, two phenomenological nurse experts and one expert in caring for stroke patients. The researcher translated the instrument from the English language to the Indonesian language, and then the researcher asked an Indonesian-English expert to approve the translation. In addition, an Indonesian nurse who had 5 years experience in caring for stroke patients made some amendments to the instrument to make it appropriate for use in an Indonesian cultural setting.

Ethical Considerations

Ethical considerations are important in all studies involving human subjects, and especially those suffering from a disease, and before such studies are conducted the protection to the human rights must always be considered. The researcher first gave information verbally to potential study 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.

In this study there was no direct risk to the participants physically, and plans were prepared in case any newly developing psychological problems were detected during the interview stage to immediately offer assistance to prevent harm to the participants. Those steps were (1) the researcher would stop interview at that moment, (2) be attentive to the subject's expressions and try to understand what the participant was experiencing, (3) the researcher, as a nurse, would try to alleviate the problems related to the psychological effects occurring, and (4) if the problem persisted, the researcher would refer the patient to the nearest hospital.

Study Context

This study was conducted in Bandung, West Java, Indonesia, in the homes of the stroke survivors who participated in the study. First contact with the eventual participants was made at the outpatient neurological department of Dr. Hasan Sadikin Hospital, in Bandung.

West Java province is located in central Indonesia. Bandung is the capital city of West Java, located about 180 km southeast of Jakarta. It is situated on a plateau some 768 meters above sea level, surrounded by mountains with a cool climate throughout the year. Bandung itself is a very interesting place city, with many old art deco buildings, beautiful parks, and fine landscapes. In the past, Bandung was well known as "Parijs van Java" because of the beauty of this city. The Sundanesse people of Bandung possess uncommon warmth along with courtesy, friendliness and

politeness. They have a strong sense of helping each other when in need (http://www.geocities.com/Bandung city).

The population of Indonesian in 1999 was about 211,000,000 million, with about 85% Muslim, 10% Christian, 2% Hindu, and 1.5% Buddhist. West Java is the most populous province, with over 35 million people in 2000 (Strategic Planning of West Java, 2001). The large population of West Java is Sundanese and follows by Javanese, Batak, Padang, and Chinese, and some other small ethnic groups. Socioculturally, the people of West Java are strongly religious, primarily Muslim, although four other religions thrive in Bandung as well. The Sundanese people honor ancient cultural traditions and their social behavior is based on a philosophy of compassion, giving knowledge to each other, and taking care of each other with kindness (Strategic Planning of West Java, 2001). This brief description of the study location was included in order to provide an understanding of the background of the stroke survivors and their social environment, and the people living around them and their cultural background.

Data Collection

The data collection was divided into two phases: preparation and collection. In the preparation phase, the researcher undertook several preliminary activities before beginning the actual study. These activities included self-preparation, tool preparation, and correspondent or administration preparation. For self-preparation, the researcher studied qualitative research methods such as concepts, approaches to data collection, and data analysis, and also the researcher practiced in-depth-interviews and data analysis with his advisors. For tool preparation, the researcher prepared

demographic, interview, and observational guides, field notes, and also practiced using a tape-recorder. For correspondent or administration preparation, the researcher obtained letters of permission from the Faculty of Nursing of Prince of Songkla University and from Dr. Hasan Sadikin Hospital.

In collection phase, 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 Hospital. For participant preparation, the researcher spent a few days at the outpatient neurological clinic, selecting 1-2 participants per time, giving them information about the objectives of the study and asking them if they would be interested in joining the study. They were asked to sign or give verbal consent if they agreed. When a potential participant agreed to join, the researcher then made an appointment for interviewing that patient at another meeting. At the first contact with the participant after the patient has agreed to participate, the researcher established trust with the participants and their family members. The researcher spent a few days to give the participants time to become acclimatized to the researcher and for the researcher to become familiar with the conversational patterns and behavior of the participant.

Before the actual interviews began, the researcher observed the environment, in which the participants lived to increase his understanding of the participant's lived experience, and also assessed and examined the ability of the participant to perform the ADLs. Finally, after this initial preparation, the researcher performed the actual interview, beginning with non-threatening questions before getting into the more personal and sensitive parts of the interview. The stroke patients were asked to describe their experiences as stroke survivors. The researcher used open-ended

questions (Appendix D) as a guide when interviewing the participants regarding to their experienced during stroke recovery phase. 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.

