CHAPTER 3

RESEARCH DESIGNS AND METHODS

A review of literature indicated a need for exploration of family with long-term caregiving for stroke survivors. This study intended to explore families regarding their experiences in providing long-term care for stroke survivors at home in Chiang Mai. Consistent with the objectives, a qualitative approach based on naturalistic inquiry was used.

Methodology

The study focused on human experiences. Qualitative methods were applied as they provide a wide range of family experiences including multiple perspectives and realities (Daly, 1992). In addition, the natural context of families, such as family's interaction, environment, living patterns and other social contexts were important to generate rich description of families' experiences in providing care for a long-term stroke survivor in the context of Chiang Mai. Therefore, an ethnographic approach was chosen as the methodology for this study.

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Ethnography

Ethnographic approach has been described as " the art and science of describing a group or culture." Instead of seeking out the unusual, the researcher concentrates on the daily routine of people and allows for multiple perspectives of reality to be examined and interpreted (Fetterman, 1998). In addition, ethnography focuses on the culture and therefore is the only research method whose sole purpose is to understand the life ways of individuals

connected through group membership (Strubert & Carpenter, 1999). Thus, ethnography is a means to provide a thick description and analysis of how people live their lives within the context of their culturally constituted environment (Muecke, 1994).

Ethnographic traditions share many common features. They are grounded in a commitment to the first-hand experience and exploration of a particular social or cultural setting on the basis of participant observation (Atkinson, Coffey, Delamont, Lofland, and Lofland, 2001, p. 4). In addition, ethnography is viewed as contextual and reflexive: it emphasizes the importance of context in understanding events and meanings (Savage, 2000). In the other words, an emphasis of the ethnographic approach is on conducting research in the natural setting. Ethnographic approach can be applied to healthcare issues in numerous ways. It has been seen as a way of accessing beliefs and practices, allowing these to be viewed in the context in which they occur and thereby aiding understanding of behavior surrounding health and illness.

Through ethnography, the researcher was able to capture experiences of families with long-term stroke survivors within the context of Chiang Mai. Thai culture, social norms, and Buddhist beliefs were therefore an important influence on all aspects of the family members' lives; it guided the ways in which family members viewed and ultimate their life. Traditionally, Thai families lives as an extended family, with several generations often under one roof, or within the same compound. The basis of Thai customs and traditions lies within the family. As a child, Thais learn behaviors that guided him/her throughout his/her life, including the responsibility of caring for aging parents. Most Thais are Buddhist, thus they are very tolerant of anything and anyone and believe they receive justice (good or bad) in the next life as a result.

Consequently, to understand experiences of Thai families and the ways they manage their lives, it is important to consider the cultural context, which the families constituted. Ethnography was appropriate for this study because the research questions focused on human experiences. It provided the way to study every day lived experiences of families in providing care for a stroke survivor at home.

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Instruments

Researcher as an Instrument

"Researcher is a key and primary instrument" is one of six characteristics that are central to ethnographic research (Streubert & Carpenter, 1999). Thus, the researcher served as the primary instrument of data collection in this study. In order to illustrate credibility of the instrument, it was essential to briefly describe my background.

I am a thirty-four-year-old Thai single woman, who grew up in a middle-class Buddhist family. In 1991, I graduated with a Bachelor of Nursing degree from The College of Nursing, The Thai Red Cross Society, Bangkok and then worked two years on a delivery unit at Somdej Phraboromarajathevee at Sriracha. Since 1993, I taught at The College of Nursing, The Thai Red Cross Society while earning a master's degree in adult nursing from Faculty of Nursing, Mahidol University.

My scope of practice includes a variety of chronic diseases including a stroke. My experience has found that a stoke affects the entire family. As such, the family dynamics are altered especially those who care for long-term stroke survivors. Among Thais, obligation to care for ill family members is valued. Thus, handing this responsibility to other is rarely considered.

I had a good opportunity to study in The International PhD. Programme in Nursing at Faculty of Nursing, Chiang Mai University. I learnt and spent a part of my life in Chiang Mai Province. A pilot study aimed to explore family caregivers' experiences on caring of stroke survivors at home was conducted. The findings revealed that families provided care with love, and appreciation rather than a sense of stress due to obligation. However, health care services often provided care only during the first three to six months following a stroke. Consequently, the family dynamics remained uncertain, but without proper health care services. Therefore, I came to realize that medicine helped stroke patients to survive but limited their formal health services in the months that followed.

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Hence, my interest was in conducting research to explore the experiences of families caring for long-term stroke survivors in Chiang Mai. The findings from this study hopes to provide health care professionals gain insight into their lived experience and ways to support such as these families.

