

CHAPTER 1

INTRODUCTION

Background and Significance of the Research Problem

The incidence of congenital heart disease (CHD) in Thailand, as in western countries, is eight to ten of every 1000 live births (American Heart Association, 2009; Pongpanich, 2006; Sayasathid & Tantiwongkosri, 2009; The Cardiac Children Foundation of Thailand, 2009). Half of infants and young children born with CHD are symptomatic, requiring both medical and surgical treatments (Pediatric Cardiac Surgery Foundation, 2006; Pongpanich, 2006; Sayasathid & Tantiwongkosri, 2009). Due to a national lack of cardio-thoracic surgeons and pediatric cardiologists associated with the capacity of the health care system to treat these children in Thailand, the number of children with CHD awaiting cardiac surgery has been increasing (Khongphattanayothin et al., 2005; Pongpanich, 2006; Wongsawadiwat, 2006). About one-third of the infants with cardiac problems remain untreated (Stitt & Soontornchai, 2006). Management of the child with CHD is oriented to helping the child build and maintain strength so that surgery can be done at the most opportune time.

The period prior to surgery is critical as unoperated infants and young children are at greatest risk for several complications related to their heart disease. While some children go on to receive the surgery, a proportion die while waiting for surgery because of repeated episodes of complications, particularly congestive heart failure (CHF)

and pneumonia, which are the major causes of death among the children (Laohaprasitiporn, 2006; Laohaprasitiporn & Nana, 1993). Based on the researcher's survey, data from Siriraj and Ramathibodi Hospitals in 2003 and 2004, more than 80% of hospitalized children with CHD were infants and young children aged 0-3 years, who had not yet had the cardiac surgery. According to health care professional in those settings, some children had to be admitted before their regularly scheduled appointments, for complications, CHF and pneumonia. Unfortunately, recurrent complications could result in the child dying before surgery (S, Chottiwitayatarakorn, personal communication, March 6, 2006).

Infants and young children who are symptomatic CHD are the age group at risk for morbidity pre-and postoperatively (McGrail, 1997; Peterson & Welzel, 2004). Preoperatively, they often have trouble feeding, which results in malnutrition and growth failure (Laohaprasitiporn, 2006; Saenz, Beebe, & Triplett, 1999; Smith, 2001; Wheat, 2002), placing them at greater risk for recurrent complications, and as a result, further delaying their cardiac surgery (Pediatric Cardiac Surgery Foundation, 2006; Sriyoschart, 1999). Their limited weight gain prior to cardiac surgery can cause a long recovery post operation. The CHD children catch cold often, are susceptible to diseases, and take longer to recover from them than other normal children. They also require pharmacological management to control cardiac symptoms (American Heart Association, 2009; Laohaprasitiporn, 2006; Pongpanich, 2006). In addition, the children with CHD require health care similar to what healthy children need, including physical, developmental, and psychosocial care (Smith, 2001). In particular, infants and young children are the most important group for promoting physical, psychological, cognitive, and emotional development (Soonthorndhada, Kanugsukkasem, Punpueng,

& Tangchonlatip, 1999). Therefore, prior to cardiac surgery is a particularly important period because it is the period that the child is most unstable clinically, and thus is the most difficult to care for. This is also a complex phenomenon for parents and family members as they would have the critical responsibilities of ensuring that their child is ready for surgery.

Children with CHD aged 0-3 years rely on the parents and other family members to provide care while waiting for cardiac surgery, including monitoring growth and development, assessing the child's symptoms, and preventing complications (Laohaprasitiporn, 1991; Tungkulboriboon, 1996). While awaiting heart surgery, the children spend the majority of their time in the care of their parents at home, with occasional visits to the pediatric cardiologist. The practices of family in providing care for their children are crucial to determine quality of such children's lives. In particular, it was found that caring behaviors of mothers could decrease the children's respiratory tract infections (Kamproh, 2001), and anoxic spells (Theannamngian, 2003), which in turn determine good outcomes of cardiac surgery. Therefore, the family, including parents and family members, is the most important group and remains a consistent provider in home care needed for the children with CHD while awaiting surgery.

