

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

This chapter is divided into three parts. The first part summarizes the study findings and provides lessons that the researcher learned from doing this study. The second part presents implications of the study focusing on nursing practice, nursing education, and recommendation for future research. Finally, limitations of the study are given.

Part 1: Conclusion

The major purpose of this ethnographic study was to develop a better understanding of the practices among Thai families in caring for children with CHD aged 0-3 years prior to cardiac surgery and to explore how the Thai socio-cultural context influenced the practices. Interpretive data underpinned the ethnographic methodology and the research process of this study. Data were collected by the researcher from at least one parent from each family. Multiple collecting methods were employed to gather information, including interviews, participant observations, and field notes. Interview data were obtained from 14 key informants of eight families. Data collection and data analysis were done concurrently. Data were analyzed using content analysis based on LeCompte and Schensul (1999), Roper and Shapira (2000), and Mayan (2001). The findings of the study were divided into two major parts based on research questions: perceptions of families regarding the child's

illness and treatments, and practices of families in caring for children with CHD aged 0-3 years and how socio-cultural context influenced on the practices.

Findings from both holistic and thematic interpretations of the data indicated that families' perceptions and practices were deeply influenced by the socio-cultural context, including Buddhist teaching and cultural beliefs. Regarding perception of families, the families had negative thoughts about the child's illness. They understood that the child *Pen Laew Arj Mai Rod*, or may not survive because it was a disease with alarming and worrying symptoms, a disease of the heart, being too severe for the young child, and was incurable. They believed that it was caused by *previous karma*, and by the mother's practices during pregnancy. All families accepted that their child with CHD was *Leang Yak Toh Cha*, or difficult to bring up, and that the child required medicines followed by surgery.

The practices of families were characterized by the phrase "Doing our best to get our child ready for surgery." Promoting the child's weight gain and strong health, preventing the child from getting worse, and managing the child's care under constraints reflect the patterns of practices among Thai families who cared for children with CHD in the Thai context. The parents put all their effort into feeding sufficient and nutritious food. To prevent the child from getting worse, parents tried to prevent the child's heart from working too hard, to keep the child away from other illnesses, and to practice traditional beliefs. Apart from following modern medicines, families practiced traditional beliefs, as they believed that the practices could help their children be safe and quickly recover from the illness and heart surgery. They symbolically gave the child to former kings, prayed or asked blessing from sacred Buddha images, made offerings, and so on. In addition, following traditional beliefs

helped the families feel more relaxed and comfortable. At the same time, families tried to manage the child's care under many constraints by managing financial constraints, managing child care and household chores, managing constraints related to hospital service, and by *Tham Jai*, or making up one's mind. Parents chose to manage or adjust their own daily life or sought the cooperation from other members, including managing child care and household chores and limiting their social activities.

The findings indicated that the perceptions and practices of families caring for children with CHD aged 0-3 years were deeply influenced by the socio-culture context. Parents' perceptions and practices were influenced by traditional Thai Buddhist culture, western hospital-based biomedicine, folk medicine, and global TV culture. However, parents felt no conflict between traditional Thai practices and a biomedical perspective. The families simply integrated the new knowledge into their existing ways of life.

Part 2: Implications and Recommendations of the Study

The findings of the study will be very helpful for health professionals to become more aware of the socio-cultural context that influences family perceptions and caring practices. The study identified several implications for nursing practice as well as other health practices in Thailand. In addition, the study contributes implications for nursing education, and recommendations for future research, as follows:

Implications for Nursing Practices

There are many nursing implications linked to working with families of infants and young children with CHD. The findings of this study can promote understanding of parents and families' perceptions and practices, and lead to improved intervention strategies and support systems. Nurses should assume active roles to promote successful culturally appropriate nursing care, including nursing assessment, giving information, facilitating the support programs for families, and providing more emotional support for families in the context of family.

Nursing Assessment

It is important that each parent-child-family should be recognized and treated individually. Nurses need to assess parents' perceptions about the child's illness and treatments and listen carefully to beliefs about illness, as well as be aware of parental background and health traditions. In addition, nurses should show respect for cultural, ethnic, or religious values and health care beliefs. As the parents have their own fundamental knowledge and information about their child's illness, which they have received from many sources, it is necessary that nurses arrange time for the parents to share their information rather than providing information only. Nurses should encourage parents to express their feelings and constraints through developing relationships and trust. In addition, nurses should assess the strategies employed by the parents to manage their child's care under constraints. It is also recommended that availability of support should be assessed.

Giving Information

The findings of the study showed that parents had high stress, feelings of fear, and anxiety around the time of the child's diagnosis, and needed support and encouragement. It is important for nurses to be truthful with parents at the time of diagnosis and not hide information from them. Rather nurses should endeavor to explain the diagnosis in simple terms. In addition, nurses should provide the opportunity for parents to ask questions and voice their concerns. A comfortable, quiet, and safe environment should be arranged so that the parents can express themselves.

