# NEEDS AND RESPONSE TO NEEDS OF PARENTS OF CHILDREN WITH CONGENITAL HEART DISEASE

**JARUWAN SAWANGSRI**

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This research study is a descriptive study which investigated the needs and the response to needs of parents of children with congenital heart diseases and the demographic factors that influenced the needs of parents of these children. The subjects were 180 parents including fathers and mothers of children with congenital heart diseases who brought their ill child for follow-up and who were admitted to the heart disease clinic at Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Mongkutklao Hospital and King Chulalongkorn Memorial Hospital. Data was collected by means of questionnaires eliciting demographic data, and the needs and response to the needs of parents of children with congenital heart disease. Data was analyzed by using mean, standard deviation, ANOVA and Sheffe Test.

The results of this study indicated that the total mean score of needs of the parents of children with congenital heart disease was at a moderate level ($\overline{X}$ =3.00,S.D =0.50) and the financial need was at a high level while other needs were at a moderate level including spiritual needs, information needs, physical needs, household management needs and psychological needs. However, the total mean score of response to needs of parents of children with congenital heart disease was at a moderate level ($\overline{X}$=0.50, S.D.=0.30) and the mean score of response to needs of parents including information needs was at a moderate level, while the mean score of response to financial needs, spiritual needs, physical needs, household management needs and psychological needs were at a low level. Educational level and family income were statistically significant factors influencing the needs of parents of children with congenital heart disease. Educational level was also a statistically significant factor influencing the needs of parents of children with congenital heart disease, especially information needs ($p< .01$) and financial needs ($p< .001$). In addition, family income was a statistically significant factor influencing the needs of parents of children with congenital heart disease, particularly information needs ($p< .01$), spiritual needs ($p< .01$), household management needs ($p< .05$) and financial needs ($p< .001$).

The findings of this study suggest that pediatric nurses should realize the importance of different needs of parents whose children suffer from congenital heart disease. Furthermore, nurses should be aware that the parents' needs can vary depending on different factors especially educational level and family income. Nursing care plans should be devised accordingly so as to enable the parents to take care of their ill children as effectively as possible.

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จารุวรรณ สว่างศรี : ความต้องการและการได้รับการตอบสนองความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตร โรคหัวใจพิการแต่กำเนิด (NEEDS AND RESPONSE TO NEEDS OF PARENTS OF CHILDREN WITH CONGENITAL HEART DISEASE) คณะกรรมการควบคุมวิทยานิพนธ์: รัชนี สีดา, ค.ม (การวัดและการประเมินผลการศึกษา), ไข่มุกข์ วิเชียรเจริญ, กศ.ด. (การวิจัยและการพัฒนาหลักสูตร), ศศิธร วรรณพงษ์, วท.ม. (สรีรวิทยา) หน้า 124

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การวิจัยครั้งนี้เป็นการวิจัยเชิงพรรณนา เพื่อศึกษาความต้องการและการได้รับการตอบสนองความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด และปัจจัยที่มีอิทธิพลต่อความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด กลุ่มตัวอย่างที่ใช้ในการศึกษาครั้งนี้เป็นบิดาหรือมารดาที่มีบุตรป่วยเป็นโรคหัวใจพิการแต่กำเนิดจำนวน 180 ราย โดยบิดาหรือมารดาพาบุตรมารับการตรวจรักษา ณ คลินิกเด็กโรคหัวใจ และมาดูแลบุตรที่เข้าพักรักษาในโรงพยาบาลด้วยโรคหัวใจพิการแต่กำเนิด ที่ โรงพยาบาลศิริราช, โรงพยาบาลจุฬาลงกรณ์ สภากาชาดไทย, โรงพยาบาลพระมงกุฎเกล้า และ สถาบันสุขภาพเด็กแห่งชาติมหาราชินี เก็บข้อมูลโดยใช้แบบสัมภาษณ์ความต้องการและการได้รับการตอบสนองความต้องการของบิดาหรือมารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด นำข้อมูลที่ได้มาวิเคราะห์ด้วยสถิติพรรณนา และหาความแตกต่างโดยใช้การวิเคราะห์ความแปรปรวนทางเดียว และเปรียบเทียบรายคู่โดยใช้การวิเคราะห์ของเชพท์เฟ่

