CHAPTER 2

LITERATURE REVIEW

This chapter presents a review of literature that is relevant to the present study. The literature review is organized into four sections. The first section is an overview of CHD with increased pulmonary blood flow and effects of the defect on children and family. The second section is related to dependent care of mothers for toddlers with CHD. The third section provides a description of factors related to dependent care behaviors, including parenting stress, perceived social support, perceived self-efficacy, knowledge, educational background, and family income. The last section is theoretical framework of the study.

CHD with Increased Pulmonary Blood Flow

Congenital heart disease (CHD) is the most commonly congenital anomalies today (McGrath & Kolwaite, 2006), existing in 6-8 of 1,000 live births and has remained unchanged for many years (Curtis & Stuart, 2005). CHD is identified as a defect that is present at birth in the structure of the heart and/or in one or more of the large blood vessels that lead to and from the heart (Schulte, Price, & James, 1997). The specific cause of CHD is not clearly understood. However, several factors are associated with a higher incidence of the defect. Environmental factors and maternal factors have been identified as possible causes of CHD. Prenatal factors associated with CHD including maternal rubella during pregnancy, maternal alcoholism,

maternal age over 40 years, and maternal diabetes type I (Wong et al., 1999). Additionally, heredity often contributes to the incidence of CHD (Edwards, Hertzberg, Hays, & Youngblod, 1999; Schulte et al., 1997).

There are many heart malformations and each malformation may present with different degrees of severity. According to the hemodynamic and blood flow patterns of the defects, CHD can be classified into four categories, including defects with increased pulmonary blood flow, defects with decreased pulmonary blood flow, obstructive defects, and mixed defects (Wong et al., 2001). Considered as a group, defects with increased pulmonary blood flow are the most common structural lesions presenting for assessment and management in young children (Fitzgerald & Sherwood, 2007). In CHD with increased pulmonary blood flow which is primarily focused in this study, intracardiac communications along the septum or an abnormal connection between the great arteries allows blood to flow from the high pressure left side of the heart to the lower pressure right side of the heart (Wong et al., 2001). VSD, ASD, and PDA are typical defects in this group.

VSD is the most common congenital cardiac anomaly with the incidence of about 2 per 1,000 live births or accounts for about 25 % of all CHD (Freed, 2001; Pillitteri, 1999). With this defect, an abnormal communication is present between the right and left ventricle that permits blood to shunt from the left ventricle into the right ventricle (Edwards et al., 1999). ASD is an abnormal opening between the right and left atria, allowing blood from the higher-pressure left atrium to flow into the lower-pressure right atrium (Daberkow-Carson & Smith, 1994). ASD accounts for about 9 % of all congenital heart defects, with the incidence of about 0.53 per 1,000 live births (Samanek & Voriskova, 1999). The ductus arteriosus is a normal pathway

in the fetal circulatory system that connects the pulmonary artery to the aorta (Pillitteri, 1999). Functional closure of the PDA usually occurs spontaneously during the first 10 to 15 hours after birth. Permanent closure occurs within 5 to 7 days in most infants but may take up to several weeks (Daberkow-Carson & Smith, 1994). A persistent patent ductus accounts for about 5 % of all congenital heart defects, with the incidence of about 0.31 per 1,000 live births (Samanek & Voriskova, 1999).

Physiologic Effects of CHD with Increased Pulmonary Blood Flow

In the normal circulation, the volume of pulmonary venous return equals the left ventricular stroke volume, which equals the volume of blood that reaches metabolizing tissues. The left side of the heart is usually under higher pressure, and any communication between the right and left sides of the heart will result in blood shunting from the left to the right side. A shunt from the left to the right side of the heart will result in decreased flow to the systemic circulation and increased flow to the lungs (Patel, 2004). However, the hemodynamic significance of this group of CHD primarily is determined by size of the defect, state of the pulmonary vascular resistance (PVR), and ability of the myocardial to handle the extra load (Daberkow-Carson & Smith, 1994).

Excessive pulmonary blood flow can overwhelm the ability of the lungs to move blood to the left heart. This excess blood volume can produce boggy lungs that make gas exchange more difficult. Pulmonary congestion can lead to respiratory symptoms, frequent respiratory infections, and eventually to pulmonary edema. Moreover**,** volume overload can lead to left atrial and left ventricular enlargement and can lead to CHF. Large left-to-right shunts may also cause a relative decrease in

the systemic cardiac output because a majority of the left ventricular stroke goes to the lungs instead of the body. In addition, a large systemic to pulmonary shunt from CHD may lead to the development of pulmonary arterial hypertension (Tulloh, 2005). Due to systemic-to-pulmonary shunting, this leads to increased pressure in the pulmonary arteries, endothelial dysfunction and an increased vascular resistance. These changes may ultimately lead to a reversal of the systemic-to-pulmonary shunt accompanied by severe cyanosis and myocardial failure (Duffels et al., 2007; Raja & Basu, 2005; Steinhorn & Fineman, 1999).

Management of CHD

Management of CHD in infants and children is based on several factors. Not all congenital heart defects require treatment; some mild congenital heart defects may be asymptomatic and undergo spontaneous resolution whereas some is treated with drugs and/or surgery. However, the majority of congenital heart conditions do need treatment and this varies depending on the type of heart defect, the severity of the disease, the patient's current condition, and other health concerns. Three basic options for treating congenital heart disease including CHD with increased pulmonary blood flow are as the following:

Observation and Monitoring

Children with CHD that is not causing significant symptoms and is not life-threatening may need only observation and monitoring their conditions on a regular basis.

Medical Management

Many children with congenital heart and blood vessel defects need medical treatment. If children with CHD develop symptomatic CHF, medications are often used to improve or control symptoms, build and maintain heart capacity, and help prevent future complications. Some of the common types of medications include digoxin, diuretics, and angiotensin converting enzyme inhibitors. Digoxin is a cardiac glycoside that increases cardiac output and improves cardiac effectiveness. This drug has a positive inotropic effect that strengthens the force of ventricular contractions. It has a negative chronotropic effect that slows the heart rate. It also improves blood flow to the kidneys and enhances diuresis. Diuretics are administered to eliminate excess water and sodium through increased urine production, thereby reducing systemic and pulmonary congestion. These drugs cause the kidneys to waste potassium, therefore the child may be at risk for electrolyte disturbance, especially hypokalemia. Angiotensin converting enzyme inhibitors may be used to relax vascular smooth muscle and reduce afterload (McDanial & Gutgesell, 2008; James, Ashwill, & Droske, 2002).

Surgical Management

Surgical procedures are used to repair the defect as much as possible and restore circulation as close to normal as possible. Sometimes, multiple surgical procedures are necessary. Surgical treatment in CHD can be divided into 2 types, including palliative surgery and corrective surgery (Bowden, Dickey & Greenberg, 1998).

Palliative surgery. Palliative surgery is not curative, but rather is performed for heart defect as a surgical bridge. The objective of palliative surgery is to improve the child's condition for temporary period. This type of surgical interventions can allow the child's condition to become more stable and to provide time for the child to grow until a more definitive surgical correction is viable. Sometimes palliative surgery is performed because there are no curative surgical options for a particular heart defect.

Corrective surgery. Corrective surgery is the completely repair of the defect. The trend of surgical procedures in recent years has been toward surgical intervention early in life, often in infancy. The timing of surgeries depends on the anatomy of the lesion, the child's growth and development, any concurrent illness, and family needs.

In brief, CHD with increased pulmonary blood flow are cardiac defects that permit blood to pass between the systemic and pulmonary circulation through an abnormal opening. Physiologic effects of the defects include increased pulmonary blood flow and increased cardiac workload. Nevertheless, hemodynamic effects and management depend on severity of the lesions.

Health Deviations in Children with CHD

Health deviations exist when individual are ill or injured. When a child is born with congenital heart defect, disruption to the heart or to the major vessels leading to and from the heart can affect the efficiency and effectiveness of the circulatory system. CHD with increased pulmonary blood flow involves blood flow

from the left side of the heart to the right side of the heart through a connection between the system or the great artery. Thus, children with this type of defect often experience many of the devastating physical and psychological health effects.

Physical Health

Congestive heart failure (CHF). CHF is a clinical syndrome that reflects the inability of the heart to maintain cardiac output sufficiently to meet the metabolic demands of the body (Daberkow-Carson & Smith, 1994). CHF often occurs in infants and children with CHD leading to large left-to-right shunts and pulmonary overcirculation. Left-to-right shunt will cause oxygenated blood in the left heart to return to the right heart. The result is decrease in the left ventricular cardiac output and increase in the right ventricular cardiac output. The decrease cardiac output from the left ventricle will cause poor blood supply to the body, while the increase cardiac output from the right ventricle will cause work overload of the right ventricular myocardium.

The clinical manifestations of CHF are related to the degree of hemodynamic and neurohormonal responses. Manifestations include tachypnea, increase work of breathing, tachycardia and gallop rhythm, periorbital and facial edema, neck vein distension, hepatomegaly, splenomegaly, decreased peripheral perfusion, decreased urine output, diaphoresis, mottling, and cyanosis or pallor. Additionally, the child may be lethargic, be irritable, fatigue more easily or decreased exercise tolerance, and has difficulty feeding (Daberkow-Carson & Smith, 1994; James et al., 2002). In the study of CHF in children with CHD aged 1 month to 16 years by Kelmendi and Bejiqi (2004), of all 663 children diagnosed with CHD, 167

(25.2%) had signs of CHF. In Germany, a retrospective study by Sommers et al. (2005) reported that from 1989 to 1998, CHF occurred in 507 (39.1%) out of 1,297 children with CHD, and occurred in 23.7% of children with CHD when postoperative CHF was excluded. Moreover, a study of sudden unexpected death in children with a previously diagnosed cardiovascular disorder found that heart failure shared 20.2 % of causes of death (Polderman et al., 2004).

Infections. Children with CHD are at greater risk for developing infections such as respiratory tract infection and bacterial endocarditis than other children (Cook & Higgins, 1992; Smith, 2001). Especially, recurrent respiratory tract infections are common in children with heart lesions causing increased pulmonary blood flow (Cook & Higgins, 1992). In a study of children with CHD at the emergency department, respiratory tract infection was the most common non-CHD related illness (Savitsky et al., 2003). In a group of 760 children less than 24 months with haemodynamically significant CHD in Spain, Medrano et al. (2007) found that 79 patients (10.4%) required a total of 105 admissions to hospital related to respiratory infections. Similarly, a study conducted in Thailand also reported that upper respiratory tract infection was the most common complication in children with VSD (Nuglor, 1997). Despite respiratory tract infection may cause only mild illness in healthy children, this infection can be a life threatening disease in children with underlying disease, particularly CHD (Kaneko, Watanabe, Ueno, Hida, & Sone, 2001). There was a study reported that respiratory tract infection shared 2.6 % of sudden unexpected death in children with a previously diagnosed cardiovascular disorder (Polderman et al., 2004). Furthermore, the presence of an upper respiratory

infection has been found to be predictive of postoperative infection and multiple complications in children presenting for cardiac surgery (Malviya et al., 2003).

Among children with heart defects, infective endocarditis (IE) is a rare but serious illness because of the significant morbidity and mortality associated with the disease (Liew, Tan, & Wong, 2004). Children with CHD have a higher risk of IE, particularly in case of a lesion associated with turbulent blood flow such as a septal defect, high-pressure valvular anomaly, or cyanotic defect; but the exceptions are those with isolated secundum ASD (Dajani et al., 1997). High-velocity or turbulent flow caused by the high pressure left sided circulation causes endocardial damage (Siddiqui et al., 2007). Bacteria enters the circulation and creates a nidus for subsequent bacterial colonization and endocarditis near a susceptible endocardial lesion (Alderman, 2000).

CHD has been found to be the most common underlying cardiac condition in vast majority of children with IE (Lertsapcharoen et al., 2005; Martin, 2002). Of the 57 children diagnosed with IE at King Chulalongkorn Memorial Hospital over an 18-year period, 42 patients (74 %) had underlying CHD. Another study in Singapore reported that of a total 27 children with IE, 88.9 % of cases had CHD (Liew et al., 2004). Similarly, the study of IE in children under 16 years at the pediatric cardiology unit in developing countries found that an incidence of IE was 32 per 1,000 hospital admissions and CHD was the underlying lesion in 45 % of cases (Sadiq, Nazir, & Sheikh, 2001). Additionally, a recent study by Siddiqui et al. (2007) demonstrated that patients with left-to-right shunts, particularly in those with uncorrected VSD, ASD, and arterial ducts, were the most common underlying defects of patients diagnosed with IE.

