CHAPTER 3

METHODOLOGY

The aim of this study was to develop a better understanding of the perceptions of families regarding the child's illness and treatments and the practices of families in caring for children with CHD prior to cardiac surgery, as well as to explore how the socio-cultural context influenced the practices. Focus ethnography was employed as the methodology to achieve the objectives of the study. This chapter presented research methods used in this study. It included research design, setting, informants, instruments, data collection procedures, ethical consideration, data analysis and trustworthiness of the study.

Research Design

Interpretive paradigm served as a philosophical base for this study. The heart of this approach lies in the social construction of realities (LeCompte & Schensul, 1999). The researcher's personal experience is viewed as a basic part of the construction of the social world (Maanen, 1995). The interpretive approach relies on the participation or meaning systems of researchers and participants in constructing reality, as negotiated meaning cannot occur unless the researcher is a full participant in the process (LeCompte & Schensul, 1999).

This study focused on the construction of how Thai families perceive, and practices related to culture. The patterns of practice were different and shaped by the families' cultural beliefs and values, and their socio-cultural context. Parents' and families' understanding of their child's illness and their response to the child's cardiac treatments varied. Importantly for this study, culture informed care practices, so it was important to understand issues of culture as parts of understanding families' practices. For example, culturally prescribed gender roles inform patterns of the practices of family. Culture also shapes how families with culturally-specific beliefs about health and disease care for their child (Roper & Shapira, 2000). According to McCurdy, Spardley, and Shandy (2005), culture is "knowledge that is learned and shared and that people use to generate their behavior and interpret their experience." In order to understand the meaning of behaviors, the ethnographer focuses upon the contextual and holistic perspective (Boyle, 1994). Therefore, ethnography is the most appropriate method because the research questions focus on human experiences. It provides the way to study every day lived experiences from the emic point of view, or native's perspective of reality, and considers the culture and social elements of the families.

Ethnography has a focal concept of culture (Germain, 1993; Roper & Shapira, 2000). It is "an approach to learning about the social and cultural life of people, community, and institutions" (LeCompte & Schensul, 1999, p.1), peoples' worldview, social behavior and way of life (Boyle, 1994; Germain, 1993; LeCompte & Schensul, 1999; Roper & Shapira, 2000). This approach which requires intensive face-to-face contact over an extended period of time (Roper & Shapira, 2000), employs the method of participant observation, which is the hallmark of data collection in ethnography. Understanding families' practices cannot be separated from their broader social, political, economic, and religious context. Individuals, groups, social institutions, history, economic, and political factors, as well as physical environments, are an integrated whole, influencing the behavior and beliefs of individuals (LeCompte & Schensul, 1999). We cannot separate human behaviors from the contexts in which they have meaning and purpose. Instead, we need to collect data from multiple sources and prolong direct contact with people in the group to understand the context of individuals' practices (Boyle, 1994; Morse & Field, 1995). The ethnographic perspective allowed the researcher to investigate and examine all aspects of day-to-day practices of Thai families from their point of view, including their cultural beliefs and social organization. Of special concern was how cultural beliefs and values, and social institutions such as family structure, gender roles in the family, or the health care system influenced Thai families regarding their child's care. The ethnographic method of participant observation let the researcher observe actual practices in context, as well as provided opportunities to ask descriptive questions using in-depth interviews about the practices and the perceptions associated with those care practices. The method was crucial for studying social situations by allowing researchers to study shared knowledge and to inquire about people's behavior, customs, or emotions (Spradley, 1979), while learning the underlying meaning of those behaviors.

This study was labeled as "focus ethnography," as the intent was to concentrate efforts on very specific questions, selected behaviors, and their meanings among a specific group of people (Muecke, 1994; Roper & Shapira, 2000). Focus ethnography is a problem-focused and context-specific study (Morse, 1987). This type of ethnography shares with classical ethnographies a commitment to conducting intensive participant observation within the natural setting, asking questions to learn what is happening, and using other sources of information to gain an understanding of people and events of interest (Roper & Shapira, 2000).

Focus ethnography was employed for this study for two reasons. First, the study explored a very specific question: patterns of practices of families in caring for children who diagnosed with CHD. In addition, a small number of families of children with CHD were presented in an area of demographic interest, such as a hospital or a community. The families' residences were spread throughout Bangkok. They were linked by hospital sites rather than a place of residence. Even though families lived in different places around the study setting, they shared behavioral norms and a common language that they had developed through their experiences of caring for their child with CHD. Second, participant observations were limited to particular events and times, namely, caring for a child with CHD prior to cardiac surgery, which was uncommon in the general course of events of the informants' daily lives. Therefore, the focused ethnographic study could provide the researcher the opportunity to gain a better and deeper understanding of practices of families in caring for a child with CHD while waiting for surgery. Moreover, using the focus ethnographic method helped the researcher uncover cultural patterns of belief related to the families' perceptions regarding their child's illness and treatments, their caring practices, and how the socio-cultural context influenced the families' practices during the course of illness.

Research Settings

The settings for ethnography can be anywhere that people have cultural activities that engage their health and well-being and that provide context to their life experiences (Germain, 1993). Field settings were the places that the informants did their activities and allowed the researcher to go along. The researcher tried to be in families' natural environments as much as possible. In this study, field settings included the informants' homes and health care settings, as those settings provided the researcher opportunities to be in the informants' natural environments and to learn how families practiced in caring for their child as much as possible.

Two university hospitals were selected for this study because they had large pediatric cardiac centers for serving children with CHD who lived in Bangkok and throughout the country. The first University Hospital, Hospital A, had 2,199 beds, where 294 beds were for pediatric patients. There were 250-300 walk-in pediatric patients per day, or 97,547 per year (Informal data, Annual Statistic Report, Department of Pediatric, Hospital A, 2008). In the year 2007, 2,686 children with cardiovascular disease visited the pediatric cardio clinic (Informal data of Pediatric Cardio Unit, Hospital A, 2008). The second University Hospital, Hospital B, had 980 beds, where 115 beds were for pediatric patients. There are 240 to 250 walk-in pediatric patients per day, or 24,070 children per year (Annual Statistic Report, Hospital B, 2008). In the year 2007, 1,445 children with cardiovascular disease visited a cardio clinic there (Annual Statistic Report, Pediatric Cardio Unit, Hospital B, 2008). At Hospital A, 60-80 children with cardiovascular disease usually visit the pediatric cardio clinic every Tuesday morning, while 40 to 60 children come to the clinic of Hospital B every Monday afternoon. Children with CHD who visited these clinics were from many parts of Bangkok and some were referred from other hospitals that had less potential to treat children with CHD. Most children were referred for cardiac investigations and surgery.