ผลการศึกษาครั้งนี้พบว่า ความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด โดยรวมอยู่ในระดับปานกลาง ($\bar{X}$ =3.00, S.D = 0.50) สำหรับความต้องการที่อยู่ในระดับมาก ได้แก่ ด้านการเงิน ส่วนด้านที่ความต้องการอยู่ในระดับปานกลาง ได้แก่ ด้านการเสริมสร้างพลังทางจิตวิญญาณ, ด้านข้อมูลในการดูแลบุตรป่วย, ด้านการดูแลสุขภาพของบิดา-มารดา, ด้านการจัดการภายในบ้าน และด้านการประคับประคองจิตใจ ส่วนการได้รับการตอบสนองความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิดโดยรวมอยู่ในระดับปานกลาง ($\bar{X}$ =0.50, S.D = 0.30) โดยการได้รับการตอบสนองความต้องการด้านข้อมูลในการดูแลบุตรป่วยอยู่ในระดับปานกลาง ส่วนการได้รับการตอบสนองความต้องการที่อยู่ในระดับน้อย ได้แก่ ด้านการเงิน, ด้านการเสริมสร้างพลังทางจิตวิญญาณ, ด้านการดูแลสุขภาพของบิดา-มารดา, ด้านการจัดการภายในบ้าน และด้านการประคับประคองจิตใจ ปัจจัยที่มีอิทธิพลต่อความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด ได้แก่ ปัจจัยด้านระดับการศึกษาของบิดา-มารดาและรายได้ของครอบครัว ปัจจัยด้านระดับการศึกษาของบิดา-มารดามีอิทธิพลต่อความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด อย่างมีนัยสำคัญ ได้แก่ ด้านข้อมูลในการดูแลบุตรป่วย ($p<.01$) และด้านการเงิน ($p<.001$) ส่วนปัจจัยด้านรายได้ของครอบครัว มีอิทธิพลต่อความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด อย่างมีนัยสำคัญ ได้แก่ ด้านข้อมูลในการดูแลบุตรป่วย ($p<.01$) , ด้านการเสริมสร้างพลังทางจิตวิญญาณ ($p<.01$) , ด้านการจัดการภายในบ้าน ($p<.05$) และด้านการเงิน ($p<.001$)

ผลการวิจัยครั้งนี้ ผู้วิจัยมีข้อเสนอแนะว่า ในการพยาบาลเด็กโรคหัวใจพิการแต่กำเนิด พยาบาลควรให้ความสำคัญกับความต้องการของบิดา-มารดา ซึ่งเป็นผู้ดูแล และมีปัจจัยพื้นฐานที่แตกต่างกัน และปัจจัยพื้นฐานเหล่านี้มีผลต่อความต้องการของแต่ละบุคคล ฉะนั้นพยาบาลควรนำผลการวิจัยครั้งนี้ไปวางแผนการพยาบาลให้สอดคล้องกับความต้องการของบิดา-มารดาที่มีบุตรเป็นโรคหัวใจพิการแต่กำเนิด เพื่อให้สามารถดูแลบุตรได้อย่างดีและมีประสิทธิภาพสูงสุด

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# CHAPTER I

# INTRODUCTION

## Background and significance of the study

Nowadays, society has changed so much in socioeconomic development and environment that people' s health receives many impacts. Moreover, the rapid progress in medical technology has prolonged life for chronic illness patients.

In 1992, Ramathibodi Hospital statistics showed that there were 1734 children with congenital heart disease (Seeda, R. 1999: 48). In addition, the number of these ill children increases every year. The incidence of newborn with congenital heart disease is about 8:1000. For example, the study of Sathapoldecha, R. (1992: 52-59) found that there were various complications in 72 children with congenital heart disease between 1987 and 1992 including pneumonia (21), heart failure (8), pulmonary hypertension (43), cardiac arrest (8) and infective endocarditis (1). Nowadays the modern medical treatment for congenital heart disease has highly been enhanced and this leads to increased long life of children and changed the average age from 5 to 8 - 13 years. This will become in burden to the parents in caring for the ill child (Hiranshunha, S.1987: 1).

Congenital heart disease has the impacts on children' s daily life, both in physical and psychological conditions. For instance, the children with congenital heart disease would feel discomfort, stress and distress because they cannot perform activities like normal children. Moreover, their bodies are fatigued, have developmental delays, and bear different skin color. In addition, they may face with serious complications such as infection, anoxic spells or dyspnea which threatens their lives. Some children also have to limit their activities which contradict with the child' s habit (Phongkumpan, C. 1994: 1). Furthermore, they have painful experiences from some treatment and/or procedures they have to undergo. Finally, some children who are admitted to the hospital for serious illness will have to adjust themselves to a new and strange environment as well as be separated from their parents.

Similarly, the illness has threatened and impacted not for only the children but for their parents and family members (Anderson & Bauwens, 1981: cite in Thanutteerakul, V. 1993: 26). For instance, some parents may have stress, anxiety, sleeplessness, emotional change, exhaustion and burnout. Their decision – making ability in problems solving will decrease, and this may lead to neglect or abuse of their children (William, 1994: 161). Moreover, they may have physical problems such as gastrointestinal disturbance from changing eating patterns. They may also become socially isolated as they focus on their ill child, and having less time for themselves to satisfy their own needs or to have interactions with other people in society (Pariard & Ames, 1993: 252-256 cite in Thanutteerakul, V. 1993). In addition, economic burden and alterations in work role performance are commonly found. The family relationship will have many conflicts from less time, emotional stress, increasing responsibility, financial constraints and burden. Therefore, the parents have to adjust and seek for support in order to continue caregiving to their child (Faria, 1989: 103).