The family is one of the basic units of society, and has a profound influence on its members. When a family member, particularly a child, becomes ill, the illness affects the parents and other family members. CHD children have a considerable number of complications, and thus a considerable number of people are affected. An important consequence is that the parents and family members have increasing caring responsibilities and need to be supported during the most demanding caring phase.

Practices of family in caring for these children during this critical period are vital to maintain the children's optimal health until the surgery can be arranged.

Previous studies on families of children with CHD in western culture revealed that parents are significantly affected by a diagnosis of CHD (Emery, 1989; Gillon, 1972; Hinoki, 1998). The research focuses on parenting concerns and the effects of the child's illness on parents (Horn, DeMaso, Gonzalez-Heydrich, & Erickson, 2001; Morelius, Lundh, & Nelson, 2002), and consistently reports that families of a child with CHD experience psychological and social consequences, including stress, difficulty coping, and low quality of life (Davis, Brown, Bakeman, & Cambell, 1998; Goldberg, Simmons, Newman, Campbell, & Fowler, 1990; Lawoko & Soares, 2002, , 2003; Tak & McCubbin, 2002; Uzark & Jones, 2003). Parents were very concerned about the magnitude of their caring responsibility at home, including interpreting the infant's symptomatic behaviors, minimizing the physiologic demands of crying, difficult feedings, maximizing nutrition and weight gain, administering medication, preparing surgery, and understanding the child's conditions (Pinelli, 1981; Svavarsdottir & McCubbin, 1996). However, current literature indicates that the parents' information needs are not being met, potentially compromising the infants' and young children's care (Beeri, Haramati, Rein, & Nir, 2001; Cheuk, Wong, Chau, & Cheung, 2005). Studies exploring the day-to-day practices of families in caring for young children with CHD during preoperative period were not found.

In Thai literature, most studies focused solely upon mothers' demographics and maternal factors related to the child's care (Asumpinzub, 1997; Chotibang, Niomka, & Yunak, 2001; Mornmoung, 2001). Some researchers tested the effectiveness of health education programs or self-help groups for supporting mothers' caring

behaviors for young children with CHD and found positive findings (Dulyakasem, 1993; Kamproh, 2001; Sakulnoom, 2002; Theannamngian, 2003). Those studies were conducted in any phase of CHD, not only the preoperative phase.

Practices of family in caring for a child are culturally mediated because family has been recognized as a critical social unit mediating cultural beliefs and tradition from one generation to another. This includes the belief and practices regarding health, illness, and chronic conditions (McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993). Although western evidence-based medicine is becoming accepted as the standard for cardiac treatments, the Thai parents did not have a single or consistent theory about the cause of disease in general, nor did they totally rely on any single therapeutic approach (McCarty et al., 1999). Rather, various combinations of treatment have been perceived to have positive cumulative effects such as using local herbs, and similar Thai traditional medicine. While going to a temple to make merit was common, no single religious practice was universal among the Thai families' approaches to their children's illness (McCarty et al., 1999; Mulder, 1994).

Over time culture has influenced family functioning in a great variety of ways: kinship systems, family structures, family obligations, or family dynamics (Kespichayawattana, 1999; Sethabouppha, 2002). As majority of Thai are devoted Buddhists, Thai family life is influenced by culture and Buddhism, social norms and the socio-economic context (Junda, 2002; Kespichayawattana, 1999; Phengjard, 2001; Sethabouppha, 2002). Klunklin (2003) and Nukulkiij (1993) also found that Buddhist beliefs influenced Thai families on their children's care. As Thai families tend to have close family relationships, and to help each other from one generation to the next,

experiences from other family members' points of view, may help to round out the portrait of families affected by children with CHD prior to cardiac surgery.

