CHAPTER 2

LITERATURE REVIEW

The goal of this literature review is to explore the issues surrounding the perceptions and practices of Thai families in caring for children with CHD aged 0-3 years prior to cardiac surgery. This literature review included both theoretical and research literature and encompasses clinical issues of children with CHD, families of children with CHD, practices of families in caring for children with CHD as well as Thai socio-cultural context related to the caring practices of families.

An Overview of Children with Congenital Heart Disease

Congenital heart disease (CHD) is the most common type of heart disease (Pongpanich, 2006; Rahajoe, 2006; Saxena, 2005). It is the most frequently diagnosed chronic problem in infancy and contributes substantially to mortality during childhood, especially at the early ages (Meberg, Lindberg, & Thaulow, 2005). Like western countries, in Thailand, CHD occurs in eight to ten of every 1,000 live births (Pongpanich, 2005; Saenz, Beebe, & Triplett, 1999; Smith, 2001). There are over 675,000 infants born with CHD in Asia-Pacific each year, and most of them, over 600,000, are in the developing countries. In Thailand, in 2003, the population was 63 million, there were 742,183 live born infants with over 7,400 infants with CHD, and half of this number need medical or surgical treatments (Pongpanich,

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2006). One third of infants born with CHD develop life-threatening symptoms within the first few days of life (Saenz, Beebe, & Triplett, 1999). Since CHD is mostly unpredictable, approximately 20% of infants with CHD may die if they do not have treatments, or may die before the diagnosis is made (Pongpanich, 2006).

Most heart defects develop during the first trimester of pregnancy when the heart is forming. In most cases, the cause of CHD is unknown. Possible maternal factors include viral infections during pregnancy, particularly rubella virus, alcoholism, drug use, severe abuse, or maternal age over 40 years. A history of chronic illness such as insulin-dependent diabetes or lupus can also cause negative outcomes for fetal development (Ashwill & Droske, 1997; Cook & Higgens, 2000). Up to 30% of infants with CHD have features of various genetic syndromes such as Down's syndrome. The majority of children are diagnosed with CHD at birth or within a few weeks after birth (Pillitteri, 2003; Saenz, Beebe, & Triplett, 1999). Early diagnosis, medical advances, and aggressive treatment have dramatically improved the chances of survival for a child with CHD (Brosig, Mussatto, Khun, & Tweddell, 2007; Smith, 2001).

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Classification of Congenital Heart Disease

The classification divides CHD into two types, acyanotic heart disease and cyanotic heart disease, which are based on hemodynamic changes (Pillitteri, 2003; Saenz, Beebe, & Triplett, 1999). Acyanotic type is characterized by no mixing of desaturated blood as there is a shunt that moves blood from the arterial to the venous system (oxygenated to unoxygenated blood, or left-to-right shunts). The left-to right

shunts produce increased pulmonary blood flow and increased workload on the heart (Levi, Alejos, & Moore, 2003). These disorders cause the heart to function as ineffective pump and make the child prone to heart failure (Cook & Higgens, 2000; Pillitteri, 2003; Saenz, Beebe, & Triplett, 1999). In Siriraj Hospital, Thailand, the most common defects of acyanotic type were patent ductus arteriosus (PDA), ventricular septal defect (VSD), and atrial septal defect (ASD) respectively. Tetralogy of Fallot (TOF), complex CHD including pulmonary stenosis (PS), double outlet right ventricle (DORV) and transposition of the great arteries (TGA) were the most common defects among children with cyanotic type (Laohaprasitiporn et al., 1999; Nana, Laohaprasitiporn, Soongsawang, & Durongpisitkul, 2002).

Another classification system has been established that addresses the hemodynamic and blood flow patterns of the defects, allowing a more uniform and predictable set of signs and symptoms. The three classifications as identified by this system include disorders with 1) increased pulmonary blood flow, 2) decreased pulmonary blood flow, and 3) obstruction to systemic blood flow (Laohaprasitiporn, 1991b; Suddaby, 2001).

Severity of illness of CHD in children can be categorized as five patterns based on symptoms and the operation required (Garson, 1978) as follows:

1) Symptomatic pre-operative. The children have a severe condition and usually look ill. They require medications to control the heart function and require heart surgery.

2) Asymptomatic pre-operative. The children do not show significant symptoms, but need operative repair.

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3) Non-operative serious. Children in this group exhibit obvious symptoms of severe heart condition, but do not require corrective surgery.

4).Non-operative benign. The defects in these children are not severe and do not require operation.

5) Post-operative. The children may or may not show symptoms after the surgery. The infants with CHD may exhibit several significant symptoms.

Clinical Presentations and Complications of Congenital Heart Disease

CHD can affect any of the different parts of functions of the heart. Within the diagnostic category of CHD, there is a range of severity, treatment, and prognosis of CHD. Children who have symptoms are usually experiencing increased cardiac workload, pulmonary hypertension in response to increase in pulmonary vascular circulation, inadequate system cardiac output, or arterial desaturation in cyanotic heart disease (Suddaby, 2001; Varan, Tokel, & Yilmaz, 1999). The major signs of serious CHD are central cyanosis, tachycardia, hepatomegaly, respiratory distress, a gallop rhythm, lethargy, lack of spontaneous movement, decreased or unequal arterial pulses, and cardiomegaly on chest radiograph (Suddaby, 2001; Varan, Tokel, & Yilmaz, 1999). Symptoms at the time of diagnosis are usually related to the level of congestive heart failure (CHF) or cyanosis. These symptoms or complications include growth failure and respiratory tract infections.

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Congestive heart failure. CHF is the major cause of death in children with CHD. Because of an abnormal of cardiovascular system, children with CHD are mostly to have CHF, which occurs most often in infants under one year of age

particularly among infants under six months of age (Laohaprasitiporn, 1991b, , 2006; Saenz, Beebe, & Triplett, 1999). CHF occurs when there is a strain on myocardium caused by increased workload in the chambers from severe pressure or volume overload that reduces cardiac output to a level that is sufficient to meet the body's metabolic demands causing CHF (Bowden, Dickey, & Greenberg, 1998; Laohaprasitiporn, 2006). The infant with CHF will breathe at a faster rate, have difficulty breathing, have a fast heart rate, be pale, cool, and will fatigue easily. Most infants and young children with CHD are difficult to feed, have a poor oral intake, and poor weight gain (Bowden, Dickey, & Greenberg, 1998; Cook & Higgens, 2000; Suddaby, 2001).

Cyanosis. Children with CHD present with cyanosis, which usually appears soon after birth or during infancy. When the blood is shunted to the left side of the heart, the child is cyanotic because oxygenated blood mixes with the unoxygenated blood, causing by a lower amount of oxygen in the blood, or hypoxia. It is seen in the child's lips, nailbeds, gum, and around the eyes. With the central cyanosis, infants and young children become tired easily and out of breath with activity. Symptoms such as shortness of breath and fainting often worsen when the child exerts himself (Laohaprasitiporn, 1991a; Pillitteri, 2003).

Hypoxic spells or cyanotic spells are the most common serious problems in the cyanotic heart disease. The hypoxic spells begin with a sudden decrease of blood volume to the lungs. Subsequently the blood volume from the right ventricle will be shunted to the left ventricle through the septal defect. As a result, the patient will appear very blue and hypoxemia will occur due to metabolic acidosis. Hypoxic spells mostly occur and are associated with long deep sleep, crying, eating, sucking,

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excessive playing and exercise, or elimination. Precipitating causes include bowel movements, crying with hunger, or medical intervention. Hypoxic spells mostly occur in the Tetralogy of Fallot. Furthermore, the hypoxic spells may be found in the severe cyanosis, tricuspid atresia, transposition of great arteries with pulmonary stenosis (Fyler, 1992; Gessner & Victoria, 1993; Laohaprasitiporn, 1991a).

Cyanosis may result in a number of effects and complications including polycythemia, clubbing of fingers, diminished stature, poor weight gain, lethargy, reduced exercise tolerance, increased risk of thrombus and embolism formation, infective endocarditis, cerebral abscess, and metabolic acidosis (Carter & Hewitt, 1995).

Growth failure. In general, infants and young children with both cyanotic and acyanotic CHD exhibit a range of delays in weight gain and growth failure. Infants are the age group at greatest risk for malnutrition. In particular, infants with heart failure and/or cyanosis are more likely to present with malnutrition and growth failure (Clemente, Barenes, Shinebourne, & Stein, 2001; Leitch, 2000; Odette, 2000).

Children with multiple heart defects and/or those who had undergone surgery had worse nutritional status than those with a single heart defect or had never had surgery. Most children with CHD exhibit growth failure at birth, and that this persists into infancy and childhood before surgical correction. Since limited weight gain prior to surgery can be compounded by the metabolic demands and reduced nutritional intake of the peri-operative period, these infants are at risk for morbidity postoperatively and have longer recovery periods. In addition, severe in growth delay may limit catch-up growth after cardiac surgery (McGrail, 1997; Peterson & Welzel, 2004). In combination, the severity of the heart defects and malnutrition or growth

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failure put this group of patients at greater risk for operative morbidity and mortality. Intensive nutritional management and early corrective surgery for symptomatic infants or young children with critical CHD should be considered to optimize the outcome.