Nutritional status. The consequence of altered hemodynamics of CHD can have many effects on myocardial function. Children with CHD have the greater metabolic rate and energy requirements because of poor cardiac function and increased heart and respiratory rates. The work of heart and breathing demands all of the children's energy; therefore, little energy is left for activity and growth (Cook & Higgins, 1992; Wong et al., 1999). Moreover, contributing factors of undernutrition in children with CHD may associate with inadequate intake, intestinal malabsorption, and the increased metabolic expenditure of patients in CHF or with frequent infections (Forchielli, McColl, Walker, & Lo, 1994; Zuckerberg, Deutschman, & Caballero, 1995).

Growth and nutritional problems are of special concern to professionals who work with children with CHD. There was a study of growth in children with CHD in China reported that preschoolers with CHD had weights below the 50th percentile more than normal children (Chen et al., 2004). Another study in Thailand found varying degrees of low body weight in children with VSD (Nuglor, 1997). Moreover, there was an increase in frequency and severity of acute and chronic malnutrition after birth among Belgian children with CHD, especially the highest prevalence of acute malnutrition was found in infants and toddlers with CHD (Staebel, 2000). Therefore, malnutrition and growth failure in young children with CHD are widely recognized complications (Green, 2004). However, the severity and pattern of growth impairment is related to the type of cardiac defect and its hemodynamic effects (Varan, Tokel, & Yilmaz, 1999). In patients with increased pulmonary blood flow, a greater proportion of malnutrition was found in infants/ toddlers (Villasis-Keever, Pineda-Cruz, Halley-Castillo, & Alva-Espinosa, 2001), particularly weight is affected more than height (Mehrizi & Drash, 1962; Umansky &

Hauck, 1962 as cited in Leitchu, 2000). In addition, inadequate nutrition is well recognized as a serious problem in children with CHD because of a notable effect on the increasing morbidity and mortality after corrective surgery (Leithchu, 2000; Varan et al., 1999).

Development. Despite the majority of children with CHD show development within the normal range (Cook & Higgins, 1992), nevertheless it is widely accepted that the presence of a congenital heart defect can have deleterious effects on intelligence, development, and academic performance (Griffin, Elkin, & Smith, 2003; Wray & Sensky, 2001). In a study of infants with CHD in Japan, fourteen (18.7 %) of 75 infants had developmental delay in gross motor domain, and three each (4.0%) in the language domain and fine motor-adaptive domain, respectively (Hirose et al., 2007). Among preschool children with CHD, there was one study reported that these children had more suspicious interpretations of developmental skills than normal preschool children, especially in the language and gross motor sections (Chen et al., 2004). Despite preschool children with CHD in another study have been found to have the overall mean developmental scores within the normal range, however, the scores were significantly lower than those of the healthy group (Wray & Radley-Smith, 2004). Additionally, one study reported that among children with CHD 6-65 months of age, children with hemodynamic significance were more significantly delayed in gross and fine motor development and in personal social skills than those with no hemodynamic significance (Weinberg, Kern, Weiss, & Ross, 2001).

Psychological Health

Another area of concern for children with CHD is psychological effect. As in children with other chronic illness, psychological or social dysfunction among children with CHD has been reported in several studies. In the literature investigating the cognitive, behavioral and emotional functions of children with CHD aged 3 months to 7 years, Utens et al. (2001) reported that the children scheduled for cardiac surgery and aged from 2 to 3 years had significantly higher problem scores on the Child Behavior Checklist than did peers from normative groups. Similarly, a study of temperament and chronic illness in Egyptian children showed that children with chronic illness including children with CHD were more persistent/unstoppable, less adaptable, and more difficult than healthy children (Zahr & El-Haddad, 1998). Further, one study in Germany found that children with CHD showed an increased feeling of inferiority and of basic anxiety and a more impetuous behavior (Kramer, Awiszus, Sterzel, van Halteren, & Classen, 1989). In addition, children with CHD demonstrated more medical fears and more physiological anxiety than did the normative children (Gupta et al., 1998).

In summary, the presence of congenital heart defect places children at increased risk for adverse physical and psychological outcomes. Factors underlying this risk are assumed to be a complex result of their primary illness and environment. For children whose CHD remains unrepaired, comphrehensive care should be considered to reduce the overall morbidity and mortality associated with the defect.

Effects of Having a Child with CHD on Family

Childhood CHD like other chronic illnesses has great impact on not only the ill child but also family members. Children with CHD are susceptible to certain problems from the condition and need a unique care from their caregivers to maintain health status within an optimal health. The presence of CHD and fostering the child live with the consequences of heart disease and the treatment result in an immense affect on family. As a result, many researchers have addressed the effects of CHD on family, especially the mothers, over a number of years. Those effects include psychological effects and problems with the child's care.

Psychological Effects

There is evidence in the literature that parents experienced overwhelming emotions when they heard the diagnosis of CHD in a child (Brown, 2003). Findings from qualitative study of Sparacino et al. (1997) also found that those parents struggle as the parents of children with CHD because they experienced distress in various aspects included the dilemmas of normality, disclosure dilemmas, the challenge of uncertainty, illness management dilemmas and strategies, social integration versus social isolation, the impact of illness on the family, and coping with the problem. Moreover, parents of children with heart disease were more likely to report excessive parenting stress than the normative population, especially related to characteristics of the child that make them difficult to parent (Uzark & Jones, 2003). In the investigation of stress and adaptation of mothers and fathers in relation to the type of disability presented by their infants, Pelchat et al. (1999) reported that

parents of children with CHD reported more doubts and stress regarding their parental competence than did parents of non-disabled infants. Particularly, parents of infants with CHD, as well as parents of infants with Down's syndrome, reported greater levels of parenting stress and psychological distress than parents of cleft lip and/or palate or non-disabled infants.

Despite in a study to examine maternal perceptions of parenting infants with CHD by Meyer (1997), the findings showed that mothers of CHD infants did not experience a significantly greater degree of stress than mothers of healthy infants. Interestingly, the author pointed that mothers of CHD infants experienced unique needs and different types of stressors. The results also indicated that mothers of CHD infants were more concerned with the condition and management of their infants' condition including his/her future, time and responsibility involved in care, hospitalizations, and diet. Further, they were concerned with the external resources such as health care availability including medical care costs and traveling for medical care. In addition, it is clear that parents of children with CHD experienced a higher risk of distress and hopelessness than parents of children with other diseases and parents of healthy children (Lawoko & Soares, 2002). Interestingly, prior study has suggested that perceived social support in families of children diagnosed with CHD operated as the resiliency factor between family stress and both parental and family coping (Tak & McCubbin, 2002).

Problems with the Child's Care

Martinson et al. (1997) found that parents of children with cardiac problems faced with severe problems related to care for their children at home included

providing care, financial burden, and prevention of complications. Another study also found that parents of children with CHD rated the need of finance at the high level, while the needs of information, physical, spiritual, psychological, and household management were at a moderate level (Sawangsri, 2001). Morover, the study of care experiences of Thai parents and their school-age children who had heart disease of Nukulkij (1993) documented that parents reported most often about lack of information regarding the disease and its treatment. All parents needed more information about the activities in which the child should or should not participate, as well as, most of them were not sure if they were too strict or lenient in controlling their child's activities.

Concurrently, evidences from research studies revealed that parents of children with CHD were not very knowledgeable in care practice for their child about dental care practice (Karbkaew, Loontha, Netekaew, & Charuchareet, 2001), the effect of diet and dental care on dental decay (Saunders & Roberts, 1997), and the regime, side effects, and interaction with other drugs or food in the child with taking drugs (Chessa et al., 2005). In a preliminary study with 20 mothers of children 0-1 year of age with CHD, Kamproh (2001) reported that most of the mothers failed to provide appropriate dependent care for their CHD infants. For example, 17 of 20 mothers did not prepare low salt diet for their child because the child refused to have low salt diet and did not observe their child' s breathing and fatigue everyday. Also, 19 mothers did not take a regular oral care of their children because they thought that it was not necessary. Moreover, she found that 10 mothers did not give medicine punctually and regularly because they thought that the long-term drug treatment was dangerous. Interestingly, in investigation of knowledge, attitudes, and dental health

practices of 60 families of children aged 2 to 16 years with CHD, Saunders and Roberts (1997) found that parents' knowledge of dental health practice was good, but not universally practiced. The findings showed that 21% of the children never or hardly ever brushed twice a day and 18 % of them had never visited the dentist. These findings may reflect that other factors, not only knowledge, take part in explaining parental dental health practices for children with CHD.

Although the conclusion drawn from the above studies considering the problems in care of parents for children with CHD, in examining health promoting behaviors of mothers for children with CHD aged 6 to 12 years, Chotibang et al. (2001) found that a majority of mothers had proper health promoting behaviors, but some of the behaviors were not appropriate such as behaviors regarding taking their CHD child to visit dentist every six month, seeking information of care for CHD child from various sources and taking the child for vacation. Similarly another study by Asumpinzub (1997) also showed that most of mothers of 3-6 years old children with CHD had proper caring behaviors for children with CHD.

In brief, evidences from previous study have addressed the effects of having a child with CHD on family, especially on the mothers who often perform most of care activity. Empirical findings also support that the provision of care for children with CHD appear to vary and fail to meet optimal healthcare needs of the child in different areas. As much as the studies reflect challenges that mothers attempt to deal with the complex care needs of their children, they are also a call to healthcare professionals to response for their needs.

Dependent Care of Mothers for Toddlers with CHD

The presence of CHD contributes to alteration of hemodynamic patterns and results in health care needs toward health maintenance. According to Orem's Self-Care Deficit Theory (2001), self-care is the practice of activities that individuals must, with deliberation, perform for themselves or have performed for dependents to maintain life, functioning, and development. For children who are in the early stage of physically and psychosocially development, Orem (2001) notes that they require assistance with self-care activities from the responsible adults.

The concept of dependent care, as conceptualized by Orem (2001), is the continuing health related personal regulatory and developmental care provided by responsible adults for infants and children or persons with disabling conditions. Orem (2001) also identifies three types of self-care requisites: universal, developmental, and health deviation self-care requisite as actions that are known to be necessary or hypothesized to have validity in the regulation of aspects of human functioning and development. Thus, responsible adults who perform self-care actions to meet self-care requisites for their dependents are known dependent-care agents. As a number of studies have revealed the needs of care for children with CHD toward health maintenance, prevention and management of complications from the defect, this is especially true for toddlers with CHD who are developmentally unable to assume self-care activities. Since mothers are caregivers who spend more time of caregiving tasks with their children (Clark & Miles, 1999; Hossain et al., 2005); therefore, mothers as the dependent care agents are in positions to bear responsibility in performing self-care actions to meet all of the self-care requisites of toddlers with CHD. The term

dependent care behaviors, then, are proposed in this study as actions that the mothers do in relating to universal, developmental, and health deviation self-care requisites of toddlers with CHD.

When a child is born with congenital heart defect, the presence of this defect often results in an enormous physical and psychological affects on the child. For toddlers with CHD, while they require the same care needs from mothers as other healthy children, the added burden of heart defects places these children in certain areas that need special dependent care activities. To maintain toddlers with CHD's functioning, support development, prevent complication, and control effects of heart defect, their mothers need to perform dependent care behaviors to meet their children's self-care requisites effectively.

The premise of self-care requisite as put forth by Orem (2001) is a formulated and expressed insight about actions to be performed that are known to be necessary or hypothesized to have validity in the regulation of aspects of human functioning and development. They are understood as expressions of action to be performed by or for individuals in the interest of controlling human and environment factors that affect human functioning and human development. There are three categories of requisites, universal, developmental, and health deviation. For toddlers with CHD, self-care requisites should be as the followings:

Universal Self-Care Requisites

Universal self-care requisites are care requirements that are common to all persons during all stages of the life cycles and associated with life processes, maintenance of the integrity of human structure and functioning, and general well-

being (Orem, 2001). Eight universal self-care requisites common to all human beings are suggested: air, water, food, elimination, activity and rest, solitude and social interaction, protection from hazards, and promotion of normalcy. When universal self-care requisites are effectively provided, positive health and well-being will be fostered. For toddlers with CHD, the following is a necessary set of their universal self-care requisites.