There are two teams of physicians who generally provide treatments for children with CHD. The first team, pediatric cardiologists, prescribes medications before surgery, while the second team, cardio-vascular surgeons, provides surgical management, including cardiac surgery and/or medications after surgery. After the children receive cardiac investigations including echo-cardiogram and/or cardiac catheterization, if they are diagnosed with CHD they mostly require surgery. During the wait for surgery, some children may be admitted to a pediatric infectious ward and/or a cardio-vascular ward due to complications such as pneumonia and/or congestive heart failure. After undergoing surgery, the children receive post-operative care at the pediatric cardio-vascular ward until discharged. The researcher decided to follow the children all of the above mentioned areas that involved families of children with CHD in both hospitals.

The researcher recruited eight families from Hospitals A and B (seven from Hospital A, and one from Hospital B) when the parents took their child to visit the pediatric cardiologist at the cardio clinic following a schedule. Sometimes they took the child to the hospital without an appointment because the child had a fever or upper respiratory tract infection (URI). The researcher usually came to meet them once they arrived at the OPD and accompanied them in the whole processes in the hospitals, including meeting with the physician, and receiving medications as well as receiving an appointed card. During the period of data collection, the researcher visited the parents at the pediatric wards when their child was admitted due to pneumonia, and/or other purposes such as cardiac catheterization. The researcher also accompanied three families when their child underwent cardiac surgery.

The main study setting was informants' homes. They stayed in seven Bangkok districts including Bangkok Noi, Bangkok Yai, Pasrichareon, Thonburi, Sai Mai, Prakanong, and Hauy Khwang. The participant observations and interviews generally took place at the informants' own homes. The researcher spent time with them at home mostly during the daytime to understand their daily activities relating to the practices in caring for the child with CHD.

Research Informants

As this study was concerned with the practices of Thai families in caring for a child with CHD, a purposive sampling process was initially applied at a cardio-clinic and general pediatric wards of both hospitals.

The inclusion criteria for the informants were: 1) they were the parent(s) and/or a family member who had direct experience in caring for a child, who was aged 0-3 years, with symptomatic CHD, acyanotic or cyanotic type and received ongoing medical management, and were followed through the pediatric cardiac clinics of Hospital A or Hospital B, and would receive cardiac surgery, and 2) at least one parent had lived with the child with CHD. Family members were blood relatives, relatives by marriage, or acquired kin who were identified by the parents as a person who took part in caring for the child.

Informants were excluded from the study if the child had chromosomal and/or neural abnormalities. The informants of a child who had been admitted for cardiac surgery prior to the study period were also excluded from the study, as the researcher required an opportunity to learn about their practices of caring for the child awaiting surgery when they were at home. The researcher did not exclude informants whose child was admitted to the hospital due to complications or cardiac catheterization. Rather, the researcher could observe how the informants took care of their child during hospital admission.

In this study, key informants were considered to be the parents (mothers and/or fathers) and/or one family member who had direct experiences in caring for the child, willingness and time to participate in the study, and ability to tell their life histories through reflection on their experiences. General informants were referred to as close family friends, neighbors, relatives, who were involved in the family. They were important to the family because they helped or supported parents in other ways, such as through financial, psychological, or information support. In this study, more than ten neighbors shared their views regarding the practices of families in caring for the children.

There were some difficulties of finding potential participants who met the criteria at the pediatric cardio clinics and the pediatric wards of Hospital A and B. Many children had Down’s syndrome, or did not take medicines while awaiting surgery, and thus could not be included. The researcher then started to review a list of children from medical charts identified by the cardio clinics. When she found the children who met the criteria, she called the parents and asked for permission to meet them at the hospitals or at home. They all agreed to participate in the study at the first time of meeting with the researcher.

During the first three months, the researcher found only four informants from three families. Because of the complexity of the task in interviewing and observation as well as transporting, it took a considerable amount of time for each visit, especially because the researcher had to expand field notes before proceeding to other informants. When the researcher gained skills in data collecting, she gradually increased the number of informants. As a result, by the end of October 2007 (the 13th month of field work), 11 families were contacted and the researcher stopped acquiring informants. Of these three families were excluded for particular reasons: the child died in the initial phase of collecting data (one), they refused to participate due to difficulties in their families and could not be contacted after their child was discharged from the hospital (one). Visiting one family raised problems of safety because the house was some distance from the main street, so, although the parents did not deliberately withdraw for the study, the researcher decided not to include this family.

The final sample of informants of the study comprised of 14 key informants from eight families (13 key informants in seven families from Hospital A, one family from Hospital B) with eight children with CHD, four acyanotic and four cyanotic types. A total of 12 informants were parents (eight mothers, four fathers), whereas the remainder were one grandmother (mother's side) and one maternal aunt. Three of 14 informants were born in Bangkok, while the others had come from various parts of the country to work in Bangkok more than 10 years. They were able to speak and understand Thai, able to articulate their experiences, and willing to participate in the study. Particularly, they were the persons in whom the researcher had confidence regarding the validation of data.

Developing trust and relationship with possible informants during the initial period enhanced the process of acquiring informants. After introducing herself and simply explaining the aims of the study to the potential informants, the researcher told them that they may not directly benefit from the study; it was hoped that other families with CHD children would benefit in the future. Then the researcher asked them whether they were willing to participate to the study. At the first contact, none of them refused to participate. During the initial contact, some were shy and did not talk about their stories, but when trust and rapport was developed they provided fruitful information.

Research Instruments

The principal methods to collect data included participant observations and interviews. In addition, field notes in a personal field journal recorded what the researcher saw, felt, and reacted to, along with her insights about the research gleaned during the process. The main instrument of this study was the researcher, who served as data collector. For supplement instruments of the study, various types of data were collected by using the following techniques and instruments: demographic data sheet, interview guide, observational guide and other ethnographic tools including notepads, computer, tape-recorder, camera, paper and pen. Notepads and pen were the most common tools for ethnographers (Fetterman, 1998). These useful devices facilitated the researcher's collection of and completion of data by capturing rich details, and organizing and analyzing the data.