Children with CHD are more likely to have growth failure for several reasons including decreased energy intake, increased energy requirements, or both (Peterson & Welzel, 2004; Varan, Tokel, & Yilmaz, 1999; Wheat, 2002). Insufficient dietary intake is reported as the most important factor in the cause of growth failure (Hansen & Dorup, 1993). Decreased intake in these infants can be explained by several possibilities, including being tired and weak during feeding and malabsorption (Cameron, Rosenthal, & Olson, 1995; Varan, Tokel, & Yilmaz, 1999). In addition, infants who have chronic hypoxia are more likely to have dyspnea and tachypnea during feeding. Therefore, they are often tired easily, and as a result, reduce the quantity of food consumption. In some cases, the delay can be relatively mild, whereas in other cases, the failure to thrive can result in permanent physical or developmental impairment (Wheat, 2002). Specifically, infants who have complex heart defects that cannot be fully repaired are more likely to have both malnutrition and failure to thrive (Marino, O'Brien, & LoRe, 1995). Infants and young children often poor feeding abilities and feeding becomes a central source of concern and anxiety for parents.

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General Management of Children with CHD

Management of cardiac conditions ranges from minimal treatments to ongoing medication treatments and/or surgical repair (Ashwill & Droske, 1997; Cook &

Higgens, 2000). Whether or not surgery is needed immediately is dependent upon the type of cardiac lesion that is presented. However, management of the child with CHD is oriented to help the child grow so that surgery can be done at the most opportune time.

Medications

The aim of medical management is to allow the child to grow and to allow time for key organs to mature. Then, the operation can be performed at the suitable time. In order to relieve symptoms and to improve the ability of the heart to pump, current methods of treatment are aimed at preload and afterload reduction. The goal of medical management is to control the occurrence of CHF by using digitalis, diuretics, and angiotensin-converting enzyme (ACE) inhibitors (Laohaprasitiporn, 2006). Digitalis or lanoxin will enhance function of the heart and diuretic will assist in reducing the accumulation of body fluid (Whaley & Wong, 1993).

Optimal pharmacological management for CHF is to improve and support the function of the heart and to reduce tissue hypoxia by increasing the flow of blood and oxygen to the tissues of the body (Bowden, Dickey, & Greenberg, 1998; Laohaprasitiporn, 1991b). Hypoxia leads to feeding problems, anoxia and venous congestion of the bowel. Malabsorption and insufficient utilization of nutrients due to peripheral anoxia are possible causes of growth retardation (Hansen & Dorup, 1993). As for the medications, children decrease their difficulty breathing and fatigue during feeding. They will have sufficient dietary intake, and as result, can gain their weight and meet the nutritional requirement for surgery. If pharmacological management alone is insufficient to enable feeding, gavage feedings, and formulas with increased

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caloric concentration may be introduced (Jackson & Poskit, 1991; Wong, Hockenberry-Eaton, Wilson, Winklestein, & Schwartz, 2001).

Cardiac Surgery

The surgical procedures seek to repair the defect as much as possible and restore circulation to as close to normal as possible. It is essential to plan for optimal timing of surgery or catheterized intervention for each child as early as possible (Shrivastava, 2000; Sriyoschart, 1999). Doing so has resulted in many long-term advantages for these children. To maximize the advantage of cardiac surgery, it is important to have good teamwork, including pediatric cardiologists providing effective investigations, an expert and experienced pediatric cardiac surgeon, and cardiac anesthetists, as well as good intensive care nurses (Pornwilawan, 1996).

The success of cardiac surgery is also associated with the method of surgery. As cardiac surgery is usually dependent upon the type of cardiac lesion and the children's age, a surgeon needs to choose the method of surgery that matches to the defect and the age of that child (Pornwilawan, 1996). Cardiac lesions may be separated into three categories: simple lesion that will undergo repair in most cases, moderate lesions that may be palliated or undergo repair, and complex lesions that will repair palliation before the final stage of their management (Dooley & Bishop, 2002). Surgical treatment in CHD can be divided into two types (Bowden, Dickey, & Greenberg, 1998; Pornwilawan, 1996; Sriyoschart, 1999).

1) Palliative surgery is performed as a surgical bridge that aims to improve the child's condition temporarily. This type of surgery allows the child's condition to stabilize and provides time for the child to grow until a more definitive surgical

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correction is viable. Palliative surgeries are also performed when there are no curative surgical options for a particular heart defect. Types of palliative surgery include Blalock-Taussig's shunt, Waterston's shunt, Glenn shunt, etc.

2) Corrective surgery or complete repair is performed to correct the defect in both anatomy and/or physiology in some defects such as PDA, VSD, and ASD. Current surgical practice is to complete surgical intervention early in life, often in infancy. Some cardiac lesions require multi-staged surgical repairs. The decision to proceed with cardiac surgery depends on the severity of the defects, the child's growth and development, the presence of concurrent illness, and family needs.

Surgical readiness of children with CHD. The decision to proceed with cardiac surgery depends on the severity of the defects, the child's medical condition, the age and body weight of the child, choices of operation, and any family considerations (Sriyoschart, 1999). Infants and young children who have severe pathology of heart defects and medical conditions including CHF, hypoxemia, or growth failure, need palliative or corrective surgery as soon as possible. Children less than three months of age who have low body weight are at higher risk, and as a result, require medical managements and optimal weight gain while waiting for cardiac surgery.

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Each type of CHD can be repaired in different time. Some complex defects need palliative surgery at birth with definitive surgery occurring later. For example, infants with severe cyanosis from restricted blood flow to the lungs may be benefit from a systemic to pulmonary artery shunt such as a Blalock-Taussig shunt (Bowden, Dickey, & Greenberg, 1998). Large PDA, or large VSD and with CHF can be corrected with single operation in early infancy. Multiple VSDs with CHF is needed

for pulmonary artery banding in the neonatal period rather than total repair closure of the VSDs because 50% of the defect may be naturally closed (Pornwilawan, 1996). Small or moderate-sized VSD may close or decrease in relative size as a child grows. While waiting for surgery or waiting for the defect to close, the child needs medications to preserve the function of the heart. However, surgical repair may be delayed because of other medical conditions that make the child a poor surgical candidate or to allow the child to reach optimal size and organ development (Pornwilawan, 1996). When a child is symptomatic early, either a palliative shunt is done or total correction is performed if anatomy is suitable. More complex abnormalities such as hypoplastic left heart syndrome may require a series of two or three operations beginning in the newborn period and completed at approximately 3 years of age (Ashwill & Droske, 1997).

Surgical readiness is also related to family consideration. Parents and/or their family members should be encouraged to schedule the surgery when other family events and sources of stress are minimized (Pornwilawan, 1996; Saenz, Beebe, & Triplett, 1999). A cardiac surgeon needs to explain to family members about the procedure, the benefit and risk, and the prognosis of the surgery. The cardiologist should explain the child's condition and assure that the parents have accurate information for making decisions about the surgery of their child (Saenz, Beebe, & Triplett, 1999).

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Impacts of Congenital Heart Disease on Infants and Young Children

A chronically ill child is usually vulnerable due to illness symptoms. As the survival rate has improved due to technological advances in cardiology, evidence has

accumulated that CHD touches many aspects of lives of those affected. Development of the central nervous system is greatly impacted by the availability of adequate nutrition, good cardiac function, and most important, oxygen (Dooley & Bishop, 2002). As a result of the pathology of cardiovascular function, children with CHD are commonly reported to have specific delays including gross and fine motor developmental delays. Specifically, infants and young children in CHF or with cyanosis may have decreased gross motor achievements because of lack of energy until they undergo surgery (Leitch, 2000; Smith, 2001). Many factors will influence development in children with CHD, including the complexity of the defect, CHF, cyanosis, hypoxia, low cerebral perfusion as well as other chronic conditions, and also parental attitude (Smith, 2001). As advances in the medical and surgical management of children with CHD has impacted mortality and morbidity, the area of research regarding the caring behaviors of parents and family, and factors influencing those behaviors was fruitful and significant.

Impact on Physical Developments

Children with CHD have increased energy requirements and may also have decreased energy intake. Therefore, malnutrition and growth failure in infants and young children are widely recognized complications. Due to decreased caloric intake and greater energy expenditure, children with CHD have less energy available for fat deposition. As a result, they have an elevated percentage of lean body mass, which tends to increase their basal metabolic rate. If the child is untreated, it can dramatically worsen the child's overall health status (Wheat, 2002).