Maintaining a Sufficient of Food and Water

Adequate nutrition is essential for normal growth and development of children and plays a critical role in maintenance and restoration of good health. Nutrition plays a vital role in the body's susceptibility to disease because poor nutrition limits the ability to resist infection (Pillitteri, 1999). Children with CHD usually have normal weight for gestational age at birth; yet, growth problems usually become evident early in life (Steltzer, Rudd, & Pick, 2005). These children, including the toddlers, are prone to poor nutrition for several reasons. However, causes of this problem remain controversial and are likely multifactorial. Contributing factors of undernutrition in this population include inadequate intake, intestinal malabsorption, abnormal haemodynamics, and the increased metabolic expenditure in patients with CHF or frequent infections (Forchielli et al., 1994; van der Kuip et al., 2003; Zuckerberg et al., 1995). The severity of nutritional problem in CHD children can range from delay in weight gain to growth impairment; however the risk of developing this problem depends on the type of cardiac lesion and its hemodynamic effects. In children with increased pulmonary blood flow CHD, weight tends to be affected more than height (Salzer et al., 1989; Steltzer et al., 2005; Villasis-Keever

et al., 2001). Thus, appropriate nutritional care and careful monitoring of the nutritional status of toddlers with CHD is necessary to ensure the child's optimal growth and health status.

Generally, during the toddler years, the child's growth is steady but slower than the first year. The average weight gain is about 2.25 kilogram per year, and the height gain average 7.5 centimeter per year (James et al., 2002). By the beginning of toddlerhood, breast or bottle-feeding has decreased in proportion to solid or table food. The required caloric intake for this age is 100 calories per kilogram per day (Velasco-Whetsell et al., 2000). In Thai children, the recommended energy level considered sufficient to meet the requirements of toddlers is 1,000 calories per day and the composition should be 45 to 65 percent of calories from carbohydrates, 30 to 40 percent of calories from fat, and 8 to 10 percent of calories from protein. Moreover, an amount of protein should be 1.4 gram/kg/day or 18 grams/day and the requirement of water is 1,000 milliliter (Nutrition Division, 2003).

Since toddlers will usually eat small amounts at one time, but will eat frequently throughout the day, therefore three small meals and two or three snacks a day will probably be enough to fuel the active toddlers. In general, the food guide recommends the intake of food each day for Thai toddlers, including 3 servings of grains (3 ladles), 1.5 serving of cooked meat (3 tablespoons), 1 serving of milk (240 milliliter), 3 servings of fats (3 teaspoons), 4 servings of fruits (1 serving = 2 medium oranges or 1 banana), and serve vegetable group as needed (Nutrition Division, 2003). This recommendation has some differences in serving size for fruits, vegetables and fat recommended by the United States Department of Agriculture (USDA). According to the food guide pyramid for young children 2 to 6 years old

by USDA, the healthy children should get 2 servings of fruit group (1 serving = 1 medium orange or 1 medium banana), 3 servings of vegetable group (1 serving = 8 tablespoons of chopped raw or cooked vegetable), and eat less of fat and sugar (United States Department of Agriculture, 1999).

Providing adequate intake of nutrients and calories for optimal growth in toddlers with CHD is a caregiving challenge for mothers because the increase in basal metabolic causes the varying caloric needs depending on the child's condition. Particularly in CHD with increased pulmonary blood flow, this type of defect has been found to have an association with growth disturbances in weight more than height. Moreover, children with CHD often have poor appetites. A normal caloric intake may not be sufficient, a caloric intake of 150 percent of normal values for age is necessary to support the normal growth of these children (Nichols et al., 1995).

To promote adequate intake of nutrients and calories, mothers need to create approaches that consider food preferences, high caloric and nutritionally dense food, optimal time of day for snacks and meals, and family dynamics that encourage eating status (Dunn, 2000). Moreover, extra calories and extra protein should be added to the child's diet for instance add dry instant milk powder to whole milk, make hot cereals with whole milk instead of water, and adding eggs to meals (McDaniel, 2003). In addition, the amount of sodium in diet should be restricted in order to lower the congestion of water and sodium in toddlers with CHD who need to control CHF (Senasuthipan, 1995). Therefore, foods for these children should not be highly salted foods, for example salted fish, salted egg, and instant noodle (Sophonthammarak & Phromphan, 2005).

The physical growth of children is a direct reflection of their nutritional well-being and is the most important parameter used in assessing their nutritional status. Generally, weight and height should demonstrate no deviation in norm from their age group (Betz, Hunsberger, & Wright, 1994). Thus, weight and height of toddlers with CHD should be frequently evaluated and growth charts for each parameter can make it possible to visualize how their growth is proceeding. However, toddlers with CHD who are prone to developing CHF, rapid weight gain (more than 200 grams/day) may reflect fluid retention rather than improve nutritional state (James et al., 2002).

Maintaining a Balance between Activity and Rest and Promoting of Normalcy

Physical activity is necessary for psychological as well as physical well-being (Miller, Horgan, & Lipshultz, 2005). During the toddler stage, one major task for the toddlers is to learn to be independent. They learn to walk, run, climb, walk up and down stairs alone, throw balls, kick balls, solve problems, relate to others, and want to do things for themselves (Colson & Dworkin, 1997). This is also a time that toddlers will begin to explore the world around them and try and figure out how things work. Therefore, it is important to give praise and opportunities for exploration.

Generally, VSD, ASD, and PDA without pulmonary hypertension impose little or no limitation on children's physical activity, whereas children with more complex defects will often limit their own level of activities (Craig & Clay, 2002; Kitchiner, 1996). Toddlers with CHD, therefore, can be allowed to maintain an active lifestyle to the best of their physical abilities in order to foster muscle development, coordination, and emotional relationships with siblings and other children. Nevertheless, mothers should pay attention to warning symptoms of breathlessness,

fatigue, chest pain, palpitation, or syncope (Kitchiner, 1996). Also, mothers may be concerned about the dangers of over exertion. Thus, each toddler with CHD, particularly the child with heart defect that have increased pulmonary blood flow and often develop symptom of CHF, should be evaluated individually based on functional capacity and the type of activity involved (Smith, 2001). In this case, mothers need to take reasonable precautions and modify the amount of activity that the child should be allowed to do.

Furthermore, sleep is important to reenergize the toddlers and promote growth and development. During the toddler years, children require approximately 12 to 14 hours of sleep each day with a nap in the afternoon. However, they may begin to resist going to bed or even temper tantrums to postpone separation from loved ones and the exciting events of the day. To help the toddlers with CHD obtain adequate sleep and rest, mothers should set bedtime rituals and consistently be followed. A bedtime ritual provides structure and a feeling of security because the toddlers know what to expect and what is expected of them. Regular schedules, with set bedtimes and a story time or quiet time beforehand, often reduce the bedtime protests and settle for the night (Marks, 1998; Potts & Mandleco, 2002).

Protecting Hazards to Life, Functioning, and Well-being

Prevention of hazards to life, functioning, and well-being contributes to the maintenance of human integrity and to the effective promotion of human functioning and development. For toddlers, because of their lack of judgement related to rudimentary problem-solving skills, levels of physical co-ordination, lack of experience with many situations, and high level of curiosity about the environment,

they are at high risk to accidents and injuries. To meet this requisite, the following dependent care activities are important for toddlers with CHD.

Infection prevention. Children with CHD are susceptible for getting a variety of infections such as respiratory tract infection and sinusitis. Particularly, respiratory tract infections are common in this population. Therefore, mothers should protect toddlers with CHD from close contact with the person with respiratory tract infections. They should be limited to expose to ill contacts by avoiding crowded events and insisting on frequent hand washing. Moreover, they should be cared for having a good hygiene, bathing, and wearing cleaned and dried clothes in order to prevent infections (Sophonthammarak & Phromphan, 2005).

Furthermore, children with CHD are at increased risk of IE in comparison with the general population, but the exceptions are those with isolated secundum ASD (Dajani et al., 1997). IE typically starts at sites that are heavily colonized with bacteria and vulnerable to injury, such as the oropharynx, skin, and gastrointestinal and genitourinary tracts. Thus, toddlers with CHD should be cared by avoiding procedures that could cause bacteria to enter the bloodstream. Also, these children should avoid contacting with anyone who has any type of infection. Moreover, mothers should ask health care provider if their child should take a preventive antibiotic before having any invasive procedures (Alderman, 2000).

Dental health care. Dental health is an important consideration for children with CHD because CHD is a major risk factor in the pathogenesis of IE, a major complication with significant morbidity and mortality (Knirsch et al., 2003). The most frequent procedure associated with IE has been found to be dental procedure followed by cardiac surgery (Niwa, Nakazawa, Tateno, Yoshinaga, & Terai, 2005).

Dental disease seems to be a leading risk factor of IE because transient bacteremia occurs frequently during dental procedures with instrumentation. In addition, poor oral hygiene and plaque accumulation can be the causes of periodontal disease and resulting in bacteremia from normal chewing or brushing the teeth (Smith, 2001). Incidence of IE is known to decrease by increasing patient dental hygiene and use of infective endocarditis prophylaxis (Chatterjee, Das, Kohli, Das, & Kohli, 2004).

Generally, the primary teeth have started coming in between about six months old and at three years old, all twenty come through the gums. Proper care of the teeth is crucial for the toddler with CHD's health and for the alignment of the permanent teeth. As soon as the first tooth comes in, dental care practice is needed to start by their dependent care agents and the habit of oral hygiene is needed to establish in early childhood. Proper dental care includes adequate cleaning, removal of plaque, good nutrition, and regular dental check up. As the toddlers do not have the manual dexterity to adequately clean their teeth, mothers should assume complete responsibility for this action. Moreover, it is important to model a systematic effective cleaning by starting in the same place, following the same pattern of tooth surfaces, and brushing 6 to 8 strokes per tooth (Opperman & Cassandra, 1998). Ideally, teeth should be brushed after every meal and especially at bedtime (Ashwill & Droske, 1997). Regular dental visit for professional cleaning and check-ups should be done every 6 to 12 months and the first dental visit should occur within six months of the eruption of the first primary tooth and no later than twelve months of age (The American Academy of Pediatric Dentistry as cited in Al-Shalan, 2003).

Immunizational care. Immunization is critical to health and well-being of infants and children. However, there are certain children in whom special

consideration needs to be taken in order to optimize overall outcomes. These are children with congenital anomalies or chronic illnesses, who may require hospitalization, surgery, transfusions, or immune globulins. Generally, CHD does not appear to be contraindication to maintaining the recommended immunization schedule. Mothers play an important role in their children's vaccination, including assessing current immunization status, tracking immunization records, recognizing contraindications and complication of vacination, and taking their children to receive vaccines. The recommended immunization schedule for children with CHD during the toddler period is the same as other children, that is the fourth dose of diphtheria, tetanus, pertussis vaccines (DPT), and oral polio vaccine (OPV) at 18 months of age (Department of Disease Control, 2003).

However, as the age for surgical intervention in children with CHD has performed during the early age, potential problems for these children may exist in the scheduling of surgical intervention and maintaining the immunization schedule. Since surgery for congenital heart defects requires hospitalization, the use of cardiopulmonary bypass, and the need for blood component transfusion. Immunization in these children should be concerned about immunization side effects complicating or masking postoperative problems, potential exposure of immuno-compromised patients during hospitalization of a recently immunized child, and problems with adequate seroconversion after blood transfusion (Smith, 2001).

Promoting safety. The toddler years are a time of huge learning. Toddlers are always physically active and exploring all kinds of things. The combination of increased motor skills, immaturity, and lack of experience places the toddlers at risk for unintentional injury. Thus, promoting safety is a responsibility for all dependent

care agents. Mothers should be aware of protecting toddlers with CHD from injury and hazard, as well as keeping up with toddlers' growing mobility and curiosity. To prevent the possibility of hazard and provide a safe physical environment for the toddlers to live and play, dependent care behaviors of mothers should be as the followings (Ashwill & Droske, 1997; Pillitteri, 1999).

1. Check toys often for loose or broken parts
2. Keep small objects that may cause choking away from toddlers
3. Encourage toddlers not to put pencils or crayons in their mouth when coloring or drawing
4. Keep all sharp objects, medicines, poisons, and other household chemicals locked and out of toddlers' reach
5. Safety plugs should be in all electrical outlets
6. Keep toddlers away from appliances such as irons, heaters, and toasters to prevent burns
7. Toddlers should not be unattended in high chairs, or swings
8. Toddlers should not be left near or around water alone

Maintaining a Sufficient Intake of Air

Oxygen is necessary for all voluntary and involuntary activity of the body. The cardiorespiratory system consisting of airway, lung, heart, and blood vessels need to work together to provide oxygen to all cells of the body. In toddlers with CHD, because of their bodies are working harder under the stress of the heart defect, adequate oxygenation and lessening tissue oxygen demand are the priority requisites of these children. For this reason, mothers should be alert to signs of changing in

respiratory function, including respiratory rate, ease of respiration, and color. To maintain an adequate air exchange, the toddlers should be cared by placing them in a good environment, protecting from environmental smoke or dust, and avoiding restrict cloth. In addition, to reduce workload in the heart, metabolic needs of toddlers with CHD should be kept in a minimum by promoting appropriate activities and resting period, protecting from exposure to infections, preserving body temperature, and positioning in a semi-Fowler position to reduce effort of breathings if needed (Hockenberry, Wilson, & Winkelstein, 2005).