The information giving, advice and supports for caregiver in caring for their child are very important for the parents of children with congenital heart disease and their family. These include the encouragement of the parents and their families to face with the problems and other impacts both in the hospital and at home in order to maintain normal life. The key personal who could advise and support the parents are nurses because they are very close and understand the problems of the ill children and their families. Therefore, nurses should pay attention, to give support and advise the parents in order to prepare them for taking care of their ill child effectively. Giving information to the child' s and their parents' needs is a nurses' responsibility and it will produce good results for the children and the family.

Many studies suggest that parents have various needs which are different individually. For example, some parents need the support from experts in problems solving. They also need psychological support such as understanding and sympathy from others to continue their caring activities (Nydevik & Eller, 194: 155-156 cite in Choungsawadsak, S. 1998: 4). According to the study of May (1993: 273-278), there were three needs of caregivers in rehabilitation the patients at home including: 1) information about patient' s illness, 2) assistance needs such as advice and knowledge about caring patients, and 3) understanding needs for their own fear. In addition, the caregivers of the chronic illness patient want some help from family members (Rawlins, 1991: 213-220) in order to decrease their burden. They also need financial support from their family members and their relatives as well as effective communication when having problems (DesRosier et al, 1992: 87-90 cited in Choungsawadsak, S. 1998). Furthermore, Choungsawadsak, S. (1998: 44) indicated six need dimensions of the caregivers of the cerebrovascular accident patient including 1) spiritual needs, 2) psychological needs, 3) household management needs, 4) physical needs, 5) financial and accessory needs and 6) information needs. Likewise, Wingate & Lackey (1989: 216-224) studied the needs of the caregivers of the cancer patient at home and presented eight need dimensions as follows: 1) psychological needs, 2) household management needs, 3) information needs, 4) respite needs, 5) physical needs, 6) legal and/or financial needs, 7) spiritual needs, and 8) the other needs that did not fit into the seven other dimensions listed.

The parents' needs should be responded effectively by the cooperation and coordination between nurses and parents who take care of children with congenital heart disease before discharging the children from the hospital. The responses to need are various based on the kind of needs. Brue & Dracup (1978: 212-216 cited in Chaichan, 1997: 11-14) studied the need responses of relatives of patients with severe heart disease and categorized them into 4 dimensions: 1) phoning the relatives twice a day in order to information them about the patient' s symptom, 2) using case management, 3) flexible visit time through the day and night depending upon the relatives' need, and 4) giving the consultation to the relatives about 15 minutes in each shift to let them express feelings privately. Then, they created a nursing care plan. After two years of their study, the nursing care became more effective and could respond more directly to the needs of the relatives. Moreover, the crisis of the relatives were decreased. However, sometimes the health care team may focus the care only on ill children and neglect the parents' needs because they lacked of time or knowledge and not understanding about holistic care (Becker et al, 1977: 348-366). Therefore, Nurses should realize the family' s needs because the parents are the most significant persons for the ill children.

There are many basic factors influencing on individuals' needs and responses. Nurses should understand about needs and basic factors of parents in order to improve the quality of care. The basic factors which the researcher explored were as follows:

1. Parents' age: Age is an important factor influencing human' cognition, behavior, life experience and judgement (Srangnok, S.2000: 27-28). In general, people with different age would have differences in perception, understanding and seeking for resources to support their needs. The older the people get, the fewer questions or problems they would have. In others, older people seem to have fewer needs than the young ones (Orem, 1991: 239)

2. Parents' educational levels: The parents who have high education will be aware of the problems and better understand about the illness because the high educational levels enables people to seek more information and pass the learning process. Moreover, they have more skills in seeking helpful information and giving better care than those with lower education. (Asumpinzup, U. 1997: 102).

3. Family income: People who have high income have more opportunities to

seek for facilitating materials which are better to their health. On the contrary, the families with low income have financial constraints and burdens. As a result, they have more needs and require more support than the ones with high income.

4. Children' s age: Age is one of the influential factors on self-care behaviors including the abilities to conceptualize the health status and to respond directly to the body change (Kozier, Erb & Oliveri, 1991: 75). According to the study of Neff & Spray (1996: 58-64 cited in Ke, L. 1998: 79), children who were in different age groups had differences in the development level in term of memory, perception and response to illness as well as to hospital admission. The parents of children in different age groups may have different information needs. For example, parents with a young child need to take care of their child closely because their child cannot take care of themselves. As a result, the parents have no time for their self - care or other family members' care. Their stress is increased as a result of this. They may have more needs from other resources to support their well – being as well. Therefore, children' s age is regarded as having an influence on the parents' needs.

5. Severity of illness: Severity of illness has a great effect on the reaction of both ill child and their parents. The more severity the children experience, the more anxiety, stress, and fear the parents have and the most support they need from the health care teams. Therefore, the severity of illness is considered one factor influencing the needs of parents (Phongkumpan, C. 1994: 18).