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Children with CHD are often given limited opportunities to explore their environment and have their play restricted, in both hospital and home settings. For example, infants with multiple problems may have their developmental needs overshadowed by the technical and medical needs of their care. Young children with cardiac disease are often less physically able to interact with their environment due to the limiting nature of their condition. The effect of prolonged illness and hospitalization are likely to have had an impact on development with gross motor and language development. Moreover, impaired physical abilities have a detrimental impact on the development of other skills including exploratory behavior (Wray & Radley-Smith, 2003). An additional factor is that of feeding difficulty. The parental anxiety and feeling of inadequacy associated with feeding problems may result in parents withdrawing emotional support from their child (Goldberg, Washington, Morris, Fisher-Fay, & Simmons, 1990; Gudermuth, 1975). Development thus may be hindered by the physical and emotional difficulties associated with feeding (Wray & Sensky, 2004).

A number of research articles in western countries showed that children with CHD had difficulties with physical growth. Gross motor abnormalities are common in this group of children (Green, 2004). Limperopoulos and his colleagues, Canadian researchers, found that preoperative abnormalities were found in more than half of newborns and 38% of infants with CHD. Moreover, abnormalities persisted in most of these infants in the immediate post-operative period. Among children less than two years of age who were followed 12-18 months post cardiac surgery, abnormal neurological examinations were reported in 41%. The abnormalities included gross and/or fine motor delays (42%) and global developmental delays (23%). Risk factors

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for those deficits included increased length of stay in the intensive care unit, acyanotic lesion, palliative surgery, abnormal peri-operative neurobehavioral status, increased number of subsequent admissions, and weight below the second percentile (Limperpoulos, Majnemer, Shevell, Rohlicek, & Tchervenkov, 2000).

One of the studies conducted in the United State reported that more than 46% of children with CHD requiring cardiac surgical and catheter intervention received abnormal ratings on developmental screening. Specific delays include gross and fine motor developmental delays. In symptomatic infants, therefore, gross motor skills such as sitting, crawling, or walking may be delayed. However, these children appear to catch up quickly once they have undergone surgical repair (Leitch et al., 1998).

Impact on Psycho-Social Development

As a result of advances in biomedicines, surgery, and technology as well as an improved care standard, the number of children with CHD has been increased. However, chronic conditions have had an adverse impact on the psychological functioning and social compliance of the children (Yildiz, Savaser, & Tathoglu, 2001). While the majority of children with CHD develop intellectually within the normal range, there may be some delayed mental functions. Behavioral and psychiatric abnormalities are reported in these children. The impaired physical abilities and prolonged illness and hospitalizations can have particularly detrimental psychological effect on children with CHD. In addition, the maternal attitude to the child, i.e., over protectiveness, affects the child's emotional adjustment (DeMaso et al., 1991). The psychological factors associated with having a child with CHD also

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influences parents' attitude toward the child, which in turn are likely to have a significant impact on their child's development (Lobo, 1992).

Parents who experience guilt may become over protective and thus inhibits the child's attempts to attain independence. They may feel that socializing with peers or a return to school may expose the child to the risk of infection (Bird & Dearmun, 1995). Some parents did not take their child out or allow them to attend school or play groups, etc., and this reflects maternal anxiety concerning the risk of infection or the child being physically overwhelmed because of their small size. Such restrictions limit the child's social interactions and are likely to have had an impact on the development of speech and socialized skills, resulting in poorer performance in these areas for children with CHD (Wray & Sensky, 2004).

Families of Children with CHD

It is well recognized in the literature that chronically ill children have an impact upon not only the individual, but also upon the family (Hayes, 1997; Hentinen & Kyngas, 1998; Knalf, Breitmayer, Gallo, & Zoeller, 1996; Svavardottir & Reyens, 2005). Most nursing research related to children with CHD focuses on parents, while few stressed the involvement of whole families. In this study, a family included parent(s) and/or one family member living in the same household with the child who had CHD. Literature reviews presented here were the studies of parents as well as families of children with CHD. This section begins with a review of the research that examines parents' feelings, and perspectives on their child's illness.

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Stress and Coping of Families of Children with CHD

When an infant is diagnosed with CHD, the stress of adapting to the news and learning to care for the infants is superimposed on the normal transition to parenthood (Pye & Green, 2003). Even though there are new and successful surgical options for children with CHD, the availability of treatment options does not negate the stress that parents feel in this situation (Morelius, Lundh, & Nelson, 2002). The psychological and social effects of CHD have been studied extensively. Parental stress and coping is the most frequently studied topic related to consequences of the illness for families (DeMaso et al., 1991; Goldberg, Simmons, Newman, Campbell, & Fowler, 1990; Lawoko & Soares, 2002; Tak & McCubbin, 2002; Visconti, Saudino, Rappaport, Newburger, & Bellinger, 2002; Wray & Sensky, 2004).

Goldberg et al.(1990) used the Parenting Stress Index (PSI) to investigate three sources of stress (parent, child, and life events) among parents with infants less than one year of age. They compared three diagnostic groups: cystic fibrosis (n=15), CHD (n=26), and healthy infants (n=30). Parents of infants with CHD reported significantly more stress than those of an infant with cystic fibrosis or with healthy babies on the child factors (adaptability, mood, or hyperactivity). Goldberg et al. concluded that the immediate life threat and prognostic uncertainties associated with the diagnosis of CHD explained the differences between the groups. Nevertheless, the researchers suggested that parents of chronically ill infants consistently experienced more stress than those of healthy infants.

Meyer (1997) used the Parental Perception Inventory (PPI) to investigate maternal needs, stress and coping strategies. In addition, the Parent Role

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Questionnaire (PRQ) was used to assess the impact of infants' illness on a mother's parental roles perception at the different stage of the child's development. Although mothers of infants with CHD did not have significantly greater stress than mothers of healthy infants, the nature of their concerns were different. They were concerned with the management and status of their infant's illness as well as financial concerns, whereas mothers of healthy infants were concerned about their own needs. Furthermore, maternal stress was significantly related to marital satisfaction but not significantly related to income, marital status, or maternal age. There were no significant differences between the perceptions of the two groups on the role of characteristics at different stages of the child's development.

More recent studies also document that parents of children with CHD faced stress in different phases of their child's surgery. Wray and Sensky (2004) found that parents' stress levels were high in the immediate pre- and post-operative phase, but for the parents whose children survived, stress levels returned to levels similar to those of healthy parents one year post surgery. Similarly, Visconti, Saudino, Rappaprt, Newburger and Bellinger (2002) found that parents of children with transposition of the great arteries (TGA) had less stress one year and four years following their child's surgery, compared with those with healthy children. These findings were consistent with a study by Goldberg et al.(1990), who concluded that parents of children undergoing corrective cardiac surgery may have received positive encouragement from physicians, or may have had sufficient time to cope with having a child with critical CHD. These studies demonstrate the stressfulness of the surgical phase, and that parents whose children do well will return to normal stress levels on

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their own. It leaves in question what stress parents are experiencing in the preoperative growing phase.

Concerns of Families of Children with CHD

Parents of an infant or a young child with CHD are significantly affected by a diagnosis of CHD (Hinoki, 1998). Following the diagnosis of CHD, parents are left with questions and concerns. While there are new and successful surgical options for children with CHD, the availability of treatment options does not negate the stress that parents feel in this situation (Morelius, Lundh, & Nelson, 2002). Parents continue to have concerns about their child's care practices (Pinelli, 1981), the child's illness, treatment, and the effects of both on their child's life (Horn, DeMaso, Gonzalez-Heydrich, & Erickson, 2001).

Parental concerns about their practices were examined in one of the Canadian nursing studies. Pinelli (1981) interviews 10 mothers of infants with CHD in the hospital and after assuming responsibility for their care at home. As revealed in the open-ended interviews, mothers' main concern in both interviews was learning how to anticipate and to recognize their child's needs. However, mothers express more concerns one month after discharge. Mothers' concerns about their practices in caring for their infants at home including assessing the infant's symptomatic behaviors of the heart disease; and managing the infant's crying, feeding, nutrition, and weight gain. Additionally, they were concerned about the time for surgery, medication, normal infant's care, and understanding their child's conditions. Pinelli concluded that mothers lacked confidence and worried about their inability to differentiate between the baby's normal needs and the needs related to their child's heart disease. They

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needed additional information about the infant's care, medications, therapeutic care, the heart disease, and surgery. Specifically, mothers who had never cared for their newborn at home and those of infants with multiple heart problems required more information (Stinson & McKeever, 1995).

Horn and colleagues (2001) examined the relationships among mothers' concerns, medical severity, and mothers' emotional state. Mothers' concerns were grouped into five categories: medical diagnosis, their child's quality of life, psychosocial functioning, effects on family, and financial issues. During hospitalization, mothers were most concerned about medical prognosis and treatment including success of the current operation, side effects of medications and long-term prognosis. Mothers were also concerned about their child's life expectancy, the need for further operations as well as long-term care. The researchers suggested that maternal concerns might be independent of medical severity. They stated that it might be helpful for healthcare professions to talk with parents and help them anticipate potential areas of difficulty commonly faced by children with CHD, such as feeding difficulty after discharge.