Providing Care Associated with Eliminative Processes and Excrements

Control of elimination is one of the major tasks of toddlerhood. The daily excretion of urine for the 2-year-old child is 500 to 600 ml; for 3-year-old toddlers, the amount is 600 to 750 ml in 24 hours (Allender, 2002). Moreover, the toddlers' gastrointestinal tract reaches functional maturity and has one or two bowel movements per day (Potts & Mandleco, 2002). During this stage, the toddlers have more voluntary control of urination and are able to retain urine up to 4 hours before needing to void (Potts & Mandleco, 2002). Also, many older toddlers have sufficient voluntary control of rectal sphincter to accomplish successful bowel training (Allender, 2002).

Generally, toddlers are ready for toilet training when they are 18 to 24 months of age. Nevertheless, successful toilet training depends on the readiness of both the child and dependent care agent. Mothers should know the signs of readiness for toilet training, which include the ability to demonstrate cognitive awareness of elimination, follow directions and communicate understanding elimination needs to

caregiver, remain dry for longer periods of time (more than 2 hours), regular bowel movement, independently dress and undress, and sit, squat, and walk well. A relax approach, with positive reinforcement and praise will aid in toilet training and positive feelings toward the toddlers (Potts & Mandleco, 2002). Moreover, providing high fiber foods and fruits are helpful to establish a regular elimination pattern and prevent constipation (Opperman & Cassandra, 1998).

Maintaining a Balance between Solitude and Social Interaction

Interaction with people becomes increasingly important during the toddler year. By 2 years of age, most toddlers are interested in other children, which is manifested by looking at one another or changing toys. Yet, play before 3 years old is not really shared. Their play is described as "parallel play". That is, toddlers may be doing similar thing with the same toy but each is working independently (Allender, 2002). For toddlers with CHD, mothers can provide opportunity for social interaction by providing opportunity to look at other children or offer a toy. Moreover, mothers should allow their CHD children to participate in everyday family activities, within his/her physical limitations.

Developmental Self-Care Requisites

Developmental self-care requisites are associated with human growth and developmental processes and conditions or events occurring during various stages of a person's life cycle, such as the intrauterine stages, the neonatal stage, infancy, childhood, adulthood, and pregnancy (Orem, 2001). Each individual develops uniquely in society. Conditions and resources that promote the development of

individuals vary within families, communities, and societies. Developmental self-care requisites, therefore, consist of three types: provision of conditions that promote development, engagement in self-development, and prevention of or overcoming effects of human conditions and life situations that can adversely affect human development.

Children with CHD are at risk for delayed neurodevelopment owing to several factors such as the effects of chronic illness, structural brain abnormalities, nutritional problems, and cardiac surgery (Weinberg et al., 2001; Wray & Sensky, 1999). To promote neurodevelopmental competence of toddlers with CHD, the mothers need to understand developmental tasks of this age group and develop strategies to help their child experience appropriate activity that foster normal development without undue cardiac stress.

Motor Developmental Care

During the toddler period, the children appear to spend most of their times to perfect motor skills, especially learning to walk, until they have perfected the skill of walking. The toddlers learn to walk independently, progressing to running, jumping, and then climbing (Velasco-Whetsell et al., 2000). At this period, toddlers also engage in perfecting fine motor skills. Hand-eye coordination improves with maturity and practice. The child can hold and drink from the cup, use spoon without spilling, learn to dressing, hold crayons in fingers, imitate line and circles, and put small objects in bottle (Velasco-Whetsell et al., 2000). The increasing in motor skills allow toddlers more independence in all areas of their daily life.

Since the toddlers should become more independent and explore their environment vigorously, limitation of activities may slow the development of early independence, diminish the child's resilience, and delay the acquisition of normal developmental milestones. Therefore, mothers should encourage toddlers with CHD to do normal activities as much as they can do without making the symptoms getting worse. Dependent care of mothers to promote motor skills during the toddler period should include providing push-pull toys, noise making toys, musical toys; providing art supplies; providing large blocks and balls and providing opportunity to develop their autonomy through dressing, feeding, and playing (Ashwill & Droske, 1997; James et al., 2002).

Cognitive and Sensory Developmental Care

The toddler period is one of the transition as children complete the final stages of the sensorimotor period and begin to develop some cognitive skills of the preoperative period, as defined by Piaget (Pillitteri, 1999). During the sensorimotor period, the infant primarily learns about the world by touching, looking, and listening. Preoperational thought is marked by the development of symbolic thinking, as the child becomes capable of forming mental images and begins to solve problems by mental trial and error. The transition is characterized by the acquisition of language and the development of pretend play (Colson & Dworkin, 1997).

This progression from sensorimotor to symbolic thought occurs typically between 18 and 24 months of age. The child's recognition that one object can represent another becomes highly evident during the play. For example, a block conveniently serves as a car and a bucket becomes a hat. At this stage, the toddlers

are also able to remember actions and imitate past events later. They might pretend to do the dinner dishes, drive a car or put a baby to sleep (Ashwill & Droske, 1997). In addition, they now have developed complete object permanence, finding an object, such as a ball under a blanket, despite not seeing it hidden. The older toddlers continue to develop symbolic thinking. By 3 years, they can draw primitive figures that represent important people in their environment. Also, they can develop elaborate play and imagination. At this age, however, the toddlers still have a number of limitations in cognitive skills. They remain unable to take the viewpoint of another person, continuing to see the world egocentrically and assuming that others think and feel as they do. In addition, they can attend only to one aspect of a problem at a time, as illustrated by Piaget's classic conservation experiment: When shown equal volumes of colored water, and one is poured into a tall, thin container and the other into a short, fat one, the 3-year-old always will pick the tall, thin container as having more water because it appears "bigger" to them.

For toddlers with CHD, mothers can stimulate their child's cognitive development in a variety of ways as in other children. One of the best ways to encourage intellectual growth in toddlers with CHD is to read to them. Mothers should choose books with bright, colorful images and point each object out and tell them what it is. This is a wonderful learning experience for the toddlers and also stimulates their curiosity and enhances their vocabulary. Another way to stimulate the toddler's intellectual development is to expose them to many different activities and places. Take them to the park or simply walk around the garden and point out the different plants, insects, and birds in that place. In addition, mothers should encourage pretending by providing dolls, housekeeping toys, dress-up clothes, or toy telephones.

Language Developmental Care

Toddlehood is a critical time for language development. To master the best in language, the child needs to practice talking. Mothers can do a great deal to encourage language development by talking to the toddlers and incorporating teaching into daily routine. To promote language development in toddlers with CHD can be done as in other children. Outing to both new and familiar places will offer opportunities for verbal interaction and practice of growing language skills (Ashwill & Droske, 1997). Mothers should talk to the toddlers and allow them to talk back, or point to objects in everyday environment and let the toddlers repeat the word in their own language and the mothers say it again correctly. Moreover, mothers can help the toddlers learn words and develop language skills while doing a fun activity with them, for example do simple finger plays, sing simple song, play pat-a-cake, tell short stories, and ask them to name things in the pictures of picture books.

Psychosocial Developmental Care

According to the Theory of Psychosocial Development of Erikson, the developmental task of the toddler is to form a sense of autonomy versus shame. The child who does not develop a sense of autonomy may manifest the feeling of shame or doubt. To develop a sense of autonomy is to develop a sense of independence. If mothers provide opportunities for the toddlers to do what they are capable of doing at each child's own pace and in the child's own time, then the toddlers will develop a sense of being able to control muscles and impulses. On the other hand, if the toddlers are not allowed to do things they want to do, they will doubt their ability to do those actions, stop trying and eventually cannot do those actions. Toddlers who

leave this stage with a sense of shame than autonomy can be disabled in their attempts to achieve independence and may lack confidence in their abilities to achieve well in the future (Pillitteri, 1999).

The diagnosis of heart disease can have affect on dependent care behaviors of mothers for toddlers with CHD. When the toddlers are diagnosed with cardiac problem, mothers are tendentious to overprotect and limit activities because they believe that over activity may result in having worse heart disease condition. Since overprotection and limitation of activities may contribute to improper behaviors and effect development in toddlers with CHD, therefore mothers need to encourage their child's independence, provide opportunities for decision making, and praise for ability to make decisions, at the same time still maintaining consistently the rules for safety.

As the toddlers learn to be independent, they have their own ideas about how things should happen, and want to do things for themselves; it is a greatest challenge for mothers to balance toddlers' need for independence with discipline (Malley, 1991). To discipline means to train or instruct to produce a particular behavior pattern, especially moral or mental improvement, and self-control. Firm discipline promotes the development of autonomy by giving the child a feeling of freedom within bound (Ashwill & Droske, 1997). Although mothers of toddlers with CHD are tendentious to do nothing to upset the child's displeasure, setting limit and maintaining some kinds of control are necessary to ensure the toddlers' safety, limit aggression, and prevent destructive behaviors.

Temper tantrum and negativism are characteristic behaviors frequently seen in toddlers. Temper tantrum is an aggressive display of temper where the child reacts

with rebellion to the wishes of the dependent care agent. Reasoning, scolding, or punishing during a tantrum may be useless. Mothers should remain calm and patient to be nearby until the toddlers gain self-control; or pick up them as calmly as possible and carry them to a quiet, neutral place to regain self-control (Marks, 1998). After the tantrum is over, help them relax by diverting attention with a toy or some other interesting distraction.

Negativism is another dramatic expression of independence in toddlerhood. Negativism may result in screaming, kicking, hitting, biting, or breath holding. Mothers should deal with these behaviors with patience. Limiting the number of questions asked of the toddler and making a statement, rather than asking a question or giving a choice, is helpful in decreasing the number of negative responses from the toddlers.

In sum, if the toddlers have unacceptable behaviors, effective and positive discipline is about distraction, calmly removing from the situation, redirecting, teaching, guiding, and not forcing them to obey or spanking. Discipline should be applied with mutual respect in a firm, fair, reasonable and consistent way. Praise toddlers for good behaviors, when possible, ignore the negative behavior. Moreover, the toddlers should always know that the mothers love and support them (Ashwill & Droske, 1997; Marks, 1998).

Health-Deviation Self-Care Requisites

Health-deviation self-care requisites are associated with genetic and constitutional defects, human structure and function deviations, as well as medical

diagnosis, treatments and their effects (Orem, 2001). Health-deviation self-care requisites exist when persons are ill or injured, have specific forms of defects and disabilities, and when persons receive medical diagnosis and treatment. Health-deviations may result directly or indirectly in the perception of illness or the inability to function normally. These perceptions influence what persons may choose to do to restore normalcy of themselves or their dependents. For a child with CHD, characteristics of the defect determine what mother should do to restore normalcy of the child. The following are health-deviation self-care requisites of toddlers with CHD.

Observation of Congestive Heart Failure

In CHD with increased pulmonary blood flow, the affected children are susceptible to CHF because significant left-to-right shunt causes the heart to work hard in order to pump oxygenated blood to meet the body's demands. When the demand cannot be met, CHF will develop. Therefore, it is essential for mothers to be aware of and attending to signs of CHF. The onset of CHF symptoms is usually gradual with tachypnea (> 60 breaths/min at < 2 years old and > 40 breaths/min at > 2 years old, while asleep), dyspnea, tachycardia, pale, cool, diaphoretic, have poor exercise tolerance, easily fatigued, oliguria, peri-orbitaledema, hepatomegaly, and persistent cough (American Heart Association, 1995; Cook & Higgins, 1992). Besides observing signs and symptoms of CHF, mothers should know how to take care of the toddlers when they have abnormal symptoms, for example, mothers should position the toddlers in inclined posture of 30 to 45 degree to encourage maximum chest expansion and remove any constricting clothing from the chest when dyspnea occurs. The child with CHF is usually quite ill and may be admitted to the hospital.

The earlier the signs are detected, the sooner treatment can be begun (Cook & Higgins, 1992; Wong et al., 1999). In addition, mothers should know how to contact their child's cardiologist at all times.

Administering Medications

Some children with heart defects do not need surgery and some children who need surgery can benefit from medical treatment before and after an operation. Collaborative management using medications in pre and postoperative management are essential to the care of these patients (Miller-Hoover, 2003). A variety of medications may be prescribed based on the child's physiology and cardiac status. For toddlers with CHD, digitalis may be necessary if the child has CHF and they may also have diuretic prescribed (Edwards et al., 1999).

