CHAPTER 1

INTRODUCTION

Background and Significance of the Research Problem

Congenital heart disease (CHD), the structural defects within the heart that are present at birth, approximately occurs 6-8 per 1,000 live births and has remained unchanged for many years (Curtis & Stuart, 2005). The incidence of CHD in different studies has varied from about 4 to 50 per 1,000 live births (Hoffman & Kaplan, 2002). In Thailand, one study reported that the incidence of CHD was 4.36 per 1,000 live births (Nana, Laohaprasitiporn, Soongswang, & Durongpisitkul, 2002). As in many other countries, acyanotic cardiac defects with increasing pulmonary blood flow have been found to be the predominant group in Thailand. In particular, at Chiang Mai University Hospital in northern region of the country, of 925 new pediatric patients with CHD during 2000-2002, ventricular septal defect (VSD) was the most common cardiac defect (32.2%), followed by patent ductus arteriosus (PDA) (16.5%), and Tetralogy of Fallot (TOF) (9.8%) (Sittiwangkul, Pongprot, Silvilirat, & Phornphutkul, 2003).

Typically, the acyanotic CHD with increased pulmonary blood flow are VSD, ASD, and PDA. These defects permit blood to pass between the systemic and pulmonary circulation through an abnormal opening. The condition that allows blood flow from the high pressure left side of the heart to the lower pressure right side would result in increasing pulmonary blood flow, having a higher risk of congestive

heart failure (CHF) and respiratory tract infection (Bhatt et al., 2004; Wong, Hockenberry-Eaton, Wilson, Winkelstein, & Schwartz, 2001). CHF and respiratory tract infection have been found to be the common presenting symptoms of CHD children coming to hospital (Laohaprasitiporn et al., 1999; Nuglor, 1997; Savitsky, Alejos, & Votey, 2003; Sommers, Nagel, Neudorf, & Schmaltz, 2005) and share causes of death in 21.9 and 2.6 percent, respectively, of 150 children with heart defects who die suddenly (Polderman et al., 2004). Furthermore, it is well recognized that children with CHD are at risk to malnutrition and growth failure (Chen, Li, & Wang, 2004; Nuglor, 1997; Salzer, Haschke, Wimmer, Heil, & Schilling, 1989; Staebel, 2000), delay developmental problem (Chen et al., 2004; Hirose, Ichida, & Oshima, 2007; Wray & Radley-Smith, 2004), and emotional and behavioral problems (Gupta, Giuffre, Crawford, & Waters, 1998; Utens et al., 2001; Zahr & El-Haddad, 1998). These data not only emphasize the importance of early disease management, but also raise the need of effective care for this group of children.

Managements for children with CHD, generally, composed of observation, medical and surgical management. The advances in pediatric cardiology have contributed to curative surgical options for most acyanotic congenital heart defects. It is suggested that children with CHD are diagnosed and referred to surgical centers for further management within the first year of life (Chang, Chen, & Klitzner, 2000; Wray & Sensky, 1998). Nevertheless, the privilege of early diagnosis and treatment is restricted to children with CHD in Thailand. Because resources and infrastructure are shared by adults and pediatric care services, waiting time for cardiac surgery of Thai children has been reported to be long as approximately six months and the mean age of them at referral for surgery was 5.0 ± 4.9 years (Khongphatthanayothin et al., 2005).

Compared with report from Hong Kong, the median age at initial operation in children with CHD was 4.6 months, and approximately three fourths of those children had an operation before they were two years old (Jacobs, Leung, & Karlberg, 2000). Importantly, approximately five percent of children with CHD in Thailand died during waiting for surgical intervention (Khongphatthanayothin et al., 2005).

Health status of children with CHD is important to the schedule and chances of smooth operative, and post-operative outcomes. From the unpublished data of Chiang Mai University Hospital in 2005, nearly one fourth of 36 children with CHD who postponed the surgical plan were encountered with fever and nearly one fifth of cases had respiratory tract infection (Pediatric II Ward Report, 2005). One study reported that respiratory tract infection in children with CHD was associated with a high risk of postoperative pulmonary hypertension (Khongphatthanayothin, 1999). In addition, failure to thrive was found to be the predictor of increased hospital cost and postoperative length of stay after CHD surgery (Silberbach, Shumaker, Menashe, Cobanoglu, & Morris, 1993). This evidence indicates that the appropriate care to decrease morbidity and mortality is particularly an important issue for children with CHD while waiting for curative surgery.