The researcher interrupted the participants only for the purpose of clarification or probing for further information. During the interviews, the researcher also observed and recorded any "ex-interview" dialog between the researcher and the participant. For the participants who had difficulty in speaking and expressing their feeling, the researcher undertook built-up relationship and giving them more time in order to get more information from them. Also the researcher conformed the meaning of their experience to them. Data collection was continued until the data saturated point was reached, which was determined by reviewing the data collected after each interview session. The researcher also used different questions to try to make sure that no new information was yet unfound. The data collection was undertaken in the Indonesian language, while the reporting of the results was in English. Therefore, The researcher undertook translation of the transcribed interviews and an English-Indonesian expert checked the translation of the transcribed interviews again in order to prevent the distortion of meaning.

Data Analysis

Data analysis in this study used thematic analysis as suggested by van Manen (1990), a process which is designed to uncover recurrent themes that, in this situation, represented the participant's lived experience as a stroke survivor. The analysis

process was conducted concurrently with the data collection. The overall aims at this stage were to identify and reflect on the preliminary themes and the structure of the lived experience of stroke survivors. This involved manual exploration of the preliminary themes and structure of the lived experience. During this analysis all the interviews were transcribed into written language. Also, other sources such as field notes, assessment findings, and data collection from each participant's profile were added as appropriate to the transcriptions. In order to discover the preliminary themes, the researcher manually grouped the dominant aspects of the survivor's lived experiences, as revealed through the interviews and supporting data.

The data analysis for the thematic analysis aimed to identify the meaning of the lived experience of the stroke survivors. The researcher read and re-reads several times all the transcribed interviews with deep attention, in order to become familiar with the participants and their stories (van Manen, 1990). This step aimed to gain understanding and to get a sense of totality of the survivor's experiences as a whole, of the feeling of the stroke survivors at home.

Searching for a theme was an important aspect of the research. The theme is the form of capturing the phenomenon that the researcher must try to understand, as the central characteristic, which describes an aspect of the structure of the lived experience (van Manen, 1990). To uncover or isolate the theme, some approaches, as suggested by van Manen (1990), were used to identify the preliminary theme such as: the holistic or sententious approach, the selective or highlighting approach, and the detailed or line-by-line approach. All steps were performed in order to keep close to the meaning of the original data from the participants.

In the holistic or sententious approach, the researcher focuses intensely on the transcribed interviews to gain an overall sense of the meaning of the text as a whole. In the selective or highlight approach, the researcher uncovers a central, defining sentence or sentences of the text that relates to the stroke survivors through reading a text several times with care. These statements are then underlined. In the detail or line-by line approach, the researcher looks at every single sentence carefully to find the most important sentence(s) of the stroke survivors (van Manen, 1990).

All of these approaches were performed in this study, in order to keep as close as possible to the meaning of the original data from the participants. After a preliminary theme was identified, the researcher returned to the stroke survivors to check the appropriateness of the researcher's interpretation, and be sure that his findings truly reflected the stroke survivor's experience. After this validation, the researcher would amend his report by adding or deleting information based on his new insights, all of which then became part of the final data.

A similar process was followed for every subject, and then the researcher compared and contrasted the various themes from each participant, and then began the process of grouping the themes according to revealed similarities – and again, these findings became a part of the final data set.

After the themes from all participants were identified, the themes were grouped into clusters, and the researcher identified related groups of themes within various branches (van Manen, 1990). Finally, the results were integrated to yield a composite description of the lived experience of stroke survivors.

Trustworthiness of Data

- 1) Credibility: to establish credibility in this study the researcher used various techniques such as built up relationship, participant checks, and researcher credibility verification. The researcher built up the relationship with the participants and their family members. This activity was beneficial to enhance trust to the participants during collecting data. The researcher also was careful to foster trust in all relationships, and maintain contact with the participants beyond the study time in order to gain a more complete understanding of the patterns of life of the participants. Another technique, the researcher had the participants themselves check the data and data findings after the themes were identified, with the researcher and the participants meeting together to discuss the findings and interpretation of the data. In addition, the researcher performed declaring the background of the researcher (who had been staying at west Java province for about 31 years, and at Bandung for about 13 years; had had experience as a nurse for about 10 years, as a practitioner or practicing nurse for 5 years, and as a clinical nurse educator for 5 years related to medical and surgical nursing; had a structural understanding of the culture, language, and views of the group under study; and had training and practice concerning in-depth interviews related to phenomenological study with his advisors).
- 2). Transferability: the researcher provided a "thick" description of the research setting, in the context of lived experience of stroke survivors in Indonesia, including this in the study so that those who were interested could apply the data to other settings that shared a similar background.
- 3) Dependability: to establish dependability in this study, the researcher performed certain steps after the data was collected from the participants; the

researcher provided the data to two advisors for auditing, and their results were compared with the researcher's results.

4) Confirmability: to make the data interpretation was objective or neutral, all interviews were recorded on a tape recorder. And finally, the researcher asked two advisors to review the data and to audit the findings of the study to ensure that the data and findings were objective or neutral.