6. The number of admissions: It affects the adaptation of not only

the ill child but also their parents. The parents who bring their child for admission in the hospital frequently may receive more advice from nurses than the ones who do not. So, the number of admissions may be influencing on the needs of parents of children with congenital heart disease.

To give the best nursing care holistically, nurses should be aware of the nursing care given not only to the ill child but also their parents. However, nurses could not respond to the parents' needs appropriately without understanding of relevant factors about the parents' needs. Therefore, this research is aimed to examine the parents' needs, and how these needs are responded to in giving care to their child who has congenital heart disease so as to elicit information concerning their needs to subsequently use as a guideline in developing a nursing intervention program to promote the parents' caregiving ability according to their needs. Moreover, the research finding will be used in preparing the parents to accept the condition of their ill child and have more confidence in giving proper care. If the parents' needs are directly satisfied, they would be able to carry on their caregiving more efficiency.

## Conceptual Framework

The conceptual framework was adapted from the study of needs among the caregivers of cancer patients of Wingate & Lackey (1989: 216224). Wingate & Lackey studied the needs of the caregivers of cancer patients in eight dimensions: 1) psychological needs, 2) household management needs, 3) information needs, 4) respite needs, 5) physical needs, 6) legal and financial needs, 7) spiritual needs and 8) other needs, that did not fit into the seven other categories listed. In order to come up with a conceptual framework best suit the needs of parents of children with congenital heart disease and the ways their needs are served, the conceptual framework of Wingate and Lackey was modified and divided into 6 categories as follows: 1) Information needs, 2) Household management needs, 3) Physical needs, 4) Psychological needs, 5) Spiritual needs and 6) Financial needs, while the respite needs has been combined with the physical needs of the parents.The eighth category has been omitted in the present study as this studied congenital heart disease that a effected the patients and the family, which is considered similar to cancer because both are chronic illness as. These 6 dimensions are expected to sufficiently meet the needs of the parents of children with congenital heart disease. In addition to this, there are two important factors influencing the parents' needs including the basic factors about parents (age, educational level, and family income) and the basic factors of the ill child (age, the severity of illness and the number of admissions). The conceptual framework is shown in Figure I.