Understanding of the Families regarding the Child's Heart Disease

Several studies have explored parental understanding of the infant's diagnosis (Beeri, Haramati, Rein, & Nir, 2001; Cheuk, Wong, Chau, & Cheung, 2005; Garson, 1978; Kaden, McCarter, Johnson, & Ferencz, 1985). These findings show that parents' knowledge of the etiology and symptoms of their child' heart disease was limited. Specifically, their knowledge about side effects of cardiac medication appeared to be deficient (Cheuk, Wong, Chau, & Cheung, 2005). Most parents were

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aware of the indications and aims of their child's medical care and interventions. However, parents' understanding and knowledge was not correlated with the severity of the child's condition but was correlated with parents' educational background.

In an early study of parents' perspectives regarding their child's heart disease, Garson et al.(1978) found that parents of children with CHD had limited understanding and were unclear about which symptoms to expect in their child, especially those related to congestive heart failure (CHF) and cyanosis. Parents received inconsistent messages about whether they should treat their child normally or as a child with a precarious illness. The majority of parents felt that they could not treat their child normally because there was something wrong with the heart.

In a study by Kaden, McCarter, Johnson, and Ferencz (1985), 36% of mothers could not explain their child's conditions adequately following communication with a physician. Kaden and his colleagues concluded that mothers' understanding of the information was an important factor in the mothers' ability to cope with their child's diagnosis. Mothers' misunderstandings about the child's diagnosis caused many problems for the family. Therefore, it is very important to ensure that the communication between health care providers and family is clear and complete. The researchers also suggested that mother and family's level of formal education were related to their understanding. When describing a complex condition such as CHD, it is essential to follow up with confirmation of their knowledge. These findings suggest the need for further qualitative study exploring how parents perceive their child's vulnerability and care needs.

Stinson and McKeever (1995) examined maternal understanding regarding caring for children with CHD on discharge preparation, and found that it did not meet

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mothers' information needs. They administered the Mothers' Information Needs Instrument (MINI) and a linear analogue self-assessment (LASA) scale to 30 mothers of infants undergoing cardiac surgery. Although mothers' understanding scores and caregiving comfort levels were significantly higher post discharge, they needed additional information about the infant's care, medications, therapeutic care, the heart disease, and surgery. Specifically, mothers who had never cared for their newborn at home and those of infants with multiple heart problems required more information. Mothers indicated that information should be provided regularly during their child's hospitalization and not just prior to discharge, because that was a period of high stress. These findings underscore the importance of the effective methods and timing of discharge teaching practices.

The results of these studies were congruent with Beeri, Haramati, Rein and Nir's (2001) findings regarding parents' understandings of their child's heart disease. Seventy-four Israel families of children with CHD completed a questionnaire in which they described their child's condition. Beeri and his colleagues found that parents could not describe their child's malformation correctly. Parents' understanding and knowledge was not correlated with the severity of the child's condition, but was correlated with parents' educational background. Again, this underscores the importance of ensuring that educational efforts are tailored to parents' educational level, particularly since parents with minimal education do not know what questions to ask even though they are worried about their child.

Lok and Menahem (2004) used open-ended questions to study 40 parents of 56 infants and children with CHD to determine their understanding and perceptions following the diagnosis of minor cardiac abnormality, small VSD. When asked about

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their feelings when first told about the diagnosis, most parents had registered concern and worry as well as a degree of “shock” or “disbelief.” Although the child was diagnosed with a minor heart defect, major causes of parenting concern were that the child might need surgery, or long-term medication, or that the child’s life may be shortened. These findings support the importance of understanding how parents interpret their child’s diagnosis so that they may be supported appropriately.

In a recent study investigating parents’ understanding of their child’s CHD in China, Cheuk, Wong, Chau and Cheung (2005) assessed knowledge of 156 parents in three domains—the nature of heart disease and its treatment, the impact of heart lesion on exercise capacity, and infective endocarditis. Although more than half of the parents correctly named their child’s heart defect and knew the heart’s functions, 28% could identify the heart lesion(s) diagrammatically, and only 7% knew about the functions and side effects of their child’s medication. However, most parents were aware of the indications and aims of their child’s medical care and interventions. These findings showed that parents’ knowledge of the etiology and symptoms of their child’ heart disease were limited. Specifically, their knowledge about side effects of cardiac medication appeared to be deficient. Cheuk and her colleagues concluded that current educational programs were inadequate and needed to be refined to promote parental understanding of their child’s heart disease.

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Adaptation of Families of Children with CHD

In one of the first studies in this field, Garson et al. (1978) explored how parents adapted to their child’s care needs. Through unstructured interviews with 260 parents of children with CHD with all types of CHD, at all stages from initial

diagnosis through surgical correction, Garson and her colleagues observed certain patterns in parents' feelings. Although parents rarely asked their physicians, they had a number of questions in common. Parents of a child who was symptomatic and required surgery wanted their child to be ready for surgery as soon as possible. Much energy and attention was focused on preparing the child for surgery. Parents were often exhausted from their efforts to help the child gain weight in preparation for surgery. Parents focused all of their energy on the goal of getting their child ready for surgery, and little on what would follow the actual surgery. Although this study was conducted more than 20 years ago, the findings are congruent with those from more recent studies.

Quality of Life of Families of Children with CHD

Lowoko and Soares (2003) examined quality of life of parents with CHD and found that parents of children with CHD reported lower quality of life than parents of healthy children. In addition, parents of children with CHD spent extra time caring for their sick children, with mothers doing more than fathers. These parent variables accounted for approximately 60% of the variance in quality of life, while child variables accounted for approximately 2% of the variance. The best predictors of quality of life were parent variables, including caregiving time, sick leave, financial difficulties, distress, hopelessness, and social isolation. Parents' caring responsibilities frequently resulted in exhaustion and limited their opportunity to relax and to take part in usual social activities. Carey, Nicholson and Fox (2002) also found that mothers of children with CHD reported higher level of stress in day-to-day management compared to mothers of healthy children.

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Experience of Families of Children with CHD

The experience of parenting a child with both a chronic and a critical illness is a process that involves complex emotions and behaviors. CHD has a major impact on the child and family. For infants who are diagnosed with heart disease, parents have come to terms with the shock of finding out that their baby is less than perfect and face challenge of coping with their feelings, distress, and anxiety, combined with trying to cope with being "good parents" and learning to care for their child. Parents' experience regarding caring for an infant or a child with CHD are primarily studied through the use of qualitative methods (Brown, 2003; Clark & Miles, 1999; Lok & Menahem, 2004; Rempel, 2005). Those studies suggested that parents of children with CHD experienced a range of intense emotions in response to their child's diagnosis.

In her dissertation, Brown (2003) completed a qualitative study to provide a better understanding of parents' experiences living with a child's CHD and when the child had critical illness. Using a semi-structured interview, she included 37 parents (28 mothers and 9 fathers) in the study. All parents experienced at least one stay in the PCICU with the child following surgical intervention, and all the children are currently living.

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The process described in the study began when the child was diagnosed with CHD, progressed through the PICU and concluded with adaptation to home. "Walking a tightrope: living with your child's congenital heart disease" was the core category. The main theme was one of balancing forces and trying to find the positive in face of threats to the child's life. Parents remained uncertain about their baby's

care and future even after they had returned home post-operation. While this study provided insight into diagnosis and operative phases, the issues and concerns that they faced with caring for their preoperative child were not explored. The strength of this finding is the large sample size and the data collected from both mothers and fathers including the results representing a process of parents' experiences when their child was diagnosed, was admitted in PCICU, and was discharged to their home.

Fathers' experiences have not been well described in the literature. Clark and Miles (1999) explored fathers' experiences by interviewing eight fathers whose infants aged 12 months old were newly diagnosed with severe CHD. All infants underwent at least one surgery. The sample was drawn from a large longitudinal study of parents of medically fragile infants. The data were analyzed using content analysis. Their findings illustrated four areas in which fathers experienced both positive and negative aspects concurrently. The excitement of having a new baby was coupled with the distress related to the loss of their expected normal child. Fathers were developing an attachment to their infant while dealing with fears about the infants' health. Similarly they tried to maintain control in the face of the unpredictable nature of the infant's heart disease and the hospitalization while feeling like they were losing control. Finally, fathers felt that they needed to provide strength while hiding their own emotions and worries. These are important findings because there are few studies that examine fathers' experience. The results demonstrated that fathers are also under considerable stress and experience a range of complex and conflicting emotions.