Mothers are caregivers who take primary responsibility for the care of children in family (Gantt, 2002). Care behaviors of mothers, therefore, directly affect outcomes of the child's health. As the surgical treatment for Thai CHD children usually performs in preschoolers (Khongphatthanayothin et al., 2005), the demands of care due to nature of disease and developmental stage have placed mothers of the toddlers in a crucial position to keep the child's health as normal as possible before surgery. The care required by toddlers with CHD is not only the same care as other

children but also the addition of extra care toward health maintenance, prevention and management of complications from the defect.

Given the importance of care behaviors of mothers for toddlers with CHD, there have been a few investigations on care behaviors of those mothers. A study by Chatrum (2003) has shown that care behavior of mothers for infants with CHD was at high level, but it was at moderate level for toddlers and preschoolers. There are some studies concentrating on oral health care for children with CHD indicated that care of parents failed below the recommended activities for the child's care needs (Kongsrichareon et al., 2002; Saunders & Roberts, 1997; Silva, Souza, & Cunha, 2002). Nevertheless, those studies did not specifically focus on the toddlers, and they rarely restricted their population to specific types of CHD.

In the Self-Care Deficit Nursing Theory (Orem, 2001), mothers function as dependent care agents who perform care behaviors on behalf of their children in maintaining life and health. Orem (2001), further explains that individuals who engage in dependent care are assumed to have abilities (dependent-care agency) to meet requirements of the dependents. However, variations in dependent-care agency and dependent care practice of individuals are conditioned by factors internal or external to individuals named basic conditioning factors. Orem identified 10 basic conditioning factors including age, gender, developmental state, health state, sociocultural factors, health care system factors, family system factors, pattern of living, environmental factors, resources availability and adequacy. The Orem's theory has been successfully applied to explain the factors associated with health related behaviors in a variety of population, for instance in older adults (Callaghan, 2005), youth with diabetes mellitus (Dashiff, McCaleb, & Cull, 2006; Schaick, 2003), and parents of preschool

asthmatic children (Santati, 2005). Hence, the Orem's theory might be useful to explain care behaviors and associated factors among mothers of toddlers with CHD.

A few studies in CHD literature have examined relationships between maternal care behaviors and related factors. It is obvious that proper care behaviors have been reported among mothers of 3-6 and 6-12 years old children with CHD (Asumpinzub, 1997; Chotibang, Niyomka, & Yunak, 2001). Those prior studies have found relationships between care behaviors of the mothers and maternal age, education, family income, accurate perception of disease (Azumpinzub, 1997), and perception of health of children with CHD (Chotibang et al., 2001). Findings from clinical trial also demonstrated influence of self-efficacy (Chottivitayatarakorn, 2000), social support (Dulyakasem, 1993), and perception of CHD and social support (Kamproh, 2001) on care behaviors of the mothers. Importantly, little is known about the most important factors and ability of them in explaining variation of the mothers' care behaviors.

In addition, the literature has provided documentation of the stressful impact of being parents of children with CHD (McGrath & Kolwaite, 2006; Pelchat et al., 1999; Uzark & Jones, 2003). Also, other studies indicated that parents with higher education are more likely to have greater knowledge related to CHD (Beeri, Haramati, Rein, & Nir, 2001; Cheuk, Wong, Choi, Chau, & Cheung, 2004). Based on existing evidence, research is needed to explore in greater depth regarding care behaviors of the mothers, in particular for toddlers with VSD, ASD, or PDA who have not had surgery. Moreover, this highlights the need of further study regarding the potential predictors of care behaviors among mothers of toddlers with CHD, which would be useful to guide appropriately interventions for the mothers who need support.