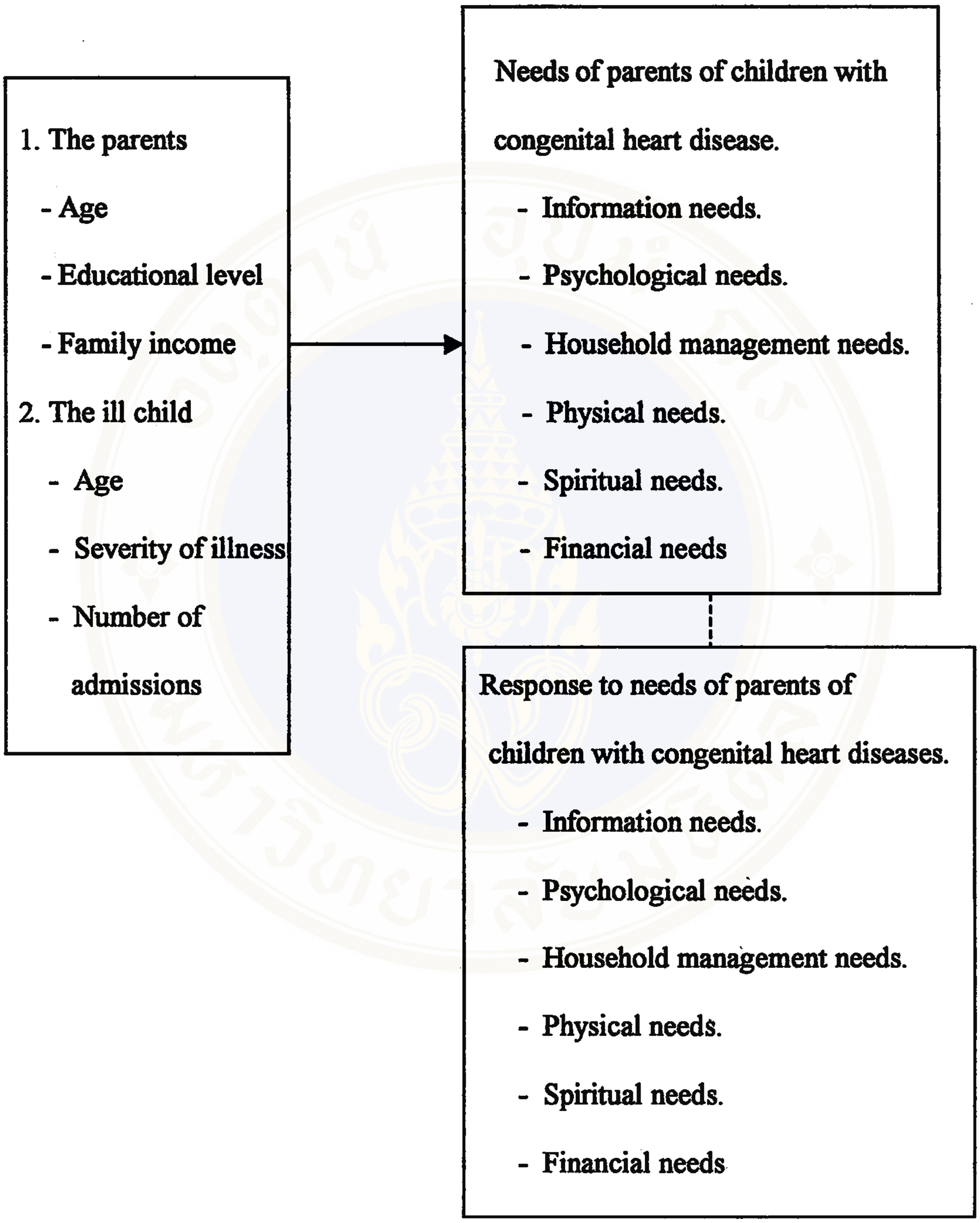

**Figure I** Conceptual framework

**Purposes of the Study**:

1. To explore the needs among the parents of children with congenital heart disease.

2. To examine the response to needs of the parents of children with congenital heart disease.

3. To compare the difference of the parents' needs according to these factors: basic factors of the parents (age, educational level and family income) and of the ill child: (age, severity of illness and number of admissions).

**Hypothesis:**

1. Needs of the parents of children with congenital heart disease are different according to their basic factors (age, educational levels and family income).

2. Needs of the parents of children with congenital heart disease are different according to children' s basic factors (age, severity of illness, and number of admissions).

**Scope of the Study**:

This study was explored needs and response to needs of fathers or mothers who took their children with congenital heart disease to follow -up in the heart clinic or to admit for medical care at Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Chulalongkorn' Memorial Hospital, and King Mongkutklao Hospital.

**Definition of Terms:**

1. Needs of parents of children with congenital heart disease meant the need for necessary elements and information in order to take responsibility in caring their children with congenital heart disease. There are 6 dimensions as follows:

1.1 Information needs meant advice about caregiving to children with congenital heart disease and information about the illness.

1.2 Household management needs meant the management or the necessary materials for facilitating in managing household work, carry on family activity and continuously care for the ill child.

1.3 Physical needs meant the methods or activities to maintain the parents' body healthy.

1.4 Psychological needs meant assistance and cooperation regarding child care, problem solving and understanding the parents gained from physician, nurse or family members.

1.5 Spiritual needs meant the advice that make parents' feeling about receiving love, sympathy, encouragement, self-esteem, and the nature of human relationship to religion in order to carry on caregiving to the parents of children with congenital heart disease.

1.6 Financial needs meant the support resource for the parents to continuously take care their children and family regarding financial matters such as medical expense in child care, curing accessories charge and expense in hospitalization.

2. Response to needs of parents meant the parents of children with congenital heart disease receive suggestions advice, consultation or assistance from the health care team during hospitalization or before discharging. While the detail of 6 response to needs as follows: information about caring, household management, psychological support, physical activity, spiritual and financial support.

3. Basic factors meant the personal data of the parents and their children with congenital heart disease. Parents' data were age, educational levels, and family income. The ill child data were age, severity of illness and number of admissions. The description are as follows:

3.1 Age of parents meant full age of the parents in year which classified into 20 years and younger, 21-40 years, 41-60 years and older than 60 years old.

3.2 Educational levels meant the highest educational level of parents which classified into no education, primary education, secondary education, diploma / vocation certificate and bachelors degree and higher.

3.3 Family income meant net monthly income earned by mother and father or by the one who gains income classified into: 5,000 bath or less, 5,001-10,000 bath, 10,001-15,000 bath and more than 15,000 bath.

3.2 Age of the ill child meant full age of children with congenital heart disease. Which classified into less than 1 years, 1-3 years, 4-6 years, 7-12 years and 13-18 years.

3.3 Severity of Illness meant the degree of physical capacity of children with congenital heart disease could achieve. The Functional Classification of Heart Disease of New York Heart Association was used to describe the severity of heart disease as follows: (Maurice & Malcolm, 1977: 37).

Class I: No limitation of physical activity. Odinary physical activity does not cause undue fatigue, palpitation, dyspnea, or anginal pain.

Class II: Slight limitation of physical activity Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, dyspnea, or anginal pain.

Class III: Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, dyspnea, or anginal pain.

Class IV: Unable to carry on any physical activity without discomfort. Symptoms of cardiac insufficiency or of the anginal syndrome, may be present even at rest. If any physical activity is under taken, discomfort is increased.

3.4 Number of admissions meant frequency of a child' s hospitalization after diagnosed congenital heart disease.

**Expected Outcomes and Benefits**:

1. The findings of this studied should be the guidelines for nurses in giving consultations, health education and assistance regarding caring of the children with congenital heart disease and should response to actual needs of the parents about how to

care for their ill child with congenital heart disease.