Researcher as Instrument

As ethnography requires an interaction between the researcher and informants to obtain data, the researcher served as the primary instrument of data collection through interviews, observations, and field notes on cultural information (Roper & Shapira, 2000). In order to present her credibility as a research instrument of data collection, and as part of the reflexive perspective, the researcher provided her background and worldview for readers to see up-front who she was, and what her biases and worldviews were. In addition, the information could ensure the readers for the researcher's qualification to conduct this ethnographic study.

The researcher was a forty-six-year-old single Thai woman. She was born and grew up surrounded by warm family ties in Prachin Buri province in the eastern part of Thailand; two hours drive from Bangkok. Her family was a middle class Buddhist family. She came to study in Bangkok at the high school level and has been living in Bangkok for 30 years. The researcher graduated with a Bachelor of Science (nursing and midwifery) from the Faculty of Nursing, Mahidol University. She had experience working as a nurse in a pediatric cardio-vascular ward for 16 years. Her main practical area involved with cardio vascular children with CHD. While working as a nurse, the researcher earned her master's degree in administrative nursing from Chulalongkorn University. Four years after graduating with the master's degree, the researcher transferred to be a nursing teacher at the Department of Pediatric Nursing, Faculty of Nursing, Mahidol University. Currently, the researcher has worked as a clinical supervisor of nursing students with experience in the area of pediatric cardio vascular ward and pediatric infectious wards. According to her work experiences, the researcher realized that families had some difficulty regarding caring for the children. Particularly, families had more stress regarding the children's diagnosis and uncertainty during the period preoperative phase. Even though nursing intervention about the children's care was provided to families, the children usually had complications prior to surgery. She had questions regarding problems related to child's care when they were at home.

The researcher began to be interested in families of children with CHD when she conducted preliminary research about perceptions of nurses on discharge planning for children with CHD during the second year of the doctoral program. The researcher employed a qualitative method as a methodology. The results showed that most nurses acknowledged the usefulness of discharge planning; however, they could not do every aspect of discharge planning, particularly when it came to assessing a family individually and evaluating families' caring practices after discharge. While collecting data for that study, she had an opportunity to talk with many families and nurses in a university hospital in Chiang Mai. Most families were Hmong and other highland people who had their own language, which differs from Thai's. It seemed their belief and practices were quite different from those of parents in Bangkok. However, they tried to care for their child using their beliefs to care for their child in their own ways. This experience helped her to look at culture carefully, and she saw things that she never paid attention to before. The experiences from her personal and professional life inspired her to answer questions regarding what practices Thai families used in caring for children with CHD prior to cardiac surgery. Consequently, the researcher was interested in conducting an ethnographic study to explore the day-to-day practices of families in caring for CHD children living in Bangkok.

To achieve the ultimate goal of the study and to use a high qualified instrument, the researcher took two qualitative courses at Chiang Mai University, Thailand and at the University of Alberta, Canada. The study had both a theoretical and practical focus. In addition, she experienced working on a qualitative study to strengthen her skills in observation, interview, writing field notes, and data analysis. Before starting data collection, however, the researcher conducted in-depth interviews and observations with parents who had the same criteria as the informants of the study. The researcher then presented her findings to the advisors in order to improve interview questions for the further interviews with study informants. Therefore, the researcher was confident of carrying out the study. Moreover, the researcher's entire research process, from data collection to an analysis of data, was under the guidance of the dissertation committee. She thus began her dissertation with confidence.

The researcher's roles varied according to the situation, between participant-as-observer and observer-as-participant. She developed the interview questions for the first or second meeting between the researcher and informants, then analyzed and constructed specific questions related to what the informants told her. The researcher also observed and recorded information about children with CHD and their parents' everyday lives over time. Families' day-to-day practices in their socio-cultural context were the focus of her study. Her observations and interviews were broad in scope to seek out specific practices to follow up on in subsequent visits. In taking the field notes and in recording her impressions, the researcher was also engaging in a reflexive process through which her experiences were an acknowledged element of the interactions. This process was referred to as “reflexivity of the researcher,” and acknowledges that the researcher could never be an entirely neutral observer. After each interview and observation, the researcher examined her field notes and interview text to see what themes and ideas emerged from that data.

Supplementary Instruments

1. The demographic data sheet. This instrument was used to obtain basic characteristics of all children and informants. It was divided into two parts: the informant’s and the child’s information.

The informant’s information included their relationship with the child, gender, marital status, age, religion, education, work/occupation, family income, welfare, hometown, accommodation, financial status, source of financial support, and number of household family members.

The child’s information included information on age, gender, birth order, number of siblings, signs and symptoms causing parents to take him/her to hospital, diagnosis, the age when he/she was diagnosed, medications, number of hospitalizations, previous health problems and/or complications, and general appearance (Appendix B).

The researcher filled out all information about the key informants and their child at the first recruitment of informants. The researcher got the child’s information from both the parents and the child’s outpatient book and from the book received after receiving vaccinations at a primary care unit or hospital (known in Thailand as the "pink book"). Some information was not completed, so, the researcher filled it in during the first home visit or the following visit.

2. The interview guide with open-ended questions. The guide was approved by the dissertation committee and three nursing professors who had proficiency in qualitative research and family nursing (Appendix A). It was used to guide the in-depth interview regarding practices in caring for children with CHD (Appendix C). The interview guide was used at the beginning of the interview process.

Even though the interview guide was used, the open-ended questions were unstructured to let informants to express their experiences in their own words. For the study goal, the researcher allowed the informants to set the agenda and identify how they parented a child according to their own frame of reference and in their own words. The researcher wanted to learn primarily from parents and families, thus she did not use a rigid prior conceptual framework to guide the interviews that dictate the nature of variables to be collected and relationships of those variables (Morse & Richards, 2002). The interview questions thus were not designed in advance. Rather, they arose from the context of interview.

3. The observational guide. This instrument was used to guide the observations of practices of families in caring for children with CHD (Appendix D).