Contents of advice. It became clear from the interviews and observation that parents in this study did not have enough information to facilitate them in understanding the child's illness and managing the child's care. Therefore, every effort should be made to provide accurate and adequate information about the child's disease and treatments in order to increase understanding and to reduce parents' feelings of sadness, guilt or uncertainty. Nurses should strive to explain the diagnosis in simple terms, guide parents, and help them find out appropriate patient education materials about the diagnosis, causes of the illness, caring practices, and treatments.

It was found that parents had limited knowledge about nutritious food, particularly about feeding powdered milk in addition to or as a replacement for breast milk. Mothers in the study realized that breast milk is the best food for their infants, but did not feed them breast milk due to misunderstanding. Nurses should assess mother's belief, and then give the accurate information about feeding breast milk. In addition, providing information about preventing the heart workload is also important. Information about restricting salty food, avoiding taking the child to crowded places,

as well as following up as a schedule should be provided in detail and regularly. Nurses should educate them about the signs and symptom of cardiac insufficiency in the child, and train parents in ways to differentiate between normal cues (such as hunger) and medical needs (respiratory distress). A leaflet of each caring practices should be provided to promote quality of care.

Prior to discharge, nurses should let the parents talk and express their feelings concerning about their child's illness and caring practices when they are at home. It is also significant for nurses to let the parents ask any questions as well as to reveal their constraints regarding the child's care and to listen to them before providing information. Also, parents should be given the name and phone number of the healthcare setting to contact after discharge. Guiding the parents toward appropriate referrals to community hospital and financial aid is also significant support.

Methods of giving advice. Based on the findings, following the diagnosis of CHD, parents are left with many questions and concerns. It is very important to consider the methods used to educate parents about the child's diagnosis and conditions. One of the most effective methods is using simple language and visual materials such as models of the heart. This gives parents a basic understanding of

“normal” heart function from which to draw when comprehending the complexity of the child's heart defect. Audiovisual materials (a video) about the diagnosis of CHD are also necessary to promote the knowledge base of parents of children with CHD.

While the child is admitted in the hospital, nurses should give a demonstration in some procedures as well as let parents have a chance to return for the demonstration, such as preparing and giving the child's medicines.

Promoting and Facilitating Group Support

Professional care for families of children with CHD must have a family focus that includes family support programs, and culturally sensitive care for families. Group support is needed to help the families share their feelings with other families. Nurses should assume active roles to promote successful culturally appropriate nursing care, facilitating the support program as well as providing more emotional support for families. In addition, nurses can institute nurse-run support groups for parents to provide them with emotional and psychological support throughout all stages of the child's heart disease, including diagnosis, treatments, and prior to surgery. Parent classes and parent-to-parent support groups need to be arranged both at the OPD and at pediatric wards. At the OPD, nurses should arrange places and time for parents after they meet a physician. Moreover, nurses should take the initiative to encourage parents to attend a support group to share their individual experiences with others. Either at the OPD or pediatric ward, it is very important to develop a more formalized system to promote a sharing-information program, which should be culturally appropriate with recognition of parents' beliefs and perceptions of the child's heart disease.

Regarding the issue of maternal guilt for their practices during pregnancy as the cause of the child's CHD, nurses should provide not only information about the causes of heart disease, but also emotional support for mothers. Nurses need to facilitate the family members to share their information and also encourage both parents to be supportive of one another. Group support within a family should be conducted to reduce maternal guilt as well as promoting right understanding about the causes of CHD. Fathers and other family member should be explained the causes of

heart disease, which are unknown. Letting the families share their beliefs and understanding with nurses is thus very significant.

Importantly for nurses as well as other physicians, they need to be flexible, listen to others, understand the family's situation and being ready to share information and learn from families. Using lay terms in explanations, establishing two-way communication, especially active listening, asking parents about their own and the child's problems, and showing concern, are all techniques that should be integrated into routine nursing care, not paying attention only to the completion of routine work. Because caring for children with CHD is difficult and requires a great deal of time and energy, parents need positive feedback for their efforts and their importance of their role in contributing to overall health of their child. Health care providers should be aware of the parents' feelings and be sensitive to a variety of perceptions and practices of parents in caring for their child. Especially, nurses should gladly tell them more whenever they do not have clear understanding.

Implications for Nursing Education

Currently, nursing education has already focused on providing holistic care to patients and families: physical, psychological, emotional, and spiritual care. The information emerging from this study regarding caring for children with CHD prior to cardiac surgery, which takes into account family traditional beliefs and culture, should be added to nursing education. Improvements in education that undergraduate nursing students receive about what parents experience when their child is ill can lead

to a better appreciation and understanding of parents' responses in the hospital and at home, and to an improvement in the quality of care.