To improve the reliability of myself as an instrument, I studied the culture of Chiang Mai through readings, radio, and familiarity of the language. In particular, I gained confidence as a reliable instrument through experts in Lanna culture; Professor Manee Payaomyong, Associate Professor Dr. Narujohn Iititeerajarus, and Dr. Phra Mahar Boonchauy. Importantly, I felt confidence to be a good instrument for my research. Additionally, to improve skills in observations, writing field notes, interviewing, and data analysis, a preliminary study with one native Chiang Mai family caring for a stroke survivor for ten years was conducted. My research began with having conducted this research.

Other Ethnographic Equipment

Notepads, computer, tape recorders, and cameras were used in this study for data collection. Researcher recorded notes from interviews during and after each sessions, sketched physical layout of the family environment and gleaned impressions and detailed conversations between the researcher and family members. Tape recorders allowed the researcher to engage in lengthy informal and in-depth interviews with all participants. A camera was used to capture photos and behaviors that were used during analysis. However, four families were uncomfortable having photos taken. Of these, two claimed that the stroke changed the survivors' physical appearance and thus refused to have their picture taken. The other two families felt that their home environment was too dirty and so they, too, refused to be photographed.

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Population and Sample

Selection of Study Participants

The researcher considered family members who cared for a survivor at home. Further, data were obtained from at least two other family members in each family as their experiences were expected to vary. Criteria for participants selection were:

1. "family" caring for a family member who survived a stroke for more than a year,
2. having experiences regarding caring for stroke survivors in the family at home in Chiang Mai Province, and may or may not live in the same household with the stroke survivors
3. able to communicate in Thai with the researcher, and
4. willing to participate in this study.

A stroke survivor was a person who had survived from a stroke and lived with disabilities that required additional care from the family at home for at least one year. The time of one-year post stroke was selected based on the fact that optimal recovery of physical function should have been achieved and both stroke survivors and their families should have adjusted to the acute event and resettlement after a period of rehabilitation. Long-term stroke survivors vary in their level of condition, so that, the lived experiences of families differed.

Purposive sampling combined with snow-ball technique were used in this study in order to create a pool of potential research families. The process began by reviewing a list of stroke survivors and their families from retrospective medical charts identified by the staffs of The Special Health Care Center of Faculty of Nursing, Chiang Mai University, rehabilitation and medical wards at Maharaj Nakorn ChiangMai. Twenty-five participants were listed contacted by telephone and then visited at their home. Of these, 11 families were excluded due to death during study (1), unable to be contacted (1), refused to

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participate (1), a survivor lived with only one family member (2), and inappropriate for home visits (6). Thus, fourteen families participated in the research.

Selection of the Research Setting

The setting for ethnography includes anywhere that provided cultural context to their life experiences (Germain, 1993). Chiang Mai province was chosen as the site for this study because it represented a mixture of both modern and traditional Thai society. Its inhabitants represented typical Thai families unlike those in Bangkok who are very modern. Chiang Mai is located in northern Thailand and was also the former capital of the Lanna empire. Its area is about 20,107 kilometers with a total population of 1,600,850 persons; male 791,537, and female 809,313 (Institute of Population, Department Local Administration, 2000). Of the provincial population, more than 200,000 lived in Chiang Mai city and a further 150,000 in its peri-urban fringes. Most of the population in Chiang Mai was Buddhists.

For this study, ten families were located in Muang District, three in Hang Dong District, and the other family lived in Mae Rim District. Participant observations and interviews were generally conducted at the participants' home for convenience. However, field visits also included places that participants were active such as a Buddhist temple, office, park, mall, or health care settings. These settings provided a natural environment for the researcher. Some participants were uncomfortable during formal interview at their home. Consequently, other options for interview were given, for example one was interviewed in a quite room at her office, while another was interviewed at a coffee shop.

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Data Collection Procedure

Gaining Access and Recruitment

Introductions and purpose of study was made to each family explaining that I was a nursing student at Faculty of Nursing, Chiang Mai University. Consent form was given to each participant. However, most people refused to sign as they were unfamiliar with this type of procedure but all eventually gave verbal consent. Family files were conducted. Participant's names were codified for protection of privacy and assigned a serial numbers of 01 to 14. Weekly home visits were made until trust was established. During these visits, the researcher participated in some activities with the families for learning and observing the basic life style such as their language, the family ties, basic structure and function of the culture under the family. Once a relationship was formed, data collection began.

Data Collection

Astedt-Kurki, Paavilainen, and Lehti (2001) suggested that a useful way to add more depth to data was to interview families on several occasions or to use different methods of data collection. Therefore, several methods for gathering data were employed in this study to achieve the study's objectives, including participant observations and in-depth interviews.

The participant observation was used to describe the context within and out of families. Observation began once rapport with participating family members was made. General observations were made before focusing on caregiving. The researcher situated myself as a nursing student intent to learn the family's life with providing long-term care for their stroke survivors at home through observations. Many observations involved caring activities such as helping primary caregivers prepare blenderized diet for the survivors,

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move the survivors in bed or to the toilet, flush after the survivors' elimination, suction, exercising and so on. Family members often asked for explanation of survivors' medications, exercise methods, and about the disease in general. All families were observed at least once during their everyday activities. Field notes were taken during observation, interviews, and in the field.