In a well designed grounded theory study, Rempel (2005) interviewed parents of children with hypoplastic left heart syndrome (HLHS) who were progressing

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through the three stages of surgical correction. Rempel interviewed nine mothers and seven fathers separately in their homes and conducted telephone interviews 6-12 months later. Similar to Brown's notion of walking a tightrope, Rempel described safeguarding precarious survival in a context of certainty and uncertainty. She emphasized that it was not only the child, but the parents' well-being that needed to be safeguarded. Parents safeguarded their child by taking charge, struggling for balance, and involving others in the child's care. Parents safeguarded their own survival against worry by directing their minds, normalizing and trusting. They also safeguarded themselves against regret by determining not to regret, reframing and delighting in their child. While focused on a select diagnostic group, this study offers detailed insight into the implications within the family context and how parents learn to manage a range of threats to their baby and themselves.

As cardiac surgery is the treatment of choice for most infants diagnosed severe CHD, it is particularly stressful for parents because the outcome is uncertain. While the existing research reported feeling a sense of loss of expected infants (e.g.,Garson, 1978), fear (e.g.,Cohn, 1996), or difficulties of parents having a child with CHD (e.g.,Brown, 2003; Rempel, 2005), little is known about parents' experiences in preoperative phase.

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Summary

Most studies related to families of children with CHD assumed that parents had high stress and concerns regarding the child's illness. The parents had limited understanding about the child's diagnosis and needed more information in order to care for the child after discharge. However, knowledge regarding family caring for

the infants and young children in the pre-operative phase seems to be left out. The current findings underscore the importance of supporting parents while their child has a heart disease and waiting for a surgery. Parents not only need nurses to take care of their child's physiological needs, but also their own psychological needs as parents.

Practices of Families in Caring for Children with CHD

Children with CHD require the same basic care as other healthy children receive including physical, developmental and psychosocial care (Green, 2004; Smith, 2001). However, there are certain areas that need special consideration and additional care requirement of family including immunization, and oral hygiene (Dooley & Bishop, 2002; Saenz, Beebe, & Triplett, 1999).

Children with CHD who are symptomatic and waiting for cardiac surgery require special care from the parents while they are at home. The goal of home-based care for a child with CHD is to maintain the child's health, minimize the risk of complications, and promote growth and development (Bowden, Dickey, & Greenberg, 1998; Pye & Green, 2003; Wong, Hockenberry-Eaton, Wilson, Winklestein, & Schwartz, 2001). These are needs include providing for infant's and children's comfort, feeding, and observing for symptoms of complications. In addition, the children with symptomatic CHD receive medicines at home such as Dogoxin and Diuretic (Wong, Hockenberry-Eaton, Wilson, Winklestein, & Schwartz, 2001). Therefore, it is crucial that parents should provide adequate home care management for the ill child including pharmacological management. These caring practices help to maintain the child's health condition, minimize the risk of

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complications, and also promote growth and development (Wong, Hockenberry-Eaton, Wilson, Winklestein, & Schwartz, 2001). The main family's caring practices for children with CHD prior to cardiac surgery are as follows:

Providing Maximum Rest

Parents have to recognize the normal pattern of the child's daily life such as sleep, feeding, and playtime. The infants and young children with CHD who have CHF frequently experience exhaustion and difficulty breathing, should not be allow to cry when they are tired. They should not allow to cry for a prolonged period. These children should be soothed and comforted before crying uses much of children's energy (Betz, 1994).

Parents should care for the child with CHD normally, as a typical child. It is not always necessary to restrict infants or children's activities. Children with CHD may spend most of time sleeping, or fall asleep during feeding. Parents should help reduce conditions that will increase metabolic demands such as fever or heat.

Providing Optimal Nutrition

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Adequate nutrition is extremely important in infants with CHD because significant heart disease impacts the child's growth and development. Feeding infants in pre-operative phase is critical because of the potential to affect infant's nutrition, and as operative risks increase with deteriorated nutritional state (Duhn, 1998). While weight gain during infancy is an ongoing problem for many infants with CHD who require a consistently high level of nutrition, parents frequently experience difficulty

feeding with their infant. Thus, feeding is the primary focus of caring for these infants because the cardiac patho-physiology and characteristic feeding difficulties place them at risk of failure to thrive (Lobo & Michel, 1995).

To attain optimal outcomes, parents need to critically monitor the child's weight gain and linear growth. Typically, children with CHF require a very high metabolic state, which require more calories than normal child. If a child need the addition of medications to their care regimen, the will often need nutritional supplementation (Dooley & Bishop, 2002). This can be achieved by increasing the calories that are ingested, which will also increase the amount of food or supplementing formula or breast milk with glucose polymers (Jackson & Poskit, 1991; Wheat, 2002).

Feeding difficulty has been recognized as priority concerns and a major source of stress for mothers with CHD (Pinelli, 1981). The infants may be too tired to consume a sufficient volume of formula at each feeding. Typically, the baby takes a few swallows of formula with frequent breaks from nipple as if catch a few breaths. Moreover, the infants frequently have vomiting (Duhn, 1998). The use of the soft nipple may help to reduce with work of sucking (Lobo & Michel, 1995). In addition, the hole in the nipple might be made a little bit larger. Smaller and more frequent feedings are better tolerated and decrease the likelihood of vomiting (Barbas & Kelleher, 2004). The infants need to rest frequently resulting in taking a longer time in feeding. Parents should not force their child to eat when tired and should be held during feeding. In particular, young children with cyanotic heart disease should be placed in the knee-chest position (Laohaprasitiporn & Nana, 1993). Feeding should be provided to infants as soon as their hunger is identified. Smaller and more frequent

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feedings, or every 2-3 hours, are better tolerated and decrease the likelihood of vomiting as well as reduce exhaustion (Jackson & Poskit, 1991).

To control CHF, the amount of sodium in diet should be restricted in order to reduce lower congestion of water and sodium in the body. Therefore, the children must consume low salt diet by not to add salt, fish sauce or other types of sauce including sodium glutamate and baking soda. Canned food needs to be inhibited. In case that the diuretic drug is used, potassium may be lost with urine. The children should be fed with high potassium vegetable and fruits, i.e., banana, orange, grapes, milk, etc. (Tungkulboriboon, 1996). One must keep in mind that formula and breast milk have more calories than solid or juices, and decreasing the free water in formula or increasing the protein content increases the renal solute load. In particular infants with CHF, they often take less volume per feeding and become dyspnoeic during feeding (Behrman, Kliegman, & Arvin, 1996; Saenz, Beebe, & Triplett, 1999).

Providing Emotional and Developmental Support

Interaction between parents and their infants such as holding, touching, eye contact, or smiling should be emphasized. Some children with CHD may have developmental delay, motor activities such as turning over, crawling, and sitting (Betz, 1994). When the child's condition improves, parents should facilitate the child to move on to the next task of development. It is significant for families to maintain each stage of the developmental process by facilitating an opportunity to play, to learn, and to interact with other peers. In addition, parents and/or other family members who take part in caring need to understand and respond to the child's signals, e.g., things to look at, touch, hear, smell, and taste (Donohue-Colletta, 1992).

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Infants and young children with CHD who are unoperated have higher rates of neuro-developmental abnormalities including fine and/or gross motor delays and than their peers (Limperpoulos, Majnemer, Shevell, Rohlicek, & Tchervenkov, 2000). They require growth and developmental care provided by their family including physical, cognitive, language, and psychosocial care. In at-risk infants such as those with CHD, family's practices including parent-relationship and psychological support can develop the immature central nervous system, and as a result, the optimal developmental outcomes (Brazelton, 1994; Maccoby, 1992).

Children with CHD need to have activities or playing following pathology, with no competition or force, i.e., running, climbing, etc. (Ashwill & Droske, 1997; Cambell & McIntosh, 1992). Demanding exercise causes an increase in oxygen consumption. As a result, the children may get more tired in acyanotic heart disease, and/or hypoxic spells may occur in cyanotic heart disease. Therefore, parents and other family members who take part in caring for their child should observe for signs of tiredness during playing or exercise, and need to stop the activities immediately.

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Monitoring Congestive Heart Failure

As mentioned earlier, CHF is the major cause of death in children of CHD, especially, in the first year of life. Parents should be able to observe their child's signs and symptoms correctly, and report their child's symptoms correctly. A typical symptom of infants in CHF is poor weight gain, which is related to poor nutritional

intake and nausea (Cook & Higgens, 2000). Other common signs are abnormal sweating which causes cold and sweaty skin, tachycardia, or breathlessness dyspnea (Laohaprasitiporn, 2006). Parents should observe the child's heart rate while the child takes a rest. If the heart rates are more than 160 beats/minute for an infant, and more than 120 beats/minute for a young child, increased cyanosis, breathlessness, dyspnea, or oliguria, etc., they should take the child to hospital and report the child's symptoms to nurses and physicians correctly. Other principles of caring for CHF are a) decreasing oxygen consumption; the child needs to have enough rest in order to reduce the amount of oxygen needed, b) keeping the body temperature to be normal, c) avoiding salty food, and d) providing medications following treatments. These caring practices are very important for children with CHF (Laohaprasitiporn, 2006; Saenz, Beebe, & Triplett, 1999).