With the guiding of Orem's theory (2001) and aforementioned empirical evidence, some variables were selected to examine for their influence and ability in prediction of dependent care behaviors among mothers of toddlers with CHD. Knowledge of CHD is considered to be essential for the mothers because knowledge is inherent in dependent-care agency that will aid mothers to understand, judge, and make decision about dependent care actions. Parenting stress or the psychological reaction of mothers to the demands of being a parent of CHD toddlers is viewed as the health state and the contributor of reactions and coping styles effecting dependent care behaviors. The availability of resources, specifically availability of social support, is crucial ingredients in positive adaptation to dependent care agents' role, as well as, buffering the mothers from negative effects of stressors. Family income is included in the study because this resource can facilitate the mothers to fulfill the necessity for basic needs. Moreover, educational background is included under the sociocultural orientation that may be a proxy for increasing cognitive appraisal skills and problem-solving skills necessary to deal effectively with a situation. In addition, as perceived self-efficacy plays an important part in judgment of the mothers about their capacity to perform dependent care behaviors in order to produce desired outcomes. This variable is linked to the transitional capability of self-care operations in self-care agency, and is anticipated to have effect on dependent care behaviors of mothers for toddlers with CHD.

This study will provide the knowledge of factors that can explain and predict variation of dependent care behaviors among mothers of toddlers with CHD. This will assist health care providers in early identification of high risk mothers and design effective intervention programs that maximize optimal dependent care

behaviors of the mothers. Once, adequately dependent care behaviors of the mothers can be enhanced, optimizing health outcomes of toddlers with CHD can be achieved.

Objectives of the Study

The objectives of this study are as follows:

1. To describe the relationships between dependent care behaviors among mothers of toddlers with CHD and parenting stress, perceived social support, perceived self-efficacy, CHD knowledge, educational background, and family income.

2. To identify the ability of parenting stress, perceived social support, perceived self-efficacy, CHD knowledge, educational background, and family income in predicting dependent care behaviors among mothers of toddlers with CHD.

Research Questions

1. What are the relationships between dependent care behaviors among mothers of toddlers with CHD and parenting stress, perceived social support, perceived self-efficacy, CHD knowledge, educational background, and family income?

2. To what extent do parenting stress, perceived social support, perceived self-efficacy, CHD knowledge, educational background, and family income explain variability of dependent care behaviors among mothers of toddlers with CHD?

Definition of Terms

Terms used in this study are defined below:

Predicting factors refer to factors that may possibly affect the mother' s dependent care behaviors, including parenting stress, perceived social support, perceived self-efficacy, CHD knowledge, educational background, and family income.

Parenting stress is the perception of mother toward discrepancy between mother's role and resources available for dealing with demands in providing care for toddlers with CHD as measured by the Parenting Stress Index-Short Form (PSI-SF- Thai version) of Abidin (1995).

Perceived social support is the perception of mother that support for providing care for toddler with CHD would be available when it is wanted as measured by the Personal Resource Questionnaire Part II (PRQ-85) (Weinert & Brant, 1987) which was translated to Thai by Prasopkittikun (2001).

Perceived self-efficacy is the judgment of mother on how effectively she can perform the tasks associated with providing care for her toddler with CHD. Perceived self-efficacy was measured by the Maternal Perceived Self-efficacy Scale which was developed by the researcher based on Bandura (1997) and literature review.

CHD knowledge is mother's remembrance and interpretation of information about care for toddlers with CHD as measured by the CHD Knowledge Scale which was developed by the researcher based on literature review.

Educational background is the number of years that the mothers spent in school from the first year of primary education to the year of graduation with the highest level of education.

Family income is the average monthly family income in Thai baht.

Dependent care behaviors refer to actions that the mother does in providing care to the toddler with CHD in response to his/her universal, developmental, and health deviation self-care requisites. Dependent care behaviors were measured by the Dependent Care Behaviors in Mothers of Toddlers with CHD Scale which was developed by the researcher based on Orem's theory (2001) and literature review.

Mothers of toddlers with CHD refers to mothers of children aged 1- 3 years diagnosed with ventricular septal defect (VSD) or atrial septal defect (ASD) or patent ductus arteriosus (PDA).