4. Other ethnographic tools. These tools, including notepads, tape-recorder, MP3 recorder, as well as paper and pens, were used to collect data in the study. These useful devices facilitated the researcher to collect data by capturing the rich detail, organizing, and analyzing the data. Notepads and pen are known as the most common tools ethnographer use (Fetterman, 1998). With these tools, the researcher recorded notes from the interviews during and after each session, sketched the physical layout or the families' environment, and also took down impressions and detailed conversations between the researcher and informants and between or among family members. The recorders let the researcher engage in lengthy informal and semi-structured interviews with the family without distraction of manual recording devices. It effectively captured long verbatim quotations and maintained a natural conversation flow. All informants allowed the researcher to audio-tape during interviewing.

Data Collection Procedure

Gaining Access and Recruitment

Once ethical approval was obtained from the IRBs of the Faculty of Nursing, Chiang Mai University and two university hospitals, the researcher contacted the head of pediatric cardiologists, head nurses, staff nurses, and officers in the hospital settings to inform them about the study and to ask for assistance in getting the informants. The researcher knew many nurses at Hospital A and B who helped her gain access to the settings and contacted potential participants. Some of them were the heads of the pediatric OPD. Some were nurses at pediatric wards. In addition, the researcher knew a nurse working in the cardio clinic with whom she used to work when they were at a pediatric cardio ward. The nurses gave the researcher information about health personnel and regulations of the OPD, starting from when the child walked in the OPD, through the cardio and cardio-vascular-thoracic surgical clinics, to the ward.

The researcher attended the cardio clinics on every duty day in order to recruit informants. At Hospital A, the researcher went there every Tuesday morning and every Monday afternoon at Hospital B. She also recruited the informants at pediatric cardiovascular wards and infectious wards from both hospitals. When she met potential informants, the researcher visited them every day until the children were discharged for the purpose of building trust and rapport and letting family members become familiar with her. The researcher did not want the parents to view her as one of the hospital staff, nor to show deference and timidness towards her as they usually did to most healthcare providers. The researcher considered that it might be a barrier to obtaining their viewpoints and attitudes. Thus, the researcher fully explained to the parents the nature of study including the aims and procedures of the study, the benefits from the study, duration of study, potential inconveniences, and the extent of their involvement. She also allowed them to ask her about unclear points of her study. The researcher realized that potential informants had perceptions and beliefs regarding the researcher's role, as a nurse, in their world. For Thai people, being health professionals is viewed as in a higher position. For that reason, the informants may hesitate to refuse to participate to the study. Therefore, the researcher informed all informants that they had right to refuse and ensured them that their cancellation to participate in the study would not be any effects on their child's treatment. Rather, their participation would be very helpful for other families whose children had heart disease.

Eighteen parents who met the criteria were approached. Neither of them refused to participate in the study when the researcher first contact. The researcher gave consent forms to each parent, and asked for individual signature at the first meeting, before visiting home. Neither of them refused to sign the consent forms. The parent then scheduled home visits by the researcher. The researcher asked the parent’s phone number in order to contact them to learn their family member’s decisions and clarify any questions they may have. One or two days before an appointed date, the researcher called to the parents to ask if they were available and what the best time for them.

As 18 potential informants’ homes were located in various parts of Bangkok, where traffic jams are normal, the researcher needed to well plan how she went and what time she should be out of her home. There were many obstacles for the first home visits. Some informant’s homes were difficult to find as they were located in small communities and had no house number. The average time for traveling from the researcher’s home to the informants’ homes was two to three hours by public transportation, including bus, van, express boat, motorcycle, or sky train. For the first home visit, parents identified their family members who involved in the child’s care. The parents invited those individuals to talk with the researcher; after they agreed, then the researcher explained the study to them and obtained their consent. However, some informants preferred to provide their oral consents.

The recruitment of families whose children were diagnosed with CHD was a major challenge. Even though the researcher has been in Bangkok more than 20 years, she has never visited many of the places where the families lived. To achieve further rich data, she went to families with differing numbers of family members, daily life, economic status, and social environments and norms. It took time to recruit each informant. Some informants wanted to participate in the study but their homes were not safe for the researcher, so she had to explain them about that limitation. However, she gave her phone number to those families if they wanted information about CHD and child care. The researcher had nice experiences for her home visits.

All informants usually welcomed the researcher as a visitor, even they were busy. The researcher's home visits were on different days and time depending on an informant's convenience.

Data Collection

Ethnographic study requires an interaction between the researcher and informants to gain data (Roper & Shapira, 2000). The success of the research is largely determined by the relationship between the researcher and the people to be studied, particularly during the initial contact. Throughout the study, the researcher established trust and rapport to ensure the reliability of data. Rapport was developed from the time of recruiting right up until the final meetings. The researcher made herself known to the families and attempted to develop rapport with them in many ways. Firstly, the researcher introduced herself, "I'm a doctoral nursing student. I worked in the faculty of nursing, Mahidol University. Now I'd like to visit families of children with CHD because I want to know and learn from them about the practices they usually follow in caring for the child. " As most Thai people are unable to distinguish the different roles of health professionals, the researcher was also called "mho" (หมอ=a doctor), or "khun" (คุณ= a polite word that means a nurse). The researcher was soon introduced to potential informants.

Secondly, the researcher met the potential informants at the cardio clinic and also visited them while their child was being admitted to the hospitals, in order to share their general experiences and to develop a trust relationship before visiting them at home. The researcher appeared with families during every visit at the hospital.

This enabled her to meet families, mostly parents. The researcher shared their activities while visiting the hospital. In addition, she visited families at their home, letting her meet other family members, relatives and their neighbors.

Thirdly, the researcher made no distinctions between the researcher and informants. When the researcher visited the informants at home, she usually dressed and acted casually, and also sat on the floor with the families during their conversation. Wearing long black pants and a yellow shirt featuring the king's logo made the researcher feel comfortable to talk with family members on the floor and participate in family activities. The researcher always visited informants' homes with some food, fruits, dessert etc. When informants invited her to have lunch or dinner with them, she accepted their invitation and helped them prepare food or held their child while parents were preparing food.

For the first home visit, to develop trust, the researcher also introduced herself and shared her working background to other family members. Objectives of the study were clearly explained to the family. She allowed the informants to ask questions about the study. The researcher reminded the informants about her real status as a researcher, and that such status would limit her role of providing health information. She confirmed informants that she was not a home visiting nurse, but rather a student who wanted to learn from them about the child care. In this way the informants felt comfortable to talk to her, and told their stories as much as they wanted. In addition, the researcher asked for permission to record interviews by tape cassette or MP3. Formal and/or informal interviews were recorded.