2. The result of the study will provide further guidelines for home health care upon the children with congenital heart disease.

# CHAPTER II

# LITERATURE REVIEW

This research study describes the needs and the response to needs of parents of children with congenital heart disease. The literature review consists of the following topics:

1. Congenital heart disease
2. Effect of congenital heart disease on children and parents
3. Needs of parents who care for children with congenital heart disease
4. Factors influencing on the needs of parents of children with congenital heart disease
5. The importance of nurses in responding to the needs of parents of children with congenital heart disease

## Congenital heart disease

The etiology of most congenital heart disease is unknown. However, several factors are associated with a higher than normal incidence of the disease. These include prenatal factors such as (Wong & Whaley, 1995: 812-818):

(1) Maternal rubella during the first three months of pregnancy

(2) Maternal alcoholism

(3) Maternal' s age over 40 years

(4) Maternal diabetes

(5) The fetus has chromosomal aberrations such as Mongolism and Down ' syndrome (Phongpanich, B. 1993: 61).

**Type of congenital heart disease**

Children with congenital heart disease has abnormal heart structure and abnormal blood circulation. The classification divides congenital heart disease into 2 types, which are based on hemodynamic changes (Wong & Whaley, 1995: 812-821):

(1) Cyanotic defects may be the result of anomalies that cause a change in the pressure; therefore, the blood is shunted from the right to the left side of the blood is shunted from the right to the left side of the heart because of an increase in pulmonary vascular resistance. Cyanosis may also result from a defect that allows mixing of blood between the pulmonary and systemic circulation. This generally occurs in tetralogy of follot and pulmonary atresia etc.

(2) Acyanotic defect is an abnormal connection between the heart chambers. If this condition is present, blood will necessarily flow from an area of higher pressure (left side) to one of lower pressure (right side). This flow of blood is termed a left to right shunt. No desaturated blood flows directly into the left side of the heart, as in Coartation of the aorta etc.

**Symptoms and signs**

1. Cyanosis: right to left shunts do mixed obstructive with shunt. In some cases, there is a combination of an obstructive lesion with a shunt; for example Follot' s tetralogy (King, 1982: 109).
2. Dyspnea caused by the insufficient organ supply to the body tissues resulted from the low cardiac output or hypoxia. This symptoms would be hinder the children

from the daily activity lining as normal children (Wong & Whaley, 1990: 826).

3. Failure to thrive. A child with congenital heart diseases usually has growth failure which has lower weight or height than normal child (Gidding & Rosenthal, 1984: 1369). This would be the result of the abnormal heart function leading to cellular hypoxia and insufficient substances for cellular growth. Moreover, the children would have decreased in appetite (Sungsawang, J.& Nana, A. 1995: 418).

4. Dysrhythmia resulted from an abnormal heart structure leading to abnormal electrical conductivity such as tachycardia, bradycardia and other dysrhythmia (Jamjureerak, V. 1993: 81).

5. Increase sweating resulted from the high metabolic rate of a child with congenital heart disease to ventilate heat from the child' s body (Sungsawang, J. & Nana, A. 1995: 415).

6. Polycythemia means an increased hemoglobin level or the number of red blood cells more than 55 % which is usually found in children with cyanotic congenital heart disease. It is the result of the body compensation of the prolonged tissue hypoxia which stimulate the bone marrow to produce more red blood cells to increase the oxygen- carrying capacity and bring oxygen to the tissue. (Wong & Whaley, 1995: 812-818).

7. Clubbing of fingers and toes: This symptom is found in children with cyanotic congenital heart disease. Fingers and toes of the patients look like drum sticks. There is an increase in peripheral blood vessels size, which causes a thickening and

flattening of the tips of fingers and toes. This is thought to occur because of chronic tissue hypoxemia (Senasuttipan, V. 1991: 14).

8. Squatting: When children with Tetralogy of Fallot get short of breath they tent to squat down for a few minutes. This decrease systemic venous return, increases peripheral systemic arterial resistance, decreases venous return to heart and decreased blood from right to left shunt (King, 1982: 108).

9. Anoxic spells: It is symptom that is found in children with cyanotic congenital heart disease, especially Tetralogy of fallot. The children will have acute brain anoxia. The children become more cyanosed and abnormal breathing. Death may occur from hypoxemia and metabolic acidosis (Wong & Whaley, 1990: 826).

10. Other symptoms such as: respiratory infection, infective endocarditis, thombosis, congestive heart failure and brain abcess (Wong & Whaley, 1995: 826-835).

**Therapeutic Management**

There is much therapeutic management for children with congenital heart disease as follows:

1. Medications. There are many important medications including:

1.1 Medications for congestive heart failure: The objective of this medication is to increase the heart contractility such as digitalis. However, some children may take both digitalis and diuretics in order to decrease the retention of sodium and water. The common diuretics used in children are Thiazide (Dichlortide), Furosemide (Lasix), and Spironolactone (Aldactone) (Louwhaprasittiporn, D. &

Nana, A. 1993: 145-156).