Recommendations for Nursing Research

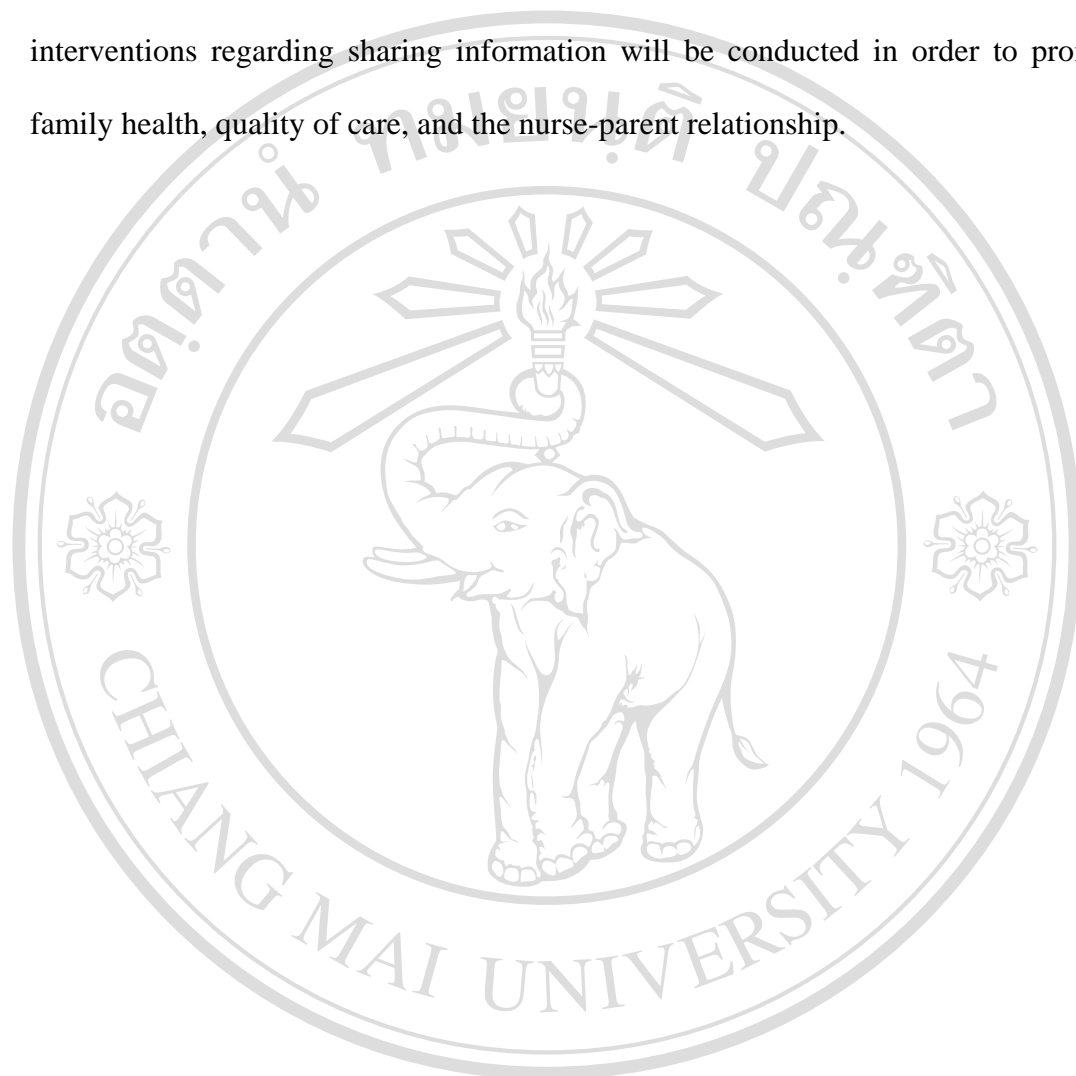
Findings from this study identified many areas that need to be explored. The areas that researchers should focus on in order to understand more regarding children with CHD and the family in Thailand are as following:

1. According to the findings of the study, a further research should be focused on developing a large scale quantitative study to explore perceptions and practices of Thai families in caring for children with CHD based on this study. It would be great to further exploring families' caring practices of children with CHD in different groups of people with different regions and cultures. Developing a measurement of the care practices among Thai families in caring for children with CHD based on Thai socio cultural context will be necessary.

2. Research exploring families' caring practices for children with heart disease, which focuses on other stages of illness—from asymptomatic children with CHD to severe CHF or cyanosis—as well as at post surgery, is needed. In addition, study regarding children with acquired heart disease is an area that needs more study.

3. Regarding the finding that the families did not get useful information and receive emotional support provided by nurses, it nonetheless still the case that nurses work hard. This interesting situation has never been explored with qualitative study. Further qualitative research, thus, is needed to explore this particular issue related to sharing information between nurses and parents of children with CHD. Then, a

further study is to develop a measurement of parent-nurse information sharing based on parents' and nurses' point of views within Thai culture. Also, nursing interventions regarding sharing information will be conducted in order to promote family health, quality of care, and the nurse-parent relationship.



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