Home visits were conducted regularly with each family for establishing rapport, at least twice a month, at a variety of times and days. As the relationship developed, and the family members actively started telling their stories regarding caring for their child, data were gathered. When she arrived at the informants' home and found that the informants were doing their housework or working, she told them not to stop. The researcher did not want her home visit to interrupt family activities as she wanted to learn how the informants cared for the child in their daily life. She tried to participate with them in many activities relating to the child such as feeding, changing diapers, or holding a child. The topic of conversations in the first visit was general according to the situation or the activity of the informants at that time, for example, "How are you doing?" or "What are you doing?" The researcher took time in those conversations until the informants felt relaxed. Then, the researcher asked for personal information and the child's informant to complete a Demographic Data sheet.

In this ethnographic study, the researcher employed two methods of gathering the data to achieve the study's objectives, including participant observation and in-depth interviews.

Participant Observation

Participant observation was a crucial method to study social situations to gain cultural context and observe the field of the study (Germain, 1993). Observers conduct observations for two reasons: to actively participate in social situations, and to observe how people act in each situation (Spradley, 1980). In this study, participant observation was the main method applied to gain the data regarding the daily practices of families. Participant observation ranged between participant-as-observer and observer-as-participant due to situations (Roper & Shapira, 2000). According to four levels of participant observations (Fetterman, 1998), in this study, the researcher's roles were the observer and observer-as-participant. Spradley (1980) categorized participant observation into five types related to the degree of involvement of the researcher: nonparticipation, passive participation, moderate participation, active participation, and complete participation.

In this study, the researcher engaged in different types of observation related to the situations she observed. When the researcher observed doctor-parent interactions, she was a passive participant. The researcher stayed at the back of the room or in front of the room in order that she could see and hear their conversation. She tried to minimize her influence by normalizing her presence as much as possible, and did not involve herself in doctors' and parents' conversations. She tried not to create any change in their interaction. The researcher was a moderate participant when she observed her colleague's interaction with parents and engaged in activities to make herself useful in the pediatric wards. The researcher was there to observe parents interaction with other parents and nurses. Sometimes the researcher had to engage to their conversations as invited by parents or nurses. The researcher became an active participant when she engaged in informants' activities in their home such as preparing food, helping informants hold the child, having lunch with informants, and so on.

To be familiar with parents and others in the family to perform subsequent observation, the observations moved from a focus on the general environment and general daily activities to seek out specific practices. The researcher participated in the lives of the family; learned the nature of the family's language, kinship ties, relationships etc.; and saw the functions of the culture, and patterns of family's practices in caring for their child over time. However, the researcher maintained a professional distance that allowed adequate observation and records of the data (Fetterman, 1998).

Participant observations were conducted during various times—in the morning, afternoon, and evening—in order to cover all activities. As the researcher could not stay with the informants overnight in their home, she observed and participated in family's daily activities as much as possible, such as during food preparation or during their meal. The researcher went to each informant's home between 4 to 6 times over thirteen months, not including visits for establishing rapport before collecting data. During the first ten months, the researcher had 4 to 6 home visits each with the first family to the fifth family; then 3 to 4 visits with the sixth to the eighth families during the final six months of data collection. The researcher spent her time with the informants at home for roughly 2 to 3 hours per visit, depending upon the informant's convenience, in order to understand their daily practices in the family life context. Participant observations were focused on the child's physical care and psychosocial care that was centered on an individual child and was potentially relevant to the family's practices (e.g., bathing, feeding, sleeping, bowel movement, playing, parent-child interaction). The informants liked the researcher to have lunch or dinner with them at home. The researcher accepted their invitations if it was their routine activity and the researcher offered to pay for the meal or brought some foods, desserts, or fruits for them.

To observe and participate in all activities related to the child's care, the researcher observed clinical interactions while the parents interacted with nurses, physicians, and other families in hospital. The researcher met the informants at the hospital 3 to 8 times per family, 3 to 5 hours per meeting with eight families during the study periods over the course of data collection; therefore, she had a lot of valuable experiences with them in the hospitals. All informants were willing to have the researcher be with them when they took the child to meet a physician at the clinic. However, the researcher stayed at the back or outside of a room, but she could see the parent-child and physician's interaction as well as could hear their conversation. The researcher could learn how the parents fed their child and gave medications in social settings as the hospital. Sometimes, the researcher helped the parents take care of the child while they went to the bathroom, or contacted other health personnel in the hospitals. In addition, the researcher accompanied the informants outside the operating room during the uncertain period while their child was undergoing surgery. Thus, it was a good opportunity to talk with the informants informally, let them release their tensions and shared their feelings related to their child. Some informants usually stopped for their lunch at the market opposite the hospital after the child met a cardiologist, and were happy to have the researcher with them. Sometimes, the researcher went home from the hospital with them by bus.

Those observations were referred to in the informal interviews, to elicit perceptions of the informative elements of the event during various activities and spontaneous conversations. In that manner, key patterns or events that were relevant to the families' practices were observed, identified, and recorded as field notes.

Interviewing

When the researcher felt that the informant could feel familiar with her, the formal interview would be introduced. Before conducting the formal interviews, informal interviews were conducted with each family member on several occasions. The researcher established rapport and trust relationships by spending time with the informants and talking with them in general terms and letting them tell their life history. She created a relaxing atmosphere by using informal conversation and talked with the informants in general depending on the topics they were interested in. The researcher also reiterated that there was no right or wrong answers about their practices in caring for their child. They could only reveal what they felt comfortable sharing. The researcher talked on general issues such as "How is your child these days?"

To increase accuracy of the interview data, the researcher constructed open-ended questions using the informal language, and asked the same questions several times in different ways over the course of her field work. In the natural setting, however, the researcher could not avoid her influence on the data collecting process. Ethnography allows researchers to be a part of the natural scene and the researcher was a part of the construction of the meaning of family experiences. However, the researcher checked with an individual parent and/or family member about how the study had affected his or her family's lives. During the interviews, the researcher employed attentive and non-judgmental listening techniques.