The primary use of digitalis is to increase the strength of cardiac muscle contractility, decreases the heart rate, prolong refractory period of the atrioventricular (AV) node and decrease conduction through the sinoatrial (SA) and AV nodes (Dooley & Bishop, 2002; Wong et al., 1999). The dose of digitalis is based on the child's weight. The preparation most widely used in infants and children is liquid form of lanoxin elixir (50 µg/ml). Oral daily maintenance dosage of lanoxin for children < 2 years is 10-12 µg/kg, and 8-10 µg/kg for > 2 years (Wong et al., 1999). Because lanoxin has a very narrow margin of safety, the dosage must be calculated exactly and given at regular intervals. Thus, mothers should draw up the correct amount of medicine in the medicine dropper or syringe and administer the drug carefully by slowly directing it on the side and back of the mouth. It's best to take this medicine on an empty stomach (1 hour before or 2 hours after feeding),

however, it can be given with a small amount of food if it upsets stomach. The lanoxin should be given at a regular time to keep a steady level in the bloodstream. If one dose is missed, give the missed dose up to 12 hours later. If more than 12 hours have passed, skip the missed dose and give only the next regularly scheduled dose. Mothers should not give a double dose of this medication. If mothers forget to give doses 2 or more days in a row, it is recommended to consult the physician. Withhold dose and notify health care provider, if pulse rate of the toddler is less than 70 beats per minute (Wong et al., 1999). Mothers should be aware of some side effects of lanoxin such as nausea, vomiting, diarrhea, drowsiness, abnormal rapid heart rate, or slow heart rate. Do not discontinue medication without consulting health care provider (Davis Company, 2007). Moreover, mothers should check with the physician or pharmacist before giving any other prescription.

Furosemide is the most commonly used diuretic in children with CHD. This drug is used to reduce the preload of the heart to improve efficiency of the cardiac injection. For maintenance therapy, oral dosage of furosemide is 2-5 mg/kg/day (Hay, Hayward, Levin, & Sondheimer, 1999). The use of large doses of this medication can sometimes lead to electrolyte imbalance, in particular, a loss of potassium (Dooley & Bishop, 2002). Therefore, dose and dose schedule must be given correctly as per the prescription. For toddlers with CHD taking the liquid form of furosemide, mothers should draw up the correct amount of medicine in the medicine dropper or a syringe. Then give a small squirt of the medicine inside the cheek. To avoid choking, let toddlers swallow each squirt before giving more. If the tablet form is prescribed and the toddlers cannot swallow pill, crush medicine between 2 spoons or inside a plastic bag and mix the powder with a very small

amount of water or of soft food. If a dose of medicine is missed, give it as soon as mothers remember and then give the next dose later. Do not give doses closer than eight hours unless otherwise directed by physician. Do not give double dose to make for a missed dose (Sanofi-aventis, 2006).

The use of large doses of furosemide can sometime lead to hypokalemia that may cause rhythm disturbances (Dooley & Bishop, 2002; Miller- Hoover, 2003). Thus, toddlers with CHD receiving diuretic drug should be observed for signs or symptoms of fluid or electrolyte imbalance: dryness of mouth, thirst, weakness, lethargy, drowsiness, restlessness, muscle pains or cramps, muscular fatigue, hypotension, oliguria, tachycardia, arrhythmia, or gastrointestinal disturbances such as nausea and vomiting. Moreover, it is important for mothers to increase amounts of potassium-rich foods in the toddlers' diet, for example bananas, prunes, raisins, legumes, orange and orange juice (Sanofi-aventis, 2006).

Appointment Keeping

The underlying hemodynamic and physiologic instability of many children with CHD may make these children particularly vulnerable to any adverse event. Appointment keeping, therefore, is important for toddlers with CHD in order to get continuing assessment and treatment from physicians regularly. It is mothers' responsibility to be aware of their child's cardiac conditions. Mothers should take the toddlers to see the physician even though not having any abnormal signs and symptoms of cardiac condition. Moreover, mothers should observe other signs that are necessary to consult the physician, for example, dyspnea, fever, cough, or sore throat.

In sum, the added burden of heart defects has placed toddlers with CHD in certain areas that need special consideration. Three types of self-care requisites are needed from the dependent care agents to regulate their function and development. When these self-care requisites are met, the toddlers would be able to maintain human structure and function within a normal range, support development in accordance with the human potentials, regulate and control the effects of pathology, and also promote their general well-being.

Factors Influencing Dependent Care Behaviors in Mothers of Children with CHD

The demands of care for toddlers with CHD appear to be crucial to keep the illness under control. In the Self-Care Deficit Nursing Theory (Orem, 2001), individuals initiate and perform activities on their own behalf in maintaining life, health, and well-being. Self-care assumptions are true except for the toddlers with CHD who are in the early stages of physical development. Generally, mothers are the dependent care agents who response to provide care or assistance with their child's self-care activities. The actions which dependent care agents perform to meet self-care requisites of their dependents are known as dependent care. Specifically, mothers deliberately perform dependent care to maintain life, health, and well-being of their children. Self-care or dependent care is learnt through interpersonal interactions and communications, and as a learning process, it needs motivation, knowledge and skills. Moreover, an individual's self/dependent care ability and self/dependent care behaviors are influenced by basic conditioning factors which include age, gender, developmental state, health state, sociocultural orientation, health

care system factors, family system factors, patterns of living, environmental factors, and resources availability and adequacy (Orem, 2001). When mothers are involved in providing care for their children, several influencing factors have been reported in previous studies. The factors that have been extensively examined in care for children with CHD area and the factors which keep guiding a way to intervene are focused in this study. The selected factors include parenting stress, perceived social support, perceived self-efficacy, knowledge, educational background, and family income.

Parenting Stress

The concept of stress has been used in different disciplines with disparate frames of reference. In the psychological and nursing fields, this concept is a well-known construct. As the work of Orem (2001) provided a theoretical basis for this investigation, stress related to parenting role is proposed in the current study as health state of the mothers under the basic conditioning factors.

Stress is defined as the feeling of tension experienced by a person. It involves both the existence of external stimuli as well as a subjective appraisal of the possible threat or risk caused by the stimuli (Lam, 1999). Stress is thought to arise when an individual perceives a discrepancy between the demands of a situation and their ability to cope with those demands (Quine & Pahl, 1991 as cited in Kelso, French, & Fernandez, 2005).

A specific form of stress related to child rearing, namely parenting stress, has received much research attention. Stress in the parenting role is one of the factors that has been proposed to affect the well-being of parents and their children (Abidin,

1995). Raising a child put primary caregiver is prone to experience stress due to high physical, financial, and emotional demands on caregiving, particularly, the woman seems to experience more stress than man (Ostberg, Hagekull, & Wettergren, 1997). Parenting stress has been conceptualized as a condition where the different aspects of parenthood result in a perceived discrepancy between situational demands and personal resources (Ostberg, 1999 as cited in Sepa, Frodi, & Ludvigsson, 2004). Rodgers (1998) defines parenting stress based on the definition of stress proposed by Lazarus and Launier (1978) as the result of the appraisal of concrete environmental demands associated with the parenting role. According to Abidin (1995) parenting stress is the tension parents feel in fulfilling their parenting functions resulting from parental dysfunctional behaviors or behavioral characteristics of the child. More specifically, Mulsow, Caldera, Pursley, Reifman, and Huston (2002) define specific parenting stress in mothers as a mother's perception, and feelings in response to that perception, that the changes and demands that are associated with the mothering role exceed the resources available for dealing with those demands. In the present study, parenting stress is defined as the tension mothers feel in providing care for their toddlers with CHD resulting from the perception toward their dysfunctional behaviors or behavioral characteristics of their child. Also, parenting stress might affect dependent care behaviors among mothers of toddlers with CHD.

Parenting stress becomes a matter of importance in the provision of care for children. Available studies reveal that parenting stress can affect mothers in several ways, for instance increased risk for poor mental health outcomes (Kwok & Wong, 2000; Ostberg, 1998) and a negative influence on childcare management (Anthony et al., 2005; Culp, Culp, Noland, & Anderson, 2006; Ostberg, 1998). In Orem's

theory, health state factors can bring about human conditions that interfere with or constitute obstacles to meeting self/dependent care requisites (Orem, 2001). Despite parenting stress is not directly mentioned in Orem's concept of basic conditioning factors, evidence from the parenting literature has suggested that this concept may be consistent with health state factor of the mothers. Thus, parenting stress can be conceptualized as health state of the mothers that might bring about effect on dependent care behaviors among mothers of toddlers with CHD.

There is empirical evidence to support the connection between parenting stress and childrearing. Hassall, Rose, and McDonald (2005) conducted a study with 46 mothers of children with intellectual disabilities (ID). Using the Short Form of the Parenting Stress Index (PSI-SF; Abidin, 1995), the results indicated that mothers of the children with higher levels of behavioral difficulties experienced higher levels of parenting stress compared with those of disabled children with fewer behavioral difficulties. Most of the variance in parenting stress was explained by parental locus of control, parenting satisfaction and child behavior difficulties. These findings demonstrate an association between parenting stress and parents' perceptions of health or behavioral problems of their children. Further, the result of this study also documented that the parents who had low availability and number of social support tended to experience greater parenting stress. The finding of a negative correlation between parenting stress and social support is in line with results from other studies. For instance, Rodenburg, Meijer, Dekovic, and Aldenkamp (2007) conducted a study with parents of children with epilepsy and found that higher levels of perception of social support was correlated with lower levels of parenting stress ($r = -.35$, $p < .001$). In providing care for children with Tourette syndrome, Lee, Chen, Wang, and Chen

(2007) found a moderate negative correlation (r = - .46, p < .01) between parenting stress and receiving of informational, emotional, moral, and substantial support. Similarly, parenting stress and receiving of partner/family support have been reported to be inversely correlated (r = - .23, p < .05) among mothers of preschool-aged children with developmental disability (Plant & Sanders, 2007). These findings highlight an important role of social support in parenting stress study.

In Waisbren, Rones, Read, Marsden, and Levy's study (2004), the PSI-SF (Abidin, 1995) was used to obtain data of parenting stress in parents of children with biochemical genetic disorders. The findings showed that the parents reported clinically significant levels of parenting stress. These results consistently reflect the impact of child health problems on parenting stress. However, findings regarding relation between parenting stress and social support is inconsistent with earlier studies. The study showed that number of people in the parents' social support network and parental satisfaction with social support were positively related to parenting stress (r = .37, r = .38, respectively, p < .0001). In a study conducted by Raikes and Thompson (2005), they also found that social support was not related to parenting stress in a sample of low-income mothers. Because research findings regarding relation between parenting stress and social support are inconsistent, these results suggest that more investigations regarding the influence of specific dimension of social support on specific situation of parenting stress is required.

Many authors have been concerned about the effect of parenting stress on behaviors of mothers in providing care for their children. In a study by Pearl (2004), correlations among mother's stress, life satisfaction, child rearing practices, and children's temperament and social-emotional function were examined in 142 mothers

of first grade children. The Parenting Stress Index (PSI; Abidin, 1995) was used to assess mother's stress, and child rearing practices were assessed in terms of nurturance and restrictiveness. A negative correlation was found between parenting stress and nurturing child rearing practices ($r = -.33$, $p < .01$). That is, as parenting stress increased, the mothers demonstrated less affection, acceptance, and responsiveness for their child's needs. Although child care practices in this study focused only on nurturance and restrictiveness aspects, the result demonstrates an effect of parenting stress on maternal care behaviors.

Similarly, Rodgers (1998) conducted a study to assess stress specific to the parenting role or parenting stress and multiple role-related stress affecting parenting behaviors among 85 mothers of young children. The results showed that parenting stress positively correlated with punishment, inconsistency, parental-coldness, sensitization, and rejection-oriented behaviors ($r = .50$, $p < .01$), as well as the multiple role-related stress ($r = .25$, $p < .05$). Moreover, parenting stress both directly and indirectly affected parenting behaviors, but multiple role-related stress indirectly affected parenting behaviors. In addition, the perceived helpfulness of social support buffered the relationship between parenting stress and parenting behaviors.

In another study, Bonds et al. (2002) assessed the direct and indirect relations between 2 types of social supports (parenting support and general social support) and optimal parenting (warmth and monitoring) in mothers of first born fourth grade children between the ages of 9 and 11 years. Parenting stress was also examined as a mediator of the relation between parenting support and optimal parenting. The parenting stress measure used in this study was adapted from the Parental Stress Item scale (Pearlin & Schooler, 1978). The analyses indicated

significant associations between parenting stress and optimal parenting ($r = -.35$, $p < .001$), parenting stress and parenting support ($r = -.33$, $p < .001$), and parenting stress and general social support ($r = -.33$, $p < .001$). Moreover, the relation between parenting support and optimal parenting was completely mediated by parenting stress. Thus, the results of these related studies evidently lend support to the influence of parenting stress on child care behaviors, especially of the mothers.