To reduce a risk of CHF, parents and other family members need to reduce precipitators, such as the child's stress, anemia, or infections. In addition, parents should be able to observe their child's signs and symptoms correctly. If they are unable to accurately interpret and report their infant's signs and symptoms, potential exists for medical misdiagnosis and complications associated with improper treatment (Laohaprasitiporn, 1991b; Saenz, Beebe, & Triplett, 1999).

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Providing Prescribed Medications

Children with CHD who are symptomatic need to be managed with medications while they grow to an appropriate weight gain and size for optimal surgical repair. It is very important that parents know how to administer all necessary cardiac medications and assess their associated actions and potential adverse effects.

Parents should be concerned about properly administering medications to the child as well as the appropriateness of omitting or repeating a dose. It is necessary to know the action of medications, dosage, time schedule, possible adverse symptoms and handing missed dose.

Children with CHD who receive digitalis in order to control the function of the heart may get side effects. Parents need to recognize the symptoms of digitalis intoxication. including nausea, excessive vomiting, and diarrhea (Laohaprasitiporn, 1991b). When the children have vomiting after taking the medicine, parents must not repeat dose. Parents can administer this medicine with dropper packaged with elixir. Digoxin should be given between feeding to decrease chance of spitting up, and should be administered the drug in the same time every day.

Right medication dosage and safe administration of medications are of particular concern. Parents need to use commercially available oral syringes to draw up and administer all oral medication. In addition, to prevent errors, encouraging parents to have their infant's prescriptions and bring all current medications, including vitamins, and herbal supplements, to each clinic visit and hospital is an effective way to ensure accuracy (Pye & Green, 2003).

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Observing Cyanosis and Managing Hypoxic Spells

Parents should know how to observe the color of the infant's skin to detect cyanosis in their child with CHD. Cyanosis is frequently noticed when the child cries, or occurs during or immediately after a feeding. It is significant to report the child's symptoms when parents found that the child who had cyanosis followed pallor or lethargy.

Hypoxic spells or cyanotic spells are the most common critical problems in the children with cyanotic heart disease (Ashwill & Droske, 1997; Laohaprasitiporn, 1991a). As an illustration, some children may experience cyanotic spells once a day while others may suffer once every forthnight (Suddaby, 2001). Characteristics of a spell are worsening cyanosis, uncontrollable crying, hyperpnea (increased rate and depth of respiration) and increased hypoxemia. These symptoms can be short- lived and subtle or can last hours. A child may become limp and may have convulsions or be death. If he/she does not receive an appropriate care when cyanotic spells occur, the symptoms may be worsened and they may eventually die (Cook & Higgens, 2000). Therefore, direct toward preventing conditions that would precipitate a cyanotic response, such as dehydration or crying is very important. Since crying and/or agitation may precipitate hypoxic spells, keeping a child as stress-free by anticipating and meeting the infant's feeding and comfort needs promptly. When a child has a known cyanotic condition, the parents must respond immediately. If hypoxic episode occurs, parents need to be able to recognize them, place or hold the child in knee-chest position. If the child is not better, parents must take him/her to meet a physician closed to their home as soon as possible (Ashwill & Droske, 1997; Cook & Higgens, 2000).

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Observing Symptoms of Infections

Children with CHD, especially those with defect causing left to right shunt) are susceptible to respiratory infections because of the pulmonary edema and lower the efficiency of lung infection (Saenz, Beebe, & Triplett, 1999). Infection leads to the occurrence of fever resulting in dilation of arteries, and increased cardiac output,

which will place the children at higher risk of CHF (Smith, 2001). Thus, parents need to have ability to identify the child's pattern of respiration. The symptoms of respiratory infections include difficulty in breathing, presence of abnormal breath sound, cough, and fever avoid taking the children close contact with the person with a cold or other infections, including not bring the children to the crowded places since respiratory infection will cause the illness gets worse (Tungkulboriboon, 1996). Moreover, parents need to identify the child's respiration.

Children with CHD are often diaphoretic, which is easily to get infection. They should be cared for cleanliness of the body regularly by taking a bath at least once a day and wearing clean and dry clothes. Parents should take a good hygiene care for the child including taking a bath at least once a day, wearing cleaned and dried clothes. For cyanotic children, parents need to give them a bath using warm water as a cold ambient temperature is related to hypoxic spells due to low cardiac output. Parents and other family members who take part in caring for the child with CHD should maintain their own personal hygiene; always wash hands before and after the child's care as well as clean personal items in order to prevent infection. The child should be raised up in a good adequate sanitation as well as provided adequate rest and nutrition. It is significant to monitor the child's fever associated with other symptoms such as decreased taking food or milk, fatigue etc. If the child had high fever, the parents should take him/her to the nearest hospital (Pillitteri, 2003).

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The infection of dental decay causes bacteria to circulate in the blood circulation and can cause bacterial endocarditis. It is very important that parents provide a good oral health care for their child by having their children brush their teeth at least twice and/or after eating in order to get rid of bacteria. For infants,

parents should use a clean cloth with clear water to clean their infant's oral cavity after feeding. A dental examination with treatments one to two months before surgery among young children is recommended that will reduce the risk of bacteria around the time of surgery. Parents must inform the dentist that the children have congenital heart defect, so the dentist can give antibiotics to prevent endocarditis (Smith, 2001).

Following up as Schedule

Children with CHD require ongoing medications and continuing management. Even though the child's symptoms are stable, the parents need to take the child to visit a cardiologist following the schedule so that the physicians can evaluate the child's cardiac function and/or adjusts the child's medications following the child's symptom. Moreover, the parents need to observe the child's clinical presentations including having a fever or cough that is the signs of respiratory tract infection. If he/she has increased tiredness, tachypnea, or swelling, which are the symptoms of CHF, the parents need to take the child to hospital as soon as possible.

Caring Responsibility, Caring Behaviours, Parenting Practices, or Caring Practices of Families of Children with CHD

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So far the literature has suggested that family and contextual variable have a greater effect than illness severity. This suggests that family issues such as concurrent responsibilities may play an important role in parents' stress. There are many terms used relating to practices in caring for children with CHD including caring responsibility, caring behaviours, parenting practices as well as caring practices.

In an American study investigating transition to parenthood among parents of infants with CHD, Svavarsdottir and McCubbin (1996) reported that mothers' time was consumed attending to their infant's physical needs, changing diapers or bathing and dressing. Mothers and fathers spent more time providing emotional support for their spouse and infant including managing their child's crying, irritability or moodiness and feeding. Feeding was the most time consuming task for mothers of infants with CHD. In addition, parents were responsible for observing and reporting the child's symptoms and progress, and for managing finances and bills related to the child's care.

Carey, Nicholson and Fox (1999) employed the PSI in their comparison study of mothers of children with moderate to severe CHD and mothers of healthy children (30 mothers in each group). The researchers used a quantitative study and included one open-ended question asking mothers what was different about parenting their children. They also assessed parent-child interaction, child behavior, and parenting stress. In quantitative measures, there were no differences in parenting stress level related to child rearing between the two groups of mothers. In addition, parent-child interaction did not differ. However, the unexpected aspects of parenting that mothers of healthy children described were qualitatively different from mothers with a child with CHD. The most frequently themes that mothers of infants with heart disease mentioned were: the unexpected nature of the diagnosis, the need for vigilant care, clinical uncertainty, the need to maintain a positive outlook, and trying to live a normal life while acknowledging the stress. Instead, mothers of healthy children mentioned temperament, strains, rewards, expectation, and discipline. These findings raise questions about whether enough is known about parenting children with CHD,

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and whether measures such as the Parenting Stress Index captures the sources of stress that are most important to parents (Rempel, 2005).

Lowoko and Soares (2003) found that parents of children with CHD spent extra time caring for their sick children, with mothers doing more than fathers. Parents' caring responsibilities frequently resulted in exhaustion and limited their opportunity to relax and to take part in usual social activities.

In Thailand, studies related to caring practices for children who have CHD have been conducted in a master and/or a doctoral program. Most of the studies examined parental perception and caring behaviors as well as the effects of health education programs on caring behaviors of parents, parents' self-efficacy, parents' self-management, and family management. The existing research provides an initial picture of life for parents caring for a child with CHD. However, there is little information about the day-to-day practices of family with CHD in Thailand.