1.2 Medications for acute cerebral hypoxia (anoxic spell): A child with cyanotic congenital heart disease can have anoxic spell which will lead that child to a sudden death. However, this condition can prevent and treat by the use of medication, such as propanolol which is a beta-adrenergic blocking agent, effective in reducing spastic obstruction to pulmonary blood flow. Moreover, this condition can induce by anemia which can prevent by taking enriched iron from food or the iron supplement drug (Louwhaprasittiporn, D. 1991: 7-9).

2 Surgical Treatment

Surgical treatment in congenital heart disease can divide into 2 types (Tissayakorn, J. 1993: 93).

2.1 Palliative surgery: the objective of alliative surgery is to improves the children condition for a temporary period.

2.2 Corrective surgery or Complete repair: The surgical technique is closure of defect or cardiac catheterization to treat of a hypercyanotic spells or a palliative shunt procedure to increase blood flow to the lungs.

**Effects of congenital heart disease**

**Effects on the children**

Congenital heart disease has many effects on the children not only physical, psychological but also social aspects as follows:

1. Physical aspect is the result of the pathology of diseases. The

manifested symptoms including dyspnea, chest discomfort and weakness which sometimes are every severe and suffering. Moreover, due to tissue hypoxia, the growth development is delayed and lack of the opportunity to other physical development.

Furthermore, a child may suffer from prolong illness from several rehospitalization due to easily having many infections. In addition, the delay in seeking treatment after having symptoms for at least one year (70%) produces the permanent deformities and may even cause death (Leesin, B. 1992: 26).

2. Psychological aspect: Because the natures of congenital heart disease are chronic and sometimes provokes severe condition, a child has to be rehospitalization for several times. As a result, that children has to adapt their minds and emotions to face with new environments during hospitalization. Therefore, the common psychological responses are anxiety about their illness and their educational life, fear about their illness, the treatment procedures such as injection or surgery, the professional personal, the relationship with their friends or their family changes. Moreover, they are fear other people condemn and feeling that they were a burden for their family problems (Gibbons & Boren, 1985 cite in Srilenawat, S. 1987: 162). In addition, they always may have irritable emotional changes because their symptoms inhibit their activity daily living as a normal child. Some children may depress, not enjoyable and having demanding behaviors on their family. Other children may be irritable and aggressive (Hanujareonkul, S. 1993: 141).

3. Social aspects: Due to the continuous follow-up and repeated

hospitalization, the ill child has to isolate from their peers and their society. As a result, some children will have behavioral changes such as aggressive, demanding behaviors or depressed. Moreover, they may receive overprotection from their family and are forbidden to some activities leading to difficult social adaptation. Other children who improve from their illness do not want to go to school or play with their peers because they are shy to take the medications. With these feeling, children will isolate themselves, aggressive and antisocial caused that no peer wants to play with. Therefore, they may feel lonely and lack of opportunity to learn the steps of social development (Futcher, 1988: 382-383).

As mentioned above, the effects of the chronic disease on the children may inhibit the physical and psychological development. Therefore, the children needs the best caring both from their parents and surrounding people.

**Effect to parents**

Effects of the illness on the children is considered a crisis in life. The illness of the child is not separated from the parents life. The illness threaten the parents' life-style all the time. The illness did not only threatens the parents but also threaten the family and friends (Anderson & Baurens, 1981: cite in Thanutteerakul, V. 1993: 28). This is specially true for the parents who care for the ill child with congenital heart disease. The people who are a caregiving for this child may receive many impacts as follows:

**1. Impacts on the parents' life-style**

The ill child has many dependent activities on their activities because they are in the physical, psychological and social development stages. Moreover, the congenital heart disease has many defects within their body and interfere many daily activities of children (Orem, 1985: 155). Therefore, the parents have to take many responsibilities including activities in daily living such as bathing, dressing, eating, rest and exercise, the treatment management such as follow-up and drug management as well as the food preparation. These responsibilities aim to maintain children's health status and well being as well as to prevent the risk factors to induce severe illness. Although these responsibilities are very heavy due to a prolong burden for continuous caregiving, parents accept and intend to do. However, the parents have to modify their daily activities in order to pay attention to take care their child by alteration their activity such as eating, dressing, rest and recreation activity. The results of this alteration will affect the parents' life-style continuously in every activity of daily living.

**2. Impacts on the parents' economic status**

Family economic status is a basic factor for every family life. However, the chronic illness especially congenital heart disease has a great effect on the financial conditions due to the continuous advanced and complex treatment (Thanutteerakul, V. 1993: 26-27), the expensive cost of medications and services in the repeated hospitalization. Furthermore, they have to pay for the transportation, food and residence, if their house were far from the hospital. In addition, some parents had to leave their work to bring their child to hospital. Other parents also have to resign from their jobs to look after their child in the hospital or at home. Sometimes, parents have to decrease duration of their jobs or modify their work schedule to have enough time for caregiving to their ill child. Especially, parents who had low or moderate family income and have a little or no saving money will be suffer stress and anxiety from these increasing financial problems.