Parenting stress also has been reported in a few studies of care for children with CHD. Pelchat et al. (1999) conducted a study with 144 mothers and fathers of 6-month-old infants, 16 infants were diagnosed with Down's syndrome (DS), 18 with congenital heart disease (CHD), 19 with cleft lip and/or palate (CLP), and 19 were non-disabled (ND). The adaptation of parents to these infants was examined, including parenting stress, stress appraisal, and psychological distress. Using the Stress Appraisal Measure (SAM; Peacock & Wong, 1990), the results indicated that parents of infants with DS and parents of infants with CHD report greater levels of parenting stress and psychological distress than parents of babies with CLP or non-disabled infants. More specifically, the parents had significantly more difficulties accepting their child, felt more threatened by their parental situation, perceived it as more uncontrollable and more stressful, and displayed more psychological distress. In particular, parents of a child with CHD reported more doubts and stress regarding their parental competence than did control parents. Moreover, the mothers were found to report greater levels of stress and distress overall.

In a study with parents of children ages 2 to 12 years with heart disease, Uzark and Jones (2003) used the Double ABCX model as a conceptual framework to

assess parenting stress with 70 mothers and 10 fathers who accompanied their child to the pediatric cardiology outpatient clinic. By using the PSI-SF (Abidin, 1995), results revealed that parents of children with heart disease were more likely than the normative population to report excessive parenting stress, especially related to characteristics of the child that make them difficult to parent. These parents also had significantly higher stress on the Difficult Child subscale, particularly with setting limits or discipline of the child with heart disease. Interestingly, parenting stress was not related to the severity of the child's heart disease, family socioeconomic status, or time since most recent surgery. This finding is consistent with the study by Morelius, Lundh, and Nelson (2002) on the parents of children with less severe cardiac malformations experience as much parenting stress as do the parents of children with more complex heart diseases.

In conclusion, whilst dealing with everyday child's care has been identified as one of a stressful life event, having a child with medical problems and behavioral problems, including having children with CHD, has been shown to be especially stressful. Despite previous studies showed relationship between parenting stress and care behaviors of parents in variety conditions, however there are few data on parenting stress levels and potential effect of parenting stress on dependent care behaviors among mothers of toddlers with CHD. Moreover, some studies in the literature pertaining to parenting stress suggest that social support might have an important influence on parenting stress.

Perceived Social Support

Social support has been acknowledged as an important concept in nursing due to the potentially strong impact of social support on positive health and psychological well-being (Kitamura et al., 2002). Social support has been defined and measured in different ways. As examples, Krahn (1993) defines social support in a general sense as the supportive assistance, from important others, that addresses perceived needs. Langford, Bowsher, Maloney, and Lillis (1997) provide broad definition of social support as the assistance and protection given to others. Assistance may be tangible as in financial aid or intangible as in emotional help. Moreover, protection may present as shielding people from the adverse effects of life stress. In the Self-Care Deficit Nursing Theory, Orem (2001) proposes that resources availability and adequacy can affect the selection of means to meet self/depenedent care requisites and self/depenedent behaviors. In this study, therefore, perceived social support is linked to the perception of resource availability in basic conditioning factors.

Although definitions of social support vary by different authors, Langford et al. (1997) propose that the attributes of social support can be classified into four aspects: emotional, instrumental, informational, and appraisal support. Emotional support involves the provision of caring, empathy, love, and touch. Instrumental support is referred to the provision of tangible goods and services, or tangible aid. Informational support is described as the information provided to others during a time of stress. Appraisal support is defined as the communication of information that is relevant to self-evaluation or expressions that affirm the appropriateness of acts or statements made by another.

Furthermore, Barrera (1986 as cited in Varni, Setoguchi, Rappaport, & Talbot, 1992) classified social support into perceived social support, social embeddedness, and received (enacted) social support. Perceived social support is referred to the perception of individuals that support would be available when it is wanted. Whereas social embeddedness is described as social support network size, and received social support is defined as the actual support individuals have received in recent situations where they needed it.

In addition, social support can be categorized into different components (Turner, 1983 as cited in Krahn, 1993). These components include alternatives for the person who makes the assessment (respondent versus investigator), the nature of reality assessed (perceived versus enacted), the metric used (intensity, frequency, or durability), the content or kind of support (love, status, information, aid), the status of utilization (utilized versus accessible), the social role of contacts (for example, spouse, friend, co-worker), and the focus of the problem (general versus focused problem).

Social support serves a variety of functions such as providing guidance, social reinforcement, and tangible assistance (Connelly, 1998). Cohen and Wills (1985) proposed that there have been two major hypotheses regarding effects of social support: a direct (main) and a buffer effect. The direct effect hypothesis postulates that social support is associated with well-being directly irrespective of the exposure to stressful life events. A buffering effect, on the other hand, suggests that high levels of social support protect in the face of adverse life events. Empirical support exists for both the direct and buffering effects of social support. Moreover, in reality they are not in opposition to each other, because it is now recognized that

social support influences wellbeing directly as well as indirectly through its effects on stress (Skok, Harvey, & Reddihough, 2006). The power of social support lies in its capacity to supplement the individual's experience because it is protective and facilitates coping with stressful events and adaptation to change. As noted, basic conditioning factors are variables that influence individuals' requirements for self/ dependent care and self/dependent care agency. The availability and adequacy of resources was proposed to have effect on the selection of means to meet self-care requisites and the associated self-care behavior (Orem, 2001). Thus, perceived social support will be investigated in this study as the resource that can have effect on to dependent care behaviors of mothers for toddlers with CHD.

In a review of literature on care for children, there is evidence showing that social support is important for a child's care. In the longitudinal study by Amankwaa, Pickler, and Boonmee (2007), the variables including postpartum depression, social support, stressors, self-esteem, maternal well-being, and maternal attitude were examined to determine the correlation with maternal responsiveness. The Postpartum Support Questionnaire was used to measure the importance of specific support and actual support received in 23 mothers of preterm infants. Despite the study sample was quite small, social support was found to have a moderate positive relationship with maternal responsiveness ($r = .42$, $p < .05$) and level of everyday stressors had a significant inverse relationship with maternal responsiveness ($r = -.31$, $p < .05$).

Ruchala and James (1997) conducted a study to explore the influence of social support on maternal confidence in performing infant care tasks among adolescent and adult mothers. Part 2 of the Personal Resource Questionnaire (PRQ; Weinert & Brandt, 1987) was used to measure the respondent's level of perceived

social support. The study revealed that perceived social support was positively correlated with confidence in providing infant care in both adolescent ($r = .28$, $p < .001$) and adult mothers ($r = .30$, $p < .001$).

Consistent with previous study, Santati (2005) studied the causal relationship among perceived social support, family hardiness, quality of professional care, and caregiver burden as they related to asthma management abilities of 253 parents of the preschool asthmatic children. The Social Support Questionnaire (SSQ) developed by Pipatananond (2001) was used to assess perceived social support, including provision of information, emotion, and tangible support that caregivers got from: 1) family members; 2) siblings and relatives; 3) friends, co-workers, and neighbors; 4) other providers in the community. Results showed that perceived social support positively correlated with asthma management abilities ($r = .32$, $p < .01$), and with family hardiness, ($r = .23$, $p < .01$); but negatively correlated with caregiver burden ($r = - .15$, $p < .05$). Moreover, perceived social support had an indirect influence on asthma management abilities through caregiver burden ($\gamma = .06$, $p < .05$). These findings evidently support the influence of perceived social support on care behaviors of the mothers.

The relationship between perceived social support and child's care is affirmed in Bonds et al.'s (2002) study. In assessment of the relations between two types of social support (general social support and parenting support) and optimal parenting (warmth and monitoring) among 165 married mothers of first born fourth grade children between the ages of 9 and 11 years. The Interpersonal Support Evaluation List consisting of four subscales: appraisal, belonging, tangible, self-esteem, was used to measure the general social support. A measure of parenting support from

family and friends was developed by the authors for this study. The results revealed that optimal parenting positively correlated with general social support ($r = .28$, $p < .001$) and with parenting support ($r = .17$, $p < .05$). However, optimal parenting negatively correlated with parenting stress ($r = -.35$, $p < .001$). Furthermore, results from path analysis indicated that perceived general social support had a significant direct relation with optimal parenting when controlling for parenting stress or general psychological distress. Yet, the relationship between specific parenting support and optimal parenting was completely mediated by parenting stress. These findings support the association between social support and optimal parenting, however, each type of support has distinct pathway in relation to parenting behaviors.

Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) examined the relationships of stress and social support to maternal attitudes and early mother-infant interactive behaviors in 52 mothers-premature infant pairs and 53 mothers-full-term infant pairs. The social support measure adapted from Henderson's scale was used to measure the present or absence and satisfaction with available of social support at three levels: 1) intimate relationships 2) friendships, and 3) neighborhood or community support. The study found no significant group differences on any of the measures. Mothers of premature and full-term infants with greater stress were less positive in their attitudes and behaviors, while the mothers with greater availabity of social support had more positive attitudes and maternal behaviors. These results indicate the importance of stress and social support to mother-infant interactive behaviors.

Regarding effects of social support on psychological well-being of mothers, Hassall et al. (2005) used the Family Support Scale to measure the total number of

sources of support available to mothers of children aged 6 to 12 years with intellectual disabilities. The results indicated that there was a strong correlation between family support and parenting stress ($r = -.49$, $p < .001$). Interestingly, the subscale of the family support measuring the number of sources of support available for mothers showed no correlation with parenting stress. Thus, the critical variable seems to be the perceived helpfulness of the support received by mothers rather than the range of supports. This is consistent with a study of relationships between social support, stress and mother-child interactions in 30 mothers with intellectual disabilities by Feldman, Varghese, Ramsay, and Rajska's study (2002). In this study, the Telleen Parent Social Support Index was used to measure the number of social support network (resource size), perceived satisfaction with social support, and need for social support. Satisfaction with social support, but not resource size, was found negatively correlated with total score of parenting stress ($r = -.33$, $p < .05$), and support need also positively correlated with parenting stress ($r = .56$, $p < .01$). Only social support satisfaction ratings were positively correlated with positive maternal interactions ($r = .53$, $p < .05$).

Interestingly, Asberg, Vogel, and Bowers (2008) conducted a study to explore relationships among parenting stress, social support, and mode of communication in parents of children with hearing loss. Zero order correlations were calculated to assess relationships among variables. The findings indicated a significant negative correlation between parenting stress and perceived adequacy of social support ($r = -.41$, $p < .01$). However, significant correlation was not found between received social support and parenting stress scores. Specifically, perceived social support was a significant predictor in the overall model of parenting stress, while receipt of

support was not. In addition, this study found that parents' perception of social support adequacy was not related to actual receipt of support. These findings support not only the effect of perceived social support on parenting stress but also support the notion that perceived social support and receipt of support are distinct constructs.

In providing care for children with CHD, few researchers have studied social support among parents of this group of children. Lawoko and Soares (2003) conducted a survey study to compare social support experiences among 691 parents of children born with CHD (PCCHD), 74 parents of children with other diseases (PCOD) and 162 parents of healthy children (PCH). Social support was assessed with the Schedule for Social Interaction (Unden & Orth-Gomer, 1989), consisting of items involved social attachment in terms of availability of deep emotional relationships and social integration in terms of availability of peripheral social networks. The analysis indicated that availability of social support was low among all parents, with no significant differences between PCCHD, PCOD, and PCH. Moreover, mothers within all parent groups had lower availability of social support than fathers, with the lowest availability among mothers of children with CHD.

In another study with 92 families of a child under age 12 diagnosed with CHD within 3-4 months, Tak and McCubbin (2002) explored the relationships of family stress, perceived social support, and coping and determined the resiliency factor associated with coping by families who have a child with chronic illness. Perceived support was measured using the self-report Personal Resources Questionnaire Part-II (PRQ-85) (Weinert & Brandt, 1987). They found that family stress was a significant predictor for maternal perceived social support ($\beta = -.30$, $p = .004$), accounting for 9% of the variance in this. Maternal perceived social

support made a significant contribution to the prediction of maternal coping (β = .39, p = .000), accounting for 15% of the variance. Regarding fathers of children with CHD, family stress was a significant predictor of paternal perceived social support (β = - .20, p = .05), accounting for 4% of the variability. Paternal perceived social support made significant contribution to the prediction of paternal coping (β = .29, p = .007), accounting for 10 % of the variability. Interestingly, a non-significant direct effect was found between family stress and coping among mothers and fathers. Findings from this study provide evidence for the empirical significance of perceived social support as a factor influencing the resiliency of parents who have stress.