Parents have primary responsibility to support their children in Thai society. In the existing studies, mothers were the primary caregivers in the majority of families (Asumpinzub, 1997; Dulyakasem, 1993; Kamproh, 2001; Nukulkij, 1993; Theannamngian, 2003). The effect of self-help group on care practice in mothers of newborn to 3 years old children with CHD was described by Dulyakasem (1993). The samples of 60 were randomly assigned into two groups, 30 mothers in each. After receiving the self-help group program two times, one week and 2-3 weeks, mothers had significant higher mean scores on maternal care practice than before ($p < 0.01$). Maternal care practices included caring for their child's nutrition, activities, social interaction, development, medication and side effects, and complications. In addition, the experimental group had significantly higher scores than the control

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group ($p < 0.01$). Dulyakasem indicated that health education including empowering could help the mothers to increase caring practices for their child. The results of this story can be indicated that health education regarding caring for children with CHD including empowering can help the mothers increased care practices for the infants and young children with CHD.

The effect of maternal perception was examined in relationship to maternal caring behaviors of mothers of children with CHD. Asumpinzub (1997) identified the relationship between the maternal perception of disease and the maternal caring behaviors for their children. Their sample consisted of 120 mothers of 3 to 6 years old children with CHD taking their child for follow up at three hospitals in Bangkok. Asumpinzub found that maternal perception, education and age, and family income were the factors significantly influencing caring behaviors for children with CHD. There was no significant correlation between maternal occupations, duration of caring, and caring behavior. The results of this study are strengthen by the participants selected from different settings.

The results of this study were consistent with Chotibang, Niyomka and Yunak's (2001) study in which they found a positive significant correlation between maternal health perception and health promoting behaviors of mothers of children with CHD. Also, Mornmoung (2001) investigated maternal self-efficacy and adaptation in caring for infants with CHD and the related factors. The researcher used self-administered questionnaires to investigate 110 mothers taking their infants diagnosed as CHD or having symptoms of CHD for at least one month to follow-up at the outpatient pediatric cardiology in three hospitals in Bangkok. Mornmoung found that the majority of the mothers had moderate mean scores of self- efficacy and

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adaptation (X = 89.06, SD = 15.06, X = 144.91, SD = 13.43). They had a confidence to care for their infant. Also, they could adapt themselves to their child's care. Mothers could deal with the problems regarding their own physiological and psychological problems, role, and social interaction. Maternal self-efficacy and age could significantly explain 36.8% of the variance in maternal adaptation in caring for their child.

Kamproh (2001) investigated the effect of health education program including providing group discussion, demonstration, and practice upon maternal behaviors in caring for a child with CHD. One hundred mothers of children aged 0-1 year with VSD diagnosed as moderate to severe were divided into two groups. After receiving the eight weeks-health education program, mothers perceived their child to be more seriously ill and at greater risk for complications. However, they believed that they would be able to take care of their child, and they conveyed a stronger intent and ability to follow through with their child's care than the control group. The infants in the experimental group had significantly fewer respiratory infections ($p < 0.001$).

In her pilot study, Sakulnoom (2002) identified the effects of an empowerment program on perceived self-efficacy for self-management of 60 mothers whose children aged 3-6 years old admitted with CHD to the specific medical ward in one hospital. The researcher found that mothers lacked the confidence to care for their child and to help the child in extraordinary situations. Mothers experienced stress related to their child's care, but they did not know how to deal with that stress. Then, she tested the effects of an empowerment program on perceived self-efficacy for self-management. Sixty mothers whose children aged 3-6 years old were admitted with CHD to a specific medical ward were divided into two groups. Mothers who received

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the empowerment program had higher mean perceived self-efficacy scores post intervention ($p < 0.05$). These studies showed that maternal variables; maternal adaptation, age, education, and economic were the important factors related to caregiving for infants and young children with CHD. The findings emphasize the importance of health educational support for those mothers to have more self-efficacy. This study was consistent with a study by Theannamngian (2003). She determined the effects of a supportive-educative nursing system on primary caregiver's behavior in caring for children with cyanotic heart disease ay risk of cyanotic spells and concurrent of cyanotic spell. After 30 primary caregivers (80% were mothers) received the 16 weeks health -education program, they had higher the mean scores of caring behaviors for the child with cyanotic heart disease than before (Mean = 37.20, SD = 5.18), and as a result, the occurrence of the child's cyanotic spells was decreased (Mean 8.63, SD = 10.52).

The existing quasi-experiment studies emphasize the effectiveness of health education program or self-help groups for supporting mothers' caring behaviors for young children with CHD with positive findings. However, the studies were conducted in the hospital settings, which the context was different from the family context. It seems there is only one qualitative study exploring how Thai families define and mange childhood heart disease. In her dissertation, Nukulkij (1993) described how Thai families defined and managed childhood heart disease. Based on naturalistic inquiry, she interviewed 20 families (fathers, mothers, and children who had heart disease aged 7 to 14 years). She found that Thai parents defined CHD as a life-threatening illness because they believed that the child's heart might stop functioning suddenly and unexpectedly. Parents mentioned the lack of information

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about the disease and its treatment. They wondered if they were caring for their child appropriately, and over half of the parents felt that they could not treat the child as a typical child. Nukulkij concluded that socio-cultural context including religious belief, social value, school system, and health care system influenced Thai parents to define and manage their child's illness.

Summary

The literature related to practices of families in caring for children with CHD presents both quantitative and qualitative studies. The studies assumed that parents had high psychological stress including low quality of life. The parents had limited understanding about the child's diagnosis as well as caring practices when they were at home. Many studies conducted in Thailand presented the effectiveness of health education program on maternal caring practices. There remains an important gap in that no studies to explored family experiences prior to cardiac surgery. Only one qualitative study provided useful information about Thai families of school-age children with heart disease. The researcher offered the insights into the relationship of definition and management behaviors which was influenced by socio cultural context. These findings raise the questions, what practices parents used in caring for their child at home, and how the socio-cultural influenced the perceptions and practices of families in caring for children with CHD prior to cardiac surgery.

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Thai Socio cultural Context related to Practices of Families in Caring for Children with CHD

Complex care and medical treatments for CHD are associated with cultural beliefs and social and economic issues, including changing of cultural institutions in the Thai society that challenge families who involved with CHD care and management. The best way to comprehend family caring practices of children with CHD is to focus on the socio-cultural context influencing on Thai families.

More than 30 percent of Thailand's people live in the cities (Unicef, 1997). "The urban way of life, from its diverse income opportunities, materialistic desires, to modern, often imported, value systems now reaches out and embraces virtually all rural villages, rapidly transforming the lives of children and their families in ways never expected only a generation ago" (Unicef, 1997, p.1). Rapid economic growth has led to a growing disparity between urban and rural economic well-being, as well as income disparities even within regions. Due to Thai economic growth and changes in social values, there is a growing amount of migration from rural to urban area (Phengjard, 2001). The attraction of urban-based industrial employment will continue to feed such rural to urban migration, despite national efforts to establish provincial development zones outside of Bangkok (Unicef, 1997).

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Likewise, most families of children with CHD have moved to work in Bangkok or nearby provinces after primary school graduation, hoping that they could find a better job to earn their livings. Some families only moved to Bangkok after their children were referred to the big cardiac centers, such as Siriraj and Ramathibodi

Hospitals. Those families generally undergo changes to their traditional life style under the pressure of urban demands including higher cost of living and population restructuring. With increasing economic pressure on the family after moving to Bangkok, generally both father and mother must go to work outside to earn income. This situation affects parenting practices; however, mothers remain expected to take on the traditional roles of parenting and caring for the children and other family members (Richter, 1997). Particularly, mothers are the primary caregivers, the ones most responsible for caring for an ill child. They are also the ones who take their child to the hospital for appointments while fathers are at work (Richter, 1992; Roongreungtham, khompayak, Serintawatana, & Chawalitnitikul, 1992). Thai mothers' work outside to increase family income affects their domestic roles, and in turn affected their child's development physically, emotionally, and socially (Soonthorndhada, Kanugsukkasem, Punpueng, & Tangchonlatip, 1999). While the parents are working outside, some ill children are taken care of by other family members, particularly grandparents, who have responsibility to prepare food, give medication, and monitor their child's symptoms, but often with minimal knowledge of the child's condition.

Even with increasing numbers of mothers working in the non-family sector, as is the case for most urban families today, a large number of them are not free from their traditional responsibility for household work and child care. Thus they remain the center of the house and still command more love and emotional attachment from their children (Kanungsukkasem, Soonthorndhada, & Kittisuksathit, 1996; Podhista & Pattaravanich, 1995). A change in this general pattern is emerging, especially among lower income urban dwellers. A recent study has looked into child care patterns

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among male factory workers in Bangkok to determine how they see their role within and outside of household. Fathers thought that their primary responsibility was to provide economic support for their families, whereas mothers perceived a much stronger nurturing role. Over half of the women interviewed still thought that only mothers should be responsible for child care, yet surprisingly two-thirds of fathers saw child care as a joint task (Kanungsukkasem, Soonthorndhada, & Kittisuksathit, 1996). Even though quantitative data does not exist, qualitative studies have shown that migrants who have children may try to care for the children themselves, particularly during infancy. However, more often than not children are sent back to be cared for by rural grandparents.