When the informant became more comfortable with the researcher, descriptive questions would be asked. For example, concerning an interview about daily practices of a child with CHD, the researcher asked, “Could you please tell me about how you do daily care for your child? Please tell me more about what, when, and how to do those activities, and why?” The researcher tried to let the informants tell their stories. Broad questions related to the child’s illness and the practices were asked for the purpose of exploring the situation of interest, then the specific structural question (what kinds of food have you fed your child?) and contrast questions (what’s the difference between caring for your child who had heart disease and other healthy children?) were followed for making clear understanding (Spradley, 1979). From broad questions, the form of interviews changed to focus interviews, which covered the sequence of life events until the time of interview; for example, what happened and what did it feel like during the course of taking care of the child with CHD? what was life like after caring for children with heart disease at home? have such activities brought about any changes? if so, how have the informants responded and managed them? However, the questions were not be followed strictly in the same order with every participant, but all interviews covered all topics in the interview guide, which described topics of interest in this study and allowed additional room for probing. After the interviews, all information relating to the interview was immediately noted in order to improve further data collection. The interview record was transcribed in order to completely examine information received so any further questioning was structured as necessary.

After checking and analyzing data from the first or the previous interview, the researcher would know what data was lacking, then outline a plan for the next interview. Second or third interviews were requested in order to complete data from the initial interviews. The researcher also discussed with the participants about the previous interview, within which any areas of possible misunderstanding were considered. All participants gave permission for interview to be recorded on tape or MP3. Tape recording did not make them nervous or unhappy to talk with tape recording.

Most formal and informal interviews took place by the researcher at the families' home. Some informal interviews took place in the hospital while the researcher accompanied informants when they took their child to follow up at the cardio clinics or with other purposes. In-depth interviews were conducted before or after the observations to find out the reasons beneath the practices defined by the key informants. All informants expressed appreciation for her taking time with them. One challenge of the interview was interviewing all family members together. However, the researcher could not conduct this interview with every family. Each family was interviewed formally 2 to 4 times. The duration of each interview ranged from 60 to 120 minutes. Time of interviews was arranged at the participants' convenience, sometimes occurring during the weekday or on weekends. Data collection was continued until saturation; that is, until no new information was being offered from the informants and the data were repeating.

Over the course of the study, the researcher had lots of phone conversations with all parents, at least 10 phone conversations per family and got huge amounts of information this way. The researcher used the content of telephone interviews as part of her data. While talking with the informant via telephone, the researcher took field notes about their practices and their feelings related to their child's illness, treatments, and especially their child care. These data were added to the transcription of interviews and other field notes she took from observations. Even though the researcher finished her data collection, she kept in contact with the informants by phone. Some informants called her to talk about the child or ask about the child's caring practices. They still met each other when the informants took the child to follow up at the hospital. It was a privilege that families allowed the researcher to be a part in their life. During talking with the parents via telephone, the researcher took field notes and then added that information to the information from interviews and participant observations.

Field Notes

Recording field notes was one of the methods for data collection. When associated with participant observation, field notes are "descriptive accounts in which the researcher objectively records what is happening in the setting" (Mayan, 2001). Field noted should describe the researcher's reflections, feelings, ideas, moments of confusion, hunches, and interpretations, etc. about what is observed (Morse & Field, 1995). Field notes reflected informants' actual practices, their feelings, and meaningful context over a period of observation and participation in each family. In addition, they were records of the researcher's personal biases and assumptions about the study that influenced the study.

Throughout the data collection, the researcher wrote field notes during and/or after the events as soon as possible to minimize the potential of memory loss, within 24 hours of the observation if possible. After leaving the informant's home, as soon as possible the researcher found a closed private place to take short notes, write maps or drawings about what she saw, heard, felt, or about occurrences relating to child care. These notes serve as reminders of the observation when the researcher made an expanded and permanent record of the day's event. When she arrived home, she wrote the field notes as the permanent record in detail and as literally as possible to describe the lives and social and cultural context of each family, and what occurred during the interviews.

The researcher organized her field notes for ease of use throughout the study. In each field note, the researcher identified each page according to the location, date, time of the observation, and the number of interviews. On the rest of the page, the researcher recorded detailed observation leaving a wide margin in which to note comments, reflections, points to remember, etc. (Morse & Field, 1995). In addition, recorded conversations, descriptions of the context and environment, including the occurrence of unexpected events and nonverbal behaviors of participants were recorded. (Appendix J)

The researcher recorded field notes on paper every day in order to note and obtain more information, and to reconstruct the interviews of key informants. The researcher kept the field notes and used them to provide the context and background for data analysis (Mayan, 2001). Field notes, thus, were used to supplement other forms of data collection. Field notes from observation were written up daily.

Supplementary Data Sources

To supplement the data, existing documents were reviewed, including the child's medical chart, the outpatient record, and the health book. Other available data sources included the child's body weight, medical diagnosis, treatments, other health problems, follow-up information and/or history of hospital admission. The researcher examined supplementary data sources from the beginning to the end of the data collection.

Leaving the Field

This study was conducted over a 13-month period. The researcher terminated data collection when the investigation was completed, when saturation of data was achieved, or when no new data emerged. In addition, the deadline was granted by the IRB of the faculty of the Faculty of Nursing, Chiang Mai University. The researcher told all informants that she had to leave as she had to finish the research study and should return to full time work at the Faculty of Nursing, Chiang Mai University. The researcher left the field by going less frequently and then eventually stopped altogether in order to avoid abruptly leaving the informants. The researcher also kept in contact with all informants though the conclusion of data collection. Some parents have called the researcher to talk about their child, and also met the researcher when they took their child to the hospital. Even though the study aimed to explore the practices of families in preoperative phase and the researcher did not have a plan, she had the perfect circumstances for a longitudinal follow up post surgery with these families.

Ethical Consideration

The proposal was approved by the Human Subjects Review Board of Chiang Mai University and the IRB of two University Hospitals before gathering the data.

The researcher gave a summary of the dissertation and the roles of informants in it, including the risks and benefits of participating and informants' right as human subjects, associated with a written consent form to potential recruitments between the researcher and each informant at the first meeting in the hospitals or at the first home visit. To establish safeguards that protected the rights of informants, the researcher shared concerns about informed consent, protecting participants' right, and ensuring confidentiality.