In short, social support is considered as a multidimensional construct. Previous studies have shown effects of social support on the provision of care for children in many conditions. However, the differences in sources, types, and measurements of social support might make interpreting findings difficult. In providing care for the children with CHD, earlier studies show that this situation could lead to major changes in life of their mothers including suboptimal care, parenting stress, and having lower availability of social support. Indeed, few studies have examined the associations and possible influence of the perception of available support among mothers of children with CHD.

Perceived Self-Efficacy

The concept of self-efficacy has been widely used in clinical, educational, social and organizational health contexts (Beas & Salanova, 2006). Self-efficacy was introduced by Albert Bandura, a psychologist who used Social Cognitive Theory as a

conceptual basis for analysis of this construct (van der Bijl & Shortridge-Baggett, 2002). In this sense, beliefs of self-efficacy produce effects through cognitive, motivational, affective and selective processes (Bandura, 1997). According to Bandura (1997), perceived self-efficacy refers to one's judgement of how effectively individuals can organize and execute the designated types of performances. Thus, in the current study perceived self-efficacy in mothers of toddlers with CHD can be used as an expression of the extent to which mothers have developed self-belief in their ability to carry out different dependent care tasks and responsibilities.

Although self-efficacy has not been mentioned in the Self-Care Deficit Nursing Theory, this construct has been conceptualized as motivation which is one of ten power components of self-care agency or capability to perform self-care in several studies (Onchim, 2002; Tantiwaraskool, 2003; Varitsakul, 2001). Moreover, in a study by Carroll (1995), self-efficacy was investigated by linking to the estimative-transitional phase of self-care agency which involves the investigation and identification of effective and desirable courses of action and the decision to pursue self-care actions. Similarly, Callaghan (2005) proposed that transitional capability of self-care operations involves the judgment of one's ability for self-care that is consistent with the conceptualization of self-efficacy.

Drawing on the Orem's Theory, the complex acquired ability of individual to know and meet self-care requirements is refered to as self-care agency and consists of three types of capabilities: foundational capabilities and dispositions; power components enabling for self-care operations; and capabilities for self-care operations. As perceived self-efficacy involves the judgement of how effectively individuals can organize and execute a designated type of performances. In this

study, perceived self-efficacy can be 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.

The self-efficacy literature supports its importance in influencing and predicting behaviors in several areas, as well as in various aspects of care for children. Cluskey (1999) investigated the predictive value of maternal perceived self-efficacy and maternal perception of health as they relate to healthy lifestyles in young children from low income families. Data were obtained from 94 mothers of children aged 24 to 48 months. The Parent's Survey on Child Health Practices was used to measure healthy care behaviors for young children (nutrition, safety, dental hygiene, immunization, personal hygiene, sleep and rest, and exercise) and the Toddler Care Questionnaire (TCQ) was used to measure maternal self-efficacy. A significant correlation was found between maternal self-efficacy and healthy lifestyles of the young children ($r = .3858$, $p < .01$). Maternal self-efficacy also was found to be a predictor of healthy lifestyles of the young children accounting for 14.8 % of variance. The findings of this study support the important role of maternal self-efficacy as an antecedent of providing quality care for their children.

Similarly, in the Seo's study (2003), mothers with higher self-efficacy tended to provide better home environments for toddlers. The Maternal Self-Efficacy Scale and the Toddlers Care Questionnaire were used to measure maternal self-efficacy among mothers of children aged 0 to 36 months based on the child's age. The results revealed positive relationship between age of mothers and maternal self-efficacy, as well as parenting stress and maternal self-efficacy. However, a significant relationship between maternal self-efficacy and quality of rearing environment provided by the

mother was found only among mothers with toddlers ($r = .40$, $p < .01$). This finding suggests that the contributing role of maternal self-efficacy in providing care for different child age group may be different.

Sanders and Woolley (2005) conducted a study to examine maternal self-efficacy, dysfunctional discipline practices and child conduct problems among 45 mothers of 2 to 8-year-old children with conduct problems and 79 mothers from the community. The General Self-Efficacy scale (GSE) was used to assess an individual's global and stable perceptions of competence to effectively deal with stressful situations, the Efficacy subscale of the Parenting Sense of Competence Scale (PSOC) was used to assess maternal self-efficacy, and the Parenting Tasks Checklist was used to assess mothers' task-specific self-efficacy (Behavioral Self-Efficacy). The results showed that mothers of children with conduct problems reported significantly lower self-efficacy than mothers from the community for all but one of the parenting tasks assessed. The global, domain and task self-efficacy were all negatively related to dysfunctional parenting practices, but relations between social support and self-efficacy was not found. In the sample as a whole, self-efficacy measures were significant predictors of maternal discipline style both parental overreactivity (harsh discipline) and laxness (permissive and inconsistent discipline) after controlling for other parent, child and risk factors. Of the self-efficacy variables, behavioral self-efficacy was the best predictor of mothers discipline style. These results indicate the important role of self-efficacy to maternal childcare behaviors. Despite social support has been identified as a variable that can lessen the impact of crisis related to child caregiving, this study did not support the contribution of perceived social support to self-efficacy.

In a study of the roles of parental self-efficacy, social support, and religious coping in a sample of 104 low income African American parents, Dalumpines (2005) used the Interpersonal Support Evaluation List (ISEL) to get information of different types of social support: appraisal, belonging, tangible, and self-esteem. The efficacy factor of the Parenting Sense of Competence Scale was used as the Parental Efficacy Scale. In examining correlations among study's variables, parental self-efficacy was found to be positively related to appraisal, belonging, tangible, and self-esteem social support ($r = .30, .37, .52, .38$, $p < .01$, respectively). The influence of social support on parental self-efficacy also has been shown in a study by Greenberg (2004). The relationship of the social environment to the parenting self-efficacy was explored in 20 families of children under 5 years with autism. Diversity of social support dimensions were assessed including perceived availability of social support, satisfaction with support, and perceived received support and conflict. Sense of efficacy in caring for the child in family was found to be related to support received ($r = .61$, $p = .01$).

Furthermore, Hess, Teti, and Hussey-Gardner (2004) studied the relations of maternal self-efficacy and knowledge of child development to maternal behavioral competence among mothers of high-risk infants. Sixty five mothers completed questionnaires regarding self-efficacy (The Maternal Self-Efficacy Scale; Teti & Gelfand, 1991) and knowledge of child development and were assessed for behavioral competence during a 10-min. free-play session with their infants. The results showed that there were no independent contributions of maternal self-efficacy or knowledge of development in predicting maternal behavioral competence ($r = -.07$ and $.12$, respectively, $p > .05$). However, the relation between maternal self-efficacy and

maternal behavioral competence was moderated by maternal knowledge of child development. Six percents of the variance in maternal behavioral competence was accounted for, by the interaction of maternal self-efficacy and maternal knowledge of child development. These results suggest that neither maternal self-efficacy, nor knowledge, be by itself related to maternal behaviors. The relation between maternal self-efficacy and maternal behavioral competence is moderated by maternal knowledge.

Regarding the relationship between maternal self-efficacy and maternal knowledge, result from Hess et al. (2004)'s study is not consistent with findings by Ruchala and James (1997). In a study of influence of social support and knowledge of infant development on maternal confidence in performing infant care tasks among adolescents and adult mothers, Ruchala and James found that knowledge were correlated with confidence in providing infant care in both adolescent and adult mothers ($r = .39, .28, p \leq .001$, respectively). Moreover, knowledge of infant development of adolescent mothers, accounted for approximately 15 % of the variance in confidence in providing infant care scores. Thus, more study to examine the influence of knowledge on maternal self-efficacy among mothers of toddlers with CHD may enhance existing understanding of their relationship.

In study of children with CHD, Chottivitayatarakorn (2000) conducted a quasi-experimental study with 30 mothers of newborn to 1 year old children with CHD. After enhancing maternal perceived self-efficacy through suggestions, demonstrations, practice, group discussions, guidelines for care practice, self-monitoring, and a prompt reminder letter, the mothers were more likely to have improvement in maternal perceived self-efficacy and maternal caring behaviors. Although this study is a one

group, pre-post test study, the significance of findings is particularly important to remind the effects of maternal perceived self-efficacy and maternal care behaviors for children with CHD, especially among mothers of toddlers with CHD.

Using Roy's Adaptation Model as a conceptual framework, Mornmoung (2001) explored the adaptation in caring for infants with CHD among 110 Thai mothers. In this study, the scale developed by Chottivitayatarakorn (2000) was used to measure maternal self-efficacy. The results demonstrated that majority of mothers had appropriate self-efficacy and adaptation. Moreover, the regression analysis indicated that the combination of maternal self-efficacy and age of mother could significantly explain 36.8 % of the variance in maternal adaptation in caring for infants with CHD ($p < .001$).

To summarize, a number of studies have demonstrated the contribution effect of self-efficacy to maternal care behaviors for children in different situations, but few studies are found in the area of maternal care behaviors for toddlers with CHD. Research evidence also suggests an influential effect of some factors, particularly social support and knowledge on self-efficacy. Therefore, interventions that enhance self-efficacy to modify behavior may be insufficient to promote maternal care behaviors, if other factors are not fulfilled.

Knowledge

Childcare behaviors are multiply and complexly determined. Knowledge, one dimension of cognition, has been recognized as a significant influencing factor of high quality maternal care behaviors (Huang, Caughy, Genevro, & Miller, 2005).

In this study, knowledge is proposed as the personal factor of an individual that is inherent in self-care agency that will aid mother of toddlers with CHD to understand, judge and make decisions about dependent care action. According to the Orem's theory (2001), individuals need to have knowledge of themselves and knowledge of environmental conditions in order to make a decision about the actions they will/or will not perform. Therefore, mothers of toddlers with CHD who have more knowledge of their child's disease is anticipated to be more successful in providing dependent care behaviors.

The influences of knowledge on mothers' childcare behaviors have been supported by research evidence. For example, in a study conducted by Pacharuniti, Sithan, Lapying, and Kiewkarnka (2004), oral health preventive behavior was examined among 185 mothers of preschool children. The results showed that the majority of the mothers (60.75%) had high level of knowledge in oral health. Importantly, a significant association was found between mothers' knowledge on oral health and oral health preventive behavior with p-value < .05.

The relationship between maternal knowledge and childcare behaviors is also found in a study by Anh, Hongkrailert, and Sermsri (2007). A cross sectional descriptive study was conducted to identify factors related to preventive behaviors on home injury among 205 mothers of children under five years old in Vietnam. A structured interview questionnaire was used for data collection. In this study, the findings revealed that there was a significant association between the mothers' preventive behaviors and mothers' knowledge levels (χ^2= 10.74, df= 2, p < 0.05). Consistently, Huang et al. (2005) investigated the association between maternal knowledge of child development and quality of parenting behaviors among 378

White, African-American and Hispanic mothers. The study showed that maternal knowledge significantly associated with parenting behaviors. Thus, the result of this study also supports the relationship between maternal knowledge and good childcare behaviors.

CHD is a malformation of the heart that requires ongoing care to avoid adverse complications. The goal of care for a child with CHD is to achieve a stable, asymptomatic state with the possible hemodynamic function, and continuing growth and development. Given the unique challenges inherent in providing care for children with CHD, greater knowledge about the disease is important to increase mothers' understanding and may consequently perform a better health related behaviors especially for young children. However, only a few studies have examined knowledge of CHD among parents of the affected children.

In a cross sectional survey, Cheuk, Wong, Choi, Chau, and Cheung (2004) assessed understanding of parents regarding their CHD children in various knowledge domains and identified significant determinants of parental knowledge. The questionnaire of knowledge under three domains: nature of heart disease and its treatment; impact of heart disease on exercise capacity; and infective endocarditis and its prevention were completed by156 parents of children with relatively simple CHD. The results revealed that 59% of parents correctly named their child's disease. About half of the parents were aware of possible aetiologies and of the hereditary nature and symptoms attributable to underlying heart disease. Interestingly, of the 56 parents whose children were taking cardiac medications, only 25 (44.6%) and 4 (7.1%) knew correctly the functions and important side effects of the medications, respectively. These findings are consistent with report from qualitative study in

Thailand by Nukulkij (1993) on less knowledge of medication's action and side effects among parents of school-age children with CHD. With regard to infective endocarditis, slightly more than half of the parents were aware of the need for antibiotics before dental procedures. Significant determinants of knowledge in the nature of heart disease were cardiac diagnosis, occupation of parents, and their educational level. However, the study failed to identify any significant determinants of parental knowledge in the other two domains. Findings from this study show that parents of children with CHD have important knowledge gaps, whereas some factors are found to be determinants of the parents' knowledge.