In addition to rapid changes in family and economic structure in Thai society, there is evidence that the number of people in the Thai family has been declining over the past decade (Richter, 1992). Family structure has shifted from extended family to nuclear family (Ministry of Public Health, 2007). Nuclear families living in urban areas with both parents in labour force or employed full-time face the same challenges and dilemmas when it comes to caring for children with chronic illness, such as the result of CHD at home. These broader changes have important implications for child care within the family. The consequences of these changes impact upon social structure, family life, family relationships, and may create financial stress (Lawoko & Soares, 2003; Svavarsdottir & McCubbin, 1996). These changes may inevitably affect both the children with CHD, who require ongoing care, and their families, who continue to take full responsibility for family members with the consequences of heart disease. Kinship ties as well as demographic and social factors have all been found to

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influence the decision and expectations of caregiving families in Thailand (Sirikulchayanonta, 1991).

Even though there are ongoing changes in Bangkok society, people still assign a high value to their parents and regard the family as a major force in looking after children with chronic illness. According to Nukulkij's qualitative study (1993), children with heart disease living in Bangkok were cared for by their parents. However, parents accepted that they would receive strong support from extended family members and relatives. Other family members, particularly grandmothers, even though not living under the same roof, frequently visited and provided material or financial support. Shared support between the parents and their relatives living at a distance was still well maintained.

Religion is also found to be an important factor influencing families' beliefs. Nukulkij (1993), Klunklin (2003) and Jintrawet (2005) also found that religious beliefs influence Thai families' child's care. Buddhist teaching also provides psychological support for parents and family. Thai families view disease and illness as being derived from the consequences of deeds done in previous lives and as being associated with evil spirits (Chen & Rankin, 2002). Buddhism introduces a much deeper concept of compassion for suffering and pain. Individuals are expected to tolerate and accept uncomfortable signs and symptoms, which are viewed as the consequence of their actions. Also, the parent-child relationship is believed to be the result of both individual's actions in their previous existence. Therefore, when a child gets sick with a chronic illness like heart disease, both the child and family need to experience the treatment and tolerate the pain and discomfort together because this is a part of life as a means of atoning for past misdeeds.

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Based on Buddhist philosophy some parents of children with CHD believe that heart disease is due to fate and that it is beyond anyone's control, making an understanding of pathological origins irrelevant. Some parents take their child to the Buddhist temple to pray and receive holy water from the monks to get rid of their bad fortune (Nukulkij, 1993). Parents believe that when something unfortunate happens, such as their child being ill with CHD, it is the result of their bad manner in a past of life, or the effects of past karma. They believe in karma and tend to associate illness and symptoms with evil spirits (Chunuan, Wanaleesin, Moukreungsai, & Thitimapong, 2007). Therefore, when the child is diagnosed with CHD or admitted to hospital because of complications or surgery, parents usually go to a temple and ask for forgiveness and purification. They also ask for an amulet for their ill child and put it closed to their child, such as in the pocket of the child's clothes or under the pillow. In addition, the monks may recommend a special day for surgery or treatment based on their forecasting of a good day and folk history (Nukulkij, 1993).

Apart from religious belief, Thai families believe in superstition: the belief that spirits inhibit natural things, or that supernatural forces influence natural events and people's lives such as fortune, well-being, and becoming sick. This kind of beliefs included belief in black magic, or supernatural beliefs, the belief that transcend logical reasons. For example, spiritual tattoos are supernatural in that they serve the implicit purpose of providing protection from and power over external forces. Evidence of pervasive belief in spirits can be seen in spirit guardian house or little temple-like shrines standing in the compounds of almost every house and building as well as hospitals in Thailand (Champeon, 2001). People believed that the spirit in hospital can help patients including ill children be safe and be healthier. The spirit of

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the house and in the hospital is normally treated with respect and care, offerings of food, flowers and incense are made regularly. In some cases, clay dolls representing servant and mistresses, wooden elephants or horses are also offered. These doll families are supposed to add to the comfort of the spirit. In addition, the spirit of temple is also seen among Thai families. They believed that the spirit will protect the local temples and cities from possible disease and disaster. Meanwhile, the spirit will make people happy and healthy.

Health care reform is also a significant factor related to families' caring practices. Formerly, the cost of cardiac interventions, medicines, and heart surgery was beyond the means of low income families, and access to health care service was limited. In 2001, the government of Thailand introduced a universal coverage scheme with the aim of ensuring equitable health care access for even the poorest citizens, known colloquially as either the '30-Baht Scheme' or 'Gold Card Scheme'(Ministry of Public Health, 2001). People joining the scheme receive a gold card which allows them to access services in their district, and, if necessary, be referred for special treatments elsewhere. Access to higher level health services occurs via referral from a registered primary health center or hospital, except for emergency services which can be accessed at any public health service facility (Coronini-Cronberg, Laohasiriwong, & Gericke, 2007).

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System related Issues for Surgical Readiness of Children with CHD in Thailand

Children with CHD who require complex heart surgery are often referred to cardiac centers in Bangkok, where there are six government hospitals, such as Siriraj and Ramathibodi Hospitals that have the potential to perform cardiac surgery for

children with CHD (Pediatric Cardiac Surgery Foundation, 2006). Although there are university hospitals and provincial hospitals that provide cardiac surgery in every part of Thailand, some lack specialized pediatric nurses, pediatric anesthetists and/or cardio- thoracic intensive care units. As a result, children with complex heart diseases, who need complicated cardiac surgery, are referred to the hospitals in Bangkok.

In Thailand, there are 60 pediatric cardiologists and 20 cardiac surgeons who can perform pediatric cardiac surgery, although very few for newborns and complex CHD cases (Pongpanich, 2006; Wongsawadiwat, 2006). Even though the trend of cardiac interventions is providing an investigation and a corrective surgery for children with CHD as early as possible, only 20% of Thai children who are ready for surgery actually undergo palliative or corrective surgery at the recommended time (Pediatric Cardiac Surgery Foundation, 2006; Pongpanich, 2006). It is ideal if the child receives a cardiac surgery in the first year of life. At present, though the Thai governmental health care scheme helps more of these children to get heart surgery, there are only 15 government hospitals that have the ability to perform pediatric heart surgery throughout the country. Consequently, fewer than 2,500 children are operated on each year, leaving more than 3,000 children with CHD waiting for cardiac surgery (Pediatric Cardiac Surgery Foundation, 2005). Typically, the children have been waiting almost two years for surgery (Khongphattanayothin et al., 2005; The Cardiac Children Foundation of Thailand, 2005), and consequently, are at greater risk for pre-operative complications. Mortality while waiting for surgery was approximately 5% at two years at Chulalongkorn Hosital and Children Hospital (Khongphattanayothin et al., 2005). The shortage of the physicians in the country and the associated capacity

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of the health care system to treat these children in a timely manner are the major factors affecting the outcomes of palliative and corrective cardiac surgery for children in Thailand (Khongphattanayothin et al., 2005; Wongsawadiwat, 2006). As a result of lack of centers providing cardiac investigation and surgery and insufficient pediatric cardiologists and cardiac surgeon, especially in rural areas, children are referred late for correction, making them either high risk for surgery or inoperable due to the development of irreversible pulmonary vascular obstructive disease.

Likewise, a large number of CHD children are referred from other provincial hospitals to cardiac centers in Bangkok including Siriraj and Ramathibodi Hospitals for diagnosis and palliative or corrective surgical treatments. Most of them rely on the 30 baht policy for medical cost coverage. However, some families had obstacles regarding the referral system from registered primary care hospitals to tertiary care hospitals. Some families encountered physicians at the registered hospitals who did not allow the referral and provided no useful advice, making these families worried that their CHD children would not have proper treatments and the heart surgery.

When children are referred with possible CHD, they will have further investigations such as echocardiograms by a pediatric cardiologist. After the diagnosis is confirmed, each patient will have a plan of management that may include medical or surgical interventions including oral medications, cardiac catheterization (hemodynamic study and/or intervention), or surgery as well as no treatment (follow-up) and/or discharge from hospital service.

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Summary

The literature on parenting infants and young children with CHD in western culture revealed that parents are significantly affected by a diagnosis of CHD. They are confronted with similar caring responsibility to parents in Thailand. Parents were very concerned about the magnitude of their caring responsibility at home. Studies consistently report that families of a child with heart disease experience psychological stress and social consequences. However, there was a lack of a qualitative research that explores in depth the perceptions, family caring practices, and home experiences during preoperative period.

As medical care becomes more technically advanced, the amount of families' caring responsibilities will increase and families will require greater support from health care providers. While there is a rapid Thai socio- economic change in Thailand, what we do not know is how the complex western medical care fits within Thai society. There is no data explaining how families address their caring responsibilities, and how socio-cultural context influences the perceptions and practices of families. Therefore, this study generated information that provided a deep understanding of the experiences of the Thai families when caring for children during preoperative period.

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