Demographic data of each family was obtained including age, sex, marital status, religious belief, occupation, income, history of illness, and relationship between family members and stroke survivor. Data for stroke survivor included type of stroke, length of survival time, and impairments resulting from stroke. Informal interviews were conducted with each family on several occasions. The researcher invited participants to tell their experiences in caring for stroke survivors, beginning with the question "what happened on the day your family member had a stroke?" Interviews then changed to focus interviews (Appendix B), which covered a sequence of life events until the time of interview. Interviews times were arranged at the participants' convenience. All participants gave permission to be recorded on tape. All interviews covered all topics in the interview guide, but sequence of questions varied. Second or third formal interviews were requested if data from the initial interview needed clarification. Interviews ranged from one to two hours and were transcribed verbatim as soon as possible following each interview. Data collection continued until saturation or no new information was being offered from the participants. Finally, participants gave feedback about the accuracy of the findings.

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Data Analysis Procedure

Throughout data collection, ethnographers are required to analyze data that helps structure later encounters with the social group of interest (Strubert & Carpenter, 1999, p. 161). Therefore, data analysis occurred throughout data collection. Data analysis began with a general review of all data sources. During the phase of analysis, the researcher worked with data from all sources. Transcriptions of data were processed in Thai first. All

transcripts were read in their entirety in order to become immersed in the data. The researcher selected data by reflecting the purpose of the study and the conceptual framework. Spradley's analysis method (1985) was applied. It has identified as making a domain analysis, making a taxonomic analysis, and making a componential analysis. Finally, coding was done by hand.

Making a Domain Analysis

The first step in analysis is to do a domain analysis. In this study, data from each family were initially reduced and identified word codes. Generating domain analysis led the researcher to ask additional questions and make further observations to explore the experiences of the family. The domain categories were identified and then returned to the families to discover their specific behaviors and activities. Word codes were clustered into categories and subcategories, according to similar properties or relationships.

Making a Taxonomic Analysis

The taxonomic analysis requires a more in-depth analysis of the domains than domain analysis. The researcher searched for larger categories to which the domain may belong, looked for relationships in order to identify similarities and contrasts among each participant, other participants and families. Based on these new categories, additional observations, asked or interviewed more questions were made.

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Making a Componential Analysis

The last step is a systematic search for attributes associated with cultural categories. During this stage of analysis, the researcher sought units of meaning by examining each family and its component parts. Looking for missing data was performed

in this stage. In this process, the researcher searched for contrasts, sorted them out, and then grouped them based on similarities and differences. This analysis provided important information regarding the experiences of families caring for stroke survivors.

Continuous analysis allowed emerging categories to be added or modified. This repetitive process was carried out until each data fit into a category or categories. All data analyses were first conducted in the Thai and then carefully translated into English. A native English speaker, who was also familiar with Thai culture and the context of Chiang Mai Province, approved the translation of data.

Protection of Human Subjects

Lipson (1994) (as cited in Strubert & Carpenter, 1999) suggests that ethnographers protect their study participants in five ways: (1) inform participants fully about the matter to which they are consenting, (2) inform participants they can withdraw from the study at any time for any reason, (3) reduce all unnecessary risks, (4) ensure that the benefits of the study outweigh the risks, and (5) ensure that the researcher who will be conducting the study have appropriate qualifications. As such, this study followed these guideline in order to protect all participating family members.

In this study, initially, to ensure that there was no harmful point in this research that might effect to participants, committees carefully approved this research proposal. Approved by the Institutional Review Board (IRB) of the Faculty of Nursing, Chiang Mai University was received before conducting the study. All potential participants were informed about the study as well as benefits for participating. The participants were assured that they had an option of withdrawing from participation at any time without any consequences. They were also assured that their rights of anonymity and confidentiality would be protected. Emotional distress did not happen in the time of study. Pseudonyms were used and all transcriptions and tapes were kept in secure files and safe places in order

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to protect the confidentiality of participants. When the study was completed, all materials such as tapes, transcriptions, and codebooks were destroyed.

Trustworthiness

In order to establish trustworthiness of the findings, bias needed to be controlled. Trustworthiness of data and interpretation of the study involved four categories: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Triangulation was achieved for credibility through the use of different sources of data and individual checks. Transcripts were taken back by the researcher to the participants for data verification. Moreover, the researcher worked with all family in their natural settings to establish rapport and to observe behaviors. The researcher spent at least 2-3 hours per visit. To ensure transferability, the researcher provided a thick description, which referred to the fact that the participating families presented their experiences in detail, context, and emotion in their natural setting. To attain dependability and confirmability, the analysis process was reviewed by a group of experts and approved by the advisory committee. Data analysis and research process were discussed as frequently as possible to enhance dependability.

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