Beeri et al. (2001) examined parental knowledge and attitudes among 74 families of outpatients children with CHD. The parents were asked to answer the question "what is your child's heart problem?" and to give an assessment of the problem's severity and the child's perceived prognosis. The parents were also asked whether they would undergo a prenatal echocardiogram in future pregnancies and whether they would consider terminating a pregnancy should a heart defect be found. Another part of the questionnaire related to parental knowledge on the necessity of dental hygiene and the need for prophylactic antibiotics before dental procedures. The results revealed that eighteen percent of the parents failed to describe their child's malformation correctly. Only a small minority of the families (8.5%) was unaware of the need for prophylaxis. Moreover, parental understanding of the heart defect was correlated with parental education. These findings further support an evidence of less parental knowledge of their child's disease and indicate an association between parental knowledge and their educational background.

In another study, however, finds that nearly all of the parents seem to have correct understanding and perception of their child' small VSD. Lok and Menahem (2004) conducted a study to determine the understanding and perception of parents following the diagnosis of a small VSD in their child. Questionnaires were distributed to 40 parents of the infants and children diagnosed with a small VSD. The findings showed that close to 80% of the parents perceived the small VSD as a minor problem and most understood the nature of the defect, but only two-thirds of the parents recalled the need for antibiotic prophylaxis for their child.

In summary, even though findings from the literature suggest that parental, especially maternal, knowledge has a close relationship with high-quality childcare behaviors. However, the past studies have been found in different specific situations. Thus, interpretation of the relationship and inferring those findings to particularly care for children with CHD, should be made with caution. Moreover, studies on the knowledge of parents of children with CHD are limited and showed mixed results. Less is known about maternal knowledge of toddlers with CHD and how this knowledge relates to their dependent care behaviors. Hence, further study is needed to shed the additional light on maternal knowledge of toddlers with CHD and confirm relation of maternal knowledge on their dependent care behaviors.

Educational Background

Many factors can affect the self/dependent care of an individual. Of the person's internal factors, educational background is linked under the sociocultural orientation of the basic conditioning factors in the Orem's theory (2001). Education

may be seen as a proxy for increasing cognitive appraisal skills and problem-solving skills necessary to deal effectively with self/dependent care. The evidence of relationship between education of mothers and their childcare behaviors has been demonstrated in a variety of situations. In examining influence of the maternal and household characteristics on the provision of good childcare (child feeding, use of preventive health services, and hygiene) in Pakistan, Iram and Butt (2004) found that the level of mothers' education positively associated with the provision of good childcare.

In a national survey with 2,515 mothers of infants and toddlers aged 4 to 24 months, Hendricks et al. (2006) examined the relationship between maternal/child characteristics and practices of feeding. The findings indicated that having a college education was the maternal characteristic associated with the largest number of positive child feeding behaviors. Moreover, mothers with a college education were significantly more likely to comply with the American Academy of Pediatrics juice and complementary feeding recommendations. In addition, infants and toddlers whose mother had a college education were more likely to consume fruits and less likely to consume sweetened beverages and desserts or candy.

Based on data from the 1999 National Health Interview Survey in the United States, Kuhlthau, Nyman, Ferris, Beal, and Perrin (2004) examined patterns of specialist use (having seen or talked to a medical doctor who specializes in a particular medical disease or problem about the child' health) among 11,338 children and adolescents with a chronic condition or disability aged 2 to 17 years old. The logistic regression showed that the use of specialist care was lower among children in families with lower parental educational levels and family income under 200 % of

the federal poverty level. Consistently, in examining the utilization of medical and health-related services among 3,061 children between 5 and 17 years with chronic conditions, the analyses showed that parental education was one of three variables that were significantly associated with multiple medical and health-related services. Children from less educated families were significantly less likely to use many of the services. This study has demonstrated that parental education was important in determining healthcare services for children with special healthcare needs (Weller, Minkovitz, & Anderson, 2003).

While research studies in child rearing demonstrated evidence of association between educational level of parents and variety of child care activities, Mornmoung (2001) also found a moderate positive significant correlation between education of mothers and maternal adaptation in caring for infants with CHD ($r = 0.38$, $p < 0.001$). Furthermore, the relationship between education of mothers and maternal caring behaviors for children with CHD is affirmed in Asumpinzub's study (1997; $r = 0.25$, $p < 0.01$).

Based on existing studies, it can be concluded that educational background of mother is one contributing factor of maternal childcare behaviors. However, few studies are found in the area of care for children with CHD. More empirical investigation is needed to provide evidence for the claim that educational background is one of a key influencing factor of dependent care behaviors among mothers of toddlers with CHD.

Family Income

Many researches have highlighted the role of various socioeconomic variables in childcare and family income is considered to be one of the major factors. Family income is considered as a personal resource which can affect the individual's engagement in self/dependent care (Orem, 2001). The income is important in generating resources for the child (Goyal & Kaur, 2007). While mothers with economic hardship struggle for the survival of their families, for instance paying for food, accommodation, clothing, education, utilities, as well as health care; it is possible that mothers with adequate income are in a better position to exploit economic resources to manage their child's health and perform their childcare duties with full attention. Thus, family income is considered as a key resource that can influence dependent care behaviors of the mothers in the current study.

In related literature, family income appears to be associated with childcare in some studies. Based on the United States National Maternal and Infant Health Survey in 1988, Ronsaville and Hakim (2000) found that the mothers with low income had risk to provide inadequately well childcare. Also, there is evidence that family income level is positively related to quality of childcare for preschoolers in Pakistan (Iram & Butt, 2004). Another parenting activity that has received some attention in relation to family income is physical punishment. Wissow (2001) conducted a survey study with 2,017 parents with children younger than 3 years old to explore parenting contexts of physical punishment. Family income has been found to be strongly associated with the use of physical punishment. Interestingly, the relationship was not in a linear fashion. Families with higher and lower income were

more likely to report less spanking than families with annual household incomes in the $ 20,000 to $ 30,000.

Among the few studies that have examined associations between selected factors and care behaviors of mothers for children with CHD, Azumpinzub (1997) conducted a correlational study with 120 mothers of 3-6 years children with CHD. The study found a low significant positive relationship between family income and maternal caring behaviors ($r = 0.28$, $p < 0.01$). Thus, the result of this study also supports the influence of family income on maternal childcare behaviors.

In sum, studies demonstrating relationship of family income to childcare behaviors were found in variety of situations. To date, even though the universal health care coverage program contributes to an increasing access to care among lower income population in Thailand, however, health care coverage program alone may not be sufficient to remove barriers to dependent care behaviors in mothers of toddler with CHD. Thus, the additional attention is needed to investigate the influence of family income on those mothers' care behaviors.

In conclusion, the literature review has revealed that CHD contributes an enormous impact on both the child and their parents. Mothers, as the dependent care agents require extensive efforts in providing care to meet their child's care requirements, especially toddlers with CHD whom waiting for surgical management. Even though, research study has provided evidence that parenting stress, perceived social support, perceived self-efficacy, knowledge, educational background, and family income are correlated with childcare behaviors. However, the review of the

literature has shown that little research has covered mothers of children with CHD, particularly mothers of the toddlers. Moreover, correlational study cannot draw the predictive power conclusions. With regression analysis from this study will help healthcare providers gain a better understanding of dependent care behaviors in mothers of toddlers with CHD and the variables that affect their behaviors. From this research, a more effective intervention program, therefore, can be designed to help mothers of toddlers with CHD improve their behaviors and also their child's health.

Theoretical Framework

The theoretical framework of this study is guided by the Orem's Self-Care Deficit Nursing Theory (Orem, 2001). According to Orem's theory (2001), self-care is a human regulatory function that individuals must, with deliberation, perform for themselves or have performed for dependents to maintain life, functioning, and development. The person who engages in self-care is known as self-care agent or dependent care agent for the person who provides self-care activities for his/her dependent. Orem (2001) identifies three types of self-care requisites: universal, developmental, and health deviation self-care requisite as actions that are known to be necessary or hypothesized to have validity in the regulation of aspects of human functioning and development. Individuals are assumed to have self-care agency or ability to meet one's own self-care requisites and to participate in self-care practice. Self-care agency is a broad concept that includes three capabilities: foundational capabilities, power components, and self-care operations. Furthermore, factors internal or external to individuals known as basic conditioning factors may affect

individual's abilities to engage in self-or dependent care practice (Orem & Taylor, 1995). The basic conditioning factors consist of age, gender, developmental state, health state, sociocultural orientation, health care system factors, family system factors, pattern of living, environmental factors, and resources availability and adequacy (Orem, 2001).

For toddlers with CHD who have health deviation and be developmentally unable to assume self-care activities, their therapeutic self-care demand needs to be assisted by the responsible adults. Mothers as the major dependent care agents are in positions to bear responsibility in performing care actions to meet universal, developmental, and health deviation self-care requisites of the toddlers with CHD. These actions are known as dependent care behaviors. Based on the Orem's theory, it is anticipated that relevant factors that basic conditioning factors and self-care agency may affect dependent care behaviors among mothers of toddlers with CHD.

According to Orem (2001), health state can bring about conditions that interfere or constitute obstacles to meeting self / dependent-care requisites. Accordingly, parenting stress is proposed in this study under basic conditioning factors as health state factor of the mothers. Perceived social support or the perception that mothers are able to count on others for assistance, emotional support, or information is considered a basic conditioning factor that provides essential resources for the mothers in performing dependent care for their toddlers with CHD. Educational background is linked under the sociocultural orientation. Education may be a proxy for increasing cognitive appraisal skills and problem-solving skills necessary to deal effectively with a situation. Mothers with higher level of education may increase the likelihood to obtain or understand health related information needed for performing care for their toddlers

with CHD. Family income is considered as resource in the availability and adequacy of resources in Orem's perspective. This factor is important for mothers of toddlers with CHD to engage in dependent care behaviors because it can facilitate each mother to fulfill the necessity for basic needs, healthcare information and healthcare service options. Knowledge is required for engaging in self/dependent care actions (Orem, 2001). Knowledge is the personal factor of an individual that is inherent in self/dependent care agency that will aid mothers of toddlers with CHD to understand, judge, and make decisions about dependent care actions. Self-efficacy influences how individuals think, feel, motivate themselves, and act. Drawing on the Orem's Theory, the transitional capability of self-care operations involves the judgment of one's ability for self-care. Thus, self-efficacy was integrated as part of the mothers' dependent-care agency in term of the transitional capability of dependent-care operations.

The theoretical framework for this study is summarized in the following figure.

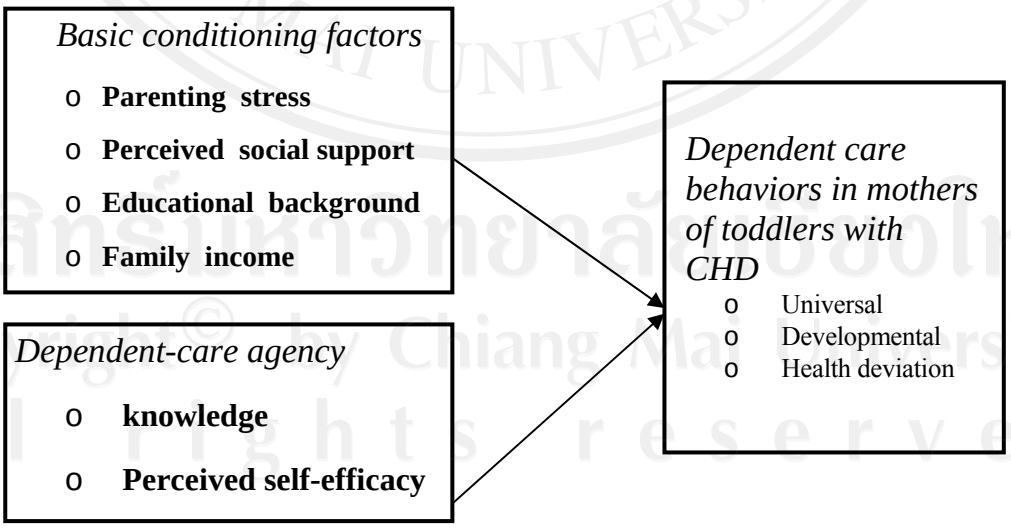

Figure 2.1 The theoretical framework of the predicting factors of dependent care behaviors among mothers of toddlers with CHD