Currently, Thailand is rapidly undergoing modernization, especially in Bangkok, the capital of Thailand. Industrialization, migration, and declining fertility are expected to affect Thai family structures as well as traditional family practices for chronically ill children (Richter, 1992, 1997). Families of children with CHD following up through the big cardiac centers in Bangkok came from various parts of the country. They generally underwent changes to their traditional life style under the pressure of urban demands, such as higher costs of living, and population restructuring. The changes may inevitably affect both CHD children and their families. Since the majority of families originally came from the rural areas, they brought with them the attitudes, values, and beliefs they knew, and then adapted those beliefs to meet the demands of urban life (Roongreungtham, Khompayak, Serintawatana, & Chawalitnitikul, 1992; Soonthorndhada, Kanugsukkasem, Punpueng, & Tangchonlatip, 1999). The function of family and roles of those within family are transformed. Child care becomes increasing complex when the mother's role must be balanced with work outside the home (Richter, 1997). Even though there are ongoing changes in Bangkok society, people still assign a high value to their parents and regard the family as a major force in looking after a child with chronic illness. Parents still afford much value to the family and regard the family as a major force in caring for the child. Shared support between the parents and their family members living at a distance was still well maintained (Poawilai, Sanga, Pinprateep, Nunthamongkonchai, & Chaoompleug, 2002; Richter, 1997; Roongreungtham, khompayak, Serintawatana, & Chawalitnitikul, 1992). However, questions remain

how the Thai socio-cultural context influenced their practices of families in caring for children with CHD.

Despite the existence of research related to families of children with CHD, there is insufficient study about practices of family in caring for children with CHD in Thai society, particularly from the view points of the families themselves. Developed programs and in-use measurements were largely focused on strategies to encourage parents to comply with professional advice, which is often oriented toward hospital-based biomedical perspective. It appears that the perspective stems from the imprecise understanding of the Thai socio-cultural context and of the influences of these factors on family caring behaviors. Such strategies seem to take a very narrow perspective of Thai people, and thus may be seen as unreasonable to the Thai because they are often at odds with traditional belief and practices (Mulder, 1997). Consequently, the implementation of existing health programs was not successful, due to a number of weaknesses. In particular, implementation lacked of sustainability and appreciation of local cultural beliefs, and failure to apply the programs to the families when the parents cared for their child at home (Nukulkiij, 1993; Klunklin, 2003).

Practices of Thai families needed to be explored and modified in order to achieve any sustainable interventions to improve the practices of families in caring for the children. It is important to start with exploring the practices of families with a focus on how the socio-cultural context influences the practices while the children are awaiting cardiac surgery, particularly from the viewpoints of families themselves, including parents and other family members. The ultimate goal for professionals is to ensure that parents are able to provide their children with the quality of care that maximizes functioning and keeps the child alive through the critical preoperative phase.

Without such research, health professionals are challenged to understand how those families integrate western medicine into their traditional culture, and thus cannot design strategies to help those families improve their child's care.

To achieve successful nursing interventions that are effective and culturally appropriate, it is essential to understand the families, including their local terms, interpretations of their perception of the illness and treatments, and particularly their practices. After the health professionals improve their understanding, they could bring such understanding to integrate with the existing health programs in order to provide more culturally congruent professional care. Focus ethnography was employed in this study to uncover the daily practices of Thai families in caring for children with CHD (Morse & Field, 1995; Muecke, 1994; Roper & Shapira, 2000). It shares with classical ethnography a commitment to conducting intensive participant observation within the natural setting, asking insightful questions, recording in detail what is witnessed, and examining other sources of information including documents and artifacts to gain an understanding of people and events of interest (Boyle, 1994; LeCompte & Schensul, 1999; Muecke, 1994; Roper & Shapira, 2000). The study will take a holistic perspective on other caring, physical, psychosocial, and spiritual care for CHD children among Thai families. It is anticipated that the information gained from this study will provide substantial knowledge regarding practices of families in caring for children with CHD in the Thai culture.

Objectives of the Study

The aims of this study was to develop a better understanding of the practices among Thai families in caring for children with congenital heart disease aged 0-3 years prior to cardiac surgery.

Research Questions

1. What were the perceptions of Thai families regarding their child's illness and treatments?
2. What were the daily practices of Thai families in caring for children with congenital heart disease aged 0-3 years prior to cardiac surgery?
3. How did Thai cultural contexts influence the practices of Thai families in caring for children with congenital heart disease aged 0-3 years prior to cardiac surgery?

Definition of Terms

“Family” refers to the parent(s) and/or other family members who take part in caring for children with congenital heart disease at home prior to cardiac surgery.

“Children with congenital heart disease” refers to children aged 0-3 years who have been diagnosed with symptomatic congenital heart disease, acyanotic or cyanotic type, which requires treatments with medications and cardiac surgery.