Informed Consent

Informed consent is central to research ethics. It ensures that "all human subjects retain autonomy and ability to judge for themselves what risks are worth taking for the purpose of furthering scientific knowledge" (Bloomberg & Volpe, 2008). All informants willing to participate in the study were asked to sign a formal consent form (Appendices E) or to provide oral consents individually before participating. Oral and full informed consents were obtained before each interview and reaffirmed as the interviews continued. As a qualitative study is dynamic, the researcher asked all informants before each interview if they were still happy to participate in the study. The researcher assured them that even if they decided to participate in the study, they could withdraw at any time without any consequences. For observing the interactions of the informants with nurses and physicians at the clinic, the researcher asked for permission from the nurses and physicians personally to sit at the back of the room without disturbance before her observations.

Protection of Human Subjects

At the first meeting at the hospital, the first home visit, and before staring the first interview, the researcher described the nature of the study, including the study purpose, study process, and about the involvement and time required for participation, as well as the benefits of research informants. The informants were initially ensured that this study was not harmful; the research committees carefully approved this research proposal. The researcher assured them that even if they decided to participate in the study, they could withdraw at any time without any consequences. They had the right to refuse to answer any questions, to tell their stories, or to discuss things that they did not want to. In addition, the researcher informed the informants that she was the only one person who would visit them at home, that the visits would last no more 4 hours per time, and that her visiting would not disturb their family life. For example, when the researcher arrived at the informants' home and found that the informants were doing their housework or working, she told them not to stop. Rather, she told them to continue working and tried to participate in those activities. However, the researcher took informants' availability and preference into consideration.

In addition to balancing role responsibilities and trusting relationships with informants, the researcher, who was a nurse, considered her professional integrity (Seed, 1995). Even though being acknowledged as a nurse is helpful in gaining entry to the setting, it is crucial for the informants to understand that the researcher is acting as a researcher and not a nurse (Field, 1989). The researcher, therefore, tried to avoid directly intervening with information related to child care during collecting data. She usually reminded the informants that her role as a researcher would limit her role of providing health information. She described to them that she could provide information or answer their questions in regards to their child care after her data collection was completed. However, the researcher considered provided information when she found that it was not related to child care and did not effect their practices. On the other hand, the researcher intervened in child care when she learned that some practices had a great impact on the child's life. For example, the researcher found that one informant fed the child wrong doses of Captopril drug because she perceived that if her child received more, the child's heart would have better function and would not work too hard. The researcher, thus, explained the informant the right way to mix that medicine.

Ensuring Confidentiality

All information was held confidential and anonymous. The researcher used a code number on information forms, interview tapes, and transcriptions instead of their names. Pseudonyms were used in all family stories. The researcher solely transcribed all audiotape interviews, and all material and data were safely kept, assuring confidentiality. The interview tapes will be erased one year after the committee approves her dissertation. The researcher will keep field notes, tapes, and all transcriptions for academic purposes in secure files and safe place for a period of seven years (Morse & Richards, 2002). If any further analysis will be conducted with the study, further ethical approval will be sought first. Results of the study will be presented in a group form and no information was included that would allow individuals to be identified. All informants granted permission for publication of the study.

Data Analysis

In this study, the data was collected from many sources, including interviews, observations, and supplementary data sources. Taped interviews were transcribed, and participant observations were converted into field notes (Roper & Shapira, 2000). Throughout data collection, reference was made continuously to both transcriptions and field notes (Morse & Field, 1995). Data analysis and data collection were done concurrently in a dialectic process to make sense of what the researcher perceived (Agar, 1980).

The researcher's first analytic goal was to learn "what was going on" in a family of children with CHD and to be comfortable in the setting. Therefore, during the first phase of analysis, the researcher completed the first level of description of essential culture of each family, and how behaviors were patterned. Demographic characteristics, maps, documents, or photographs provide background information for subsequent analytic reporting (Morse & Richards, 2002). In addition, the researcher could find emerging data while writing up family stories. Once the researcher had some understanding of the family, she obtained comprehensive, detailed descriptions.

Data were analyzed using content analysis. The methods were selected from Lecompe and Schensul (1999), Roper and Shapira (2000); and Mayan (2001). The analysis process consisted of three steps including coding, categorizing, and thematic analysis, as a guideline to analyze qualitative data.

Coding. This first step moves from the concrete to higher level of generalization or more abstract categories. All interview transcriptions were read line by line. Words, sentences, or phrases segmented each meaningful text. The researcher marked segments of data by assigning words, phrases, or concepts. The first coding identified emergent broad themes of the practices. The codes were redefined and changed repeatedly while new items/concepts emerged from the data. The researcher documented the changes in coding and the reasons for the changes in the memos to herself.

Categorizing. This step involved grouping the coding or integrating similar codings into a small number of categories. The researcher cut out the highlighted sections and grouped them through comparing, contrasting, and integrating. Similar codings that fit together were grouped into specific categories. Each category consisted of different codings that were classified into the same categories. Sub-categories were then made within each specific category. The categories became more general and abstract because they explained regularities of families' caring practices and beliefs.

Thematic analysis. It was the step of creating sub-categories and themes, which were more abstract. Once the data were categorized, the researcher took each category and read through the clippings. Sub-categories were created. Then, the researcher illustrated relationships between category and sub- categories to develop an overall picture. The categories were compared and clustered to avoid imposing etic or scientific knowledge on data. At this stage, data of observation that were recorded in the field notes could assist in managing intellectual and emotional bias. Then, a detailed reading was done to refine, discover, and specify categories. By integrating the categories, the researcher was able to identify the themes (Mayan, 2001).

While data were collected, transcribed, and analyzed, they were presented to parents who were key informants for validation and more input, and maintaining their emic perspective. That input provided guidance for additional data collection. This process continued until the key informants provided no more new information; thus, redundancy provided the criterion for ending data collection. Ultimately, the data characterized the practices based on the information gathered through interviews, participant observation, and field notes. Categories and themes of practices were determined through this inductive process. The end product of the study was presented in detail, with comprehensive descriptions, to inform the reader about the normative practices of Thai families in caring for a child with CHD.

Data analyses were conducted in the Thai language, as that was the language used by participants and in field notes. Many Thai words and Thai contexts could not be explained in English. Ongoing analyses in English produced different results. The researcher, therefore, presented the final results in Thai and carefully translated them into English by consulting an expert editor who was a native English speaker and fluent in Thai, in order to retain the meaning and quality of the Thai context.

Trustworthiness of the Study

The main goal and major strength of the ethnographic process is for the findings to reflect the reality and meanings of the studied people (Roper & Shapira, 2000). For this study, the main goal was to gain a deep understanding what parents perceived and practices related to their child's care in their natural setting. To achieve the rigor of the study, the researcher was concerned about credibility, transferability, dependability, and confirmability as follows:

Credibility

Credibility refers to the truth of findings regarding the informants' experiences. In this study, credibility was achieved by many methods including careful selection of the informants, peer debrief, member checking, prolonged engagement, and data triangulation.

Careful selection of informants. The researcher carefully selected the informants who were best representative of the parents having a child with CHD awaiting cardiac surgery. She tried to identify various informants including: type of a child's CHD (acyanotic and cyanotic CHD), level of education, economic status, type of family, and number of children. In regard to careful selection of informants, the researcher ensured efficient and effective saturation of categories, with optimum quality data and minimum low quality (Mayan, 2001).

Member checking. Credibility could be achieved by member checks after preliminary analysis of data. To ensure that the researcher's own bias did not influence how informants' perspectives were portrayed, and to determine the accuracy of the findings, the study informants will be given the opportunity to check out or verify preliminary categories and summaries of the researcher's interpretations (Bloomberg & Volpe, 2008). For this study, transcripts and the preliminary results were taken by the researcher to six key informants (four mothers and two fathers) for verifying that the data reflected their experiences, within 2 to 3 weeks after the interviews and observations. The summaries of data relating to particular practices in caring for their child were confirmed, specifically practices connected to feeding nourishing food, preventing the heart from working too hard, keeping away from other illnesses, and providing medications were confirmed. As the time passed, informants could not remember all of the data in details, but could recall the main topics they had mentioned and the patterns of their practices in caring for their child. Most of them agreed with the summaries of data as true to their own stories.

Peer debrief. In addition to member checking, peer debrief can help the qualitative researcher reduce bias. Peer debrief was obtained to attain credibility of the study to enhance the accuracy of the researcher's account (Bloomberg & Volpe, 2008). It is the process of engaging colleagues to discuss the findings, interpretations, and tentative analyses and conclusions (Mayan, 2001). In this study, the researcher discussed the data and findings with the research committee to let them examine the researcher's findings. Two members of dissertation committee and three other experts in ethnographic research, who brought their different perspectives, also approved the findings. The dissertation committee and the experts had been working in pediatric nursing family nursing and public health nursing for more than 20 years. They all had experience as clinical supervisors, and had conducted ethnographic as well as other qualitative research in their nursing specialty. They allowed the researcher to share the tentative analyses and stresses encountered in the process of fieldwork. They also asked some questions and suggested possible future steps that helped the researcher examine her assumptions and/or considered alternative ways of looking at her data. In addition, the researcher shared her experiences with other doctoral students who conducted ethnographic and other qualitative research to let them examine her interpretation.

Prolonged engagement. It was the final means that the researcher employed to increase the credibility of the study by spending sufficient time with informants to test for misinformation caused by distortions, caused either by the researcher by the informant. In regard to spending a great deal of time in the setting, the researcher became substantially involved at the site (Mayan, 2001). Prolonged engagement was assured by multiple interviews that enabled the researcher to identify and clarify apparent contradictions, or information that might be missed in an earlier interview. The researcher's direct involvement in families' lives over a period increased the validity of the study while increasing the opportunities to assess the accuracy of statements and interpretations (Fetterman, 1998; Roper & Shapira, 2000). In addition, prolonged engagement helped the researcher build trust with the informants.

In this study, the researcher spent 2 to 3 hours with each family per home visit, 4 to 6 visits per family within 2 to 10 months. Most families were visited four times. During home visiting, the researcher participated in many family activities related to child care. While participating in those activities, she could conduct informal interviews as well as participant observation. Additionally, the researcher accompanied the informants when they took the child to the hospital, 3 to 5 hours per meeting, 3 to 8 meetings per family. Over the course of study, the researcher kept in touch with all informants by calling them once a month. Some informants called the researcher to talk about their child's conditions and in general letting the researcher know more about their world.

Data triangulation. To increase credibility of data, the researcher designed multiple procedures to collect data on the same content (Brink, 1989). Ethnography, by definition, triangulates information from three activities of participant observation, interviews, and examination of supplementary data sources. With triangulation, the data from one method can be verified against other sources to increase credibility, ensuring rigor for the study (Roper & Shapira, 2000).

In this study, the researcher employed many methods to triangulate data including participant observation, in-depth interviews, and field notes as well as supplementary data. She recognized that what was learned from one method could be checked against other sources. The researcher had communications with either parents or a family member who was a key informant, and also talked with their neighbors. In addition, she visited the informant's home at different times and also accompanied the parents to the hospital to see what their practices were. These data sources provide an opportunity to examine how the event was experienced by different individuals and groups of people and at different times and different places. For example, one informant said she did not let the child cry, nor let the child have excessively long play, in order to prevent the child's heart from working too hard. The researcher, therefore, used observation data to validate what she was told in the interviews, how the mother reacted when the child started to cry, and whether she stopped the child while he/she was playing.

Transferability

Transferability occurs when findings fit other contexts as judged by the readers, or when the readers find the extensive report meaningful in term of their own experience (Germain, 1993). Transferability was facilitated by comprehensive description. To achieve transferability, the researcher provided a detailed description of the findings in explicit ways so that other researchers could make a judgment on its transferability. In addition, the researcher provided the widest possible range of information, such as families covering all adult age groups, educational levels, and occupations, in order for the readers to decide how applicable this study is to other groups. Therefore, the subjects, content, and range of data were sufficient to provide a basis for assessing relevancy to related context (Guba & Lincoln, 1994).

Dependability and Confirmabilty

These processes were achieved by auditing (Guba & Lincoln, 1994). The researcher established dependability and confirmability through the creation of an audit trail and triangulation. To gather the accurate information, all interviews were tape recorded by the one and only researcher. Non-verbal behaviors were recorded during interviews and participant observations in field notes. Both recorded interviews and field notes were transcribed verbatim by the same researcher as soon as possible after the interviews and observations. All taped transcripts were reviewed by the researcher in order to make sure that they covered all of the information needed. The dissertation committee served as auditors, reading and coding selected transcripts. Emerging patterns, categories, and themes were discussed with the auditors. In the findings chapter, to achieve confirmability, the researcher provided numerous quotes from the interviews to support the objectivity of emerging categories and properties.