**3. Impacts on the parents' society**

According to Futcher (1988, 381-385), parents were shy to talk about their children with congenital heart disease. They would isolate themselves from society, have communication failure and decrease their relationships with other people and family members which resulted in blocking the family development. Sometimes, parents would limit their social meeting because there was no one to take care their child when they went out. Some parents also gave reason that they did not want to answer questions of their peers about their child' s illness. They were afraid of their peers' responses which would increase the stress to them. Moreover, they may also stop their recreation or leisure activity because they thought that it was not the time for those activities when their children is sick. Those situations make parents feel lonely and be abandoned by everyone. Although some family members and relatives would be a good financial support, some relatives did not visit at the time of family financial shortage. According to the study of Prugh (1983: 440-441), some mothers received information about their ill child from a doctor or a nurse and even other parents who had a same ill child. In this way, parents could express their feeling to other parents and could find peers at the hospital or clinic.

### 4. Psychological and Emotional Effects

Parents who have a child with congenital heart diseases have various psychological responses. Some parents believed that the illness of their child was the result of their previous actions or bad behaviors. Especially if the children had severe condition, parents will receive many psychological impacts such as fear and anxiety (Wong & Whaley, 1995: 900). The parents would have anxiety and fear about the severity physical conditions, the child growth development, psychological and emotional development (Wallace, et al., 1987 cite in Leesin, B. 1992: 26-27). The study of Thanutteerakul, V. (1994: 25-27) also presented that the parents' psychological reactions depended upon the severity of illness, prognosis of disease, the treatments effects and results. If there was poor prognosis especially in the previous healthy child, the pressure in the family would increase due to the threatening of losing.

### 5. Relationship in the Family

The child' s illness effected the relationship between a husbands and a wives. For example, in some families, husbands and wives would be more close because they had to consult and support each others. According to the studies of Babarin, Hughes & Chesler (1985: 473-480 cite in Thanutteerakul, V. 1993: 2), the families with child had cancer would have more relationship. The spouses was the most important support. However, if the ill child had to readmit frequently, the relationship and the support would decrease. The frequency situation which usually occurred was the decrease in their relationship. This was the result of the wives' attention directed to their ill child. They had to live with their ill child in the hospital whereas their husbands had to do more work to earn more income for the increasing dispenable. Sometime, they would have conflict with the therapeutic or giving care for their ill child. The study of Sunthonchi, P (1990: 24-29) also supported that the problems with families had to solve during their child' s hospitalization were the disagreement. For example, some husbands would blame the caregiving of their wives and did not sympathy with their wives who were depress or anxiety. On the other hand, the wives would thought that their husbands neglected her to caregiving for their ill child lonely. These situations would lead a gap between marital relationship which would lead to divorce.

### 6. Roles Aspects

For the caring ill child hospitalization, the mothers always take this role. Therefore, the role problems usually would happen to mothers more than to fathers. Mothers had to pay attention only for their ill child so that they had no time for other roles as normal life (Moore, Kramer & Perin, 1986: 60-66 cite in Thanutteerakul, V. 1993). Moreover, there were some effects on the roles of the family members. For example, the healthy son or daughter had to take the household work subactivitied to their mothers who gave care for the ill child. Sometimes, the fathers had to take the mothers ' s role for their wives. The effects on role would be severe if the children had to admit the far hospital and their mothers had to lived with. The cooperation of family members would be very important to continue the happiness in the family (Leesin, B. 1992: 28).

### 7. The Attitudes Aspects about child- bearing

When there is an ill child in a family, a parents would change their attitude about child-bearing (Smith et al., 1982: 521-526 cite in Ke, L. 1998: 66). Some parents would have overprotection behavior. The others would be denial their ill child. Moreover, the child- bearing for other children would be changed (Moore, Kramer & Perin (1986: 60-66 cite in Thanutteerakul, V. 1993). Some parents would pay less attention to the other children because they thought that the ill child needed more attention. As a result, the family relationship among their children both healthy and ill children would be change. Some children would be angry or envy the ill child and felt that their parents did not love them. This situation would produced bad effects to the development of children' s personality in the future.

## Needs of parents who care for children with congenital heart disease

Needs have various meaning. For example, according to Webster' s Dictionary (1979: 276), needs is the human feeling to something that is indispenable. It is the result of the changes following the growth developments which have both physiologic and psychology condition. Kozier, Erb & Oliveri (1991: 298 cite in Asumpinzup, U. 1997: 37) they defined basic human needs as those necessary things which were required by human being in order to maintain physiological and psychological homeostasis. For the health care team, who have roles to work with other human being, they much realize and understand the needs of other humans for caring for other people and family efficiency. Other define needs of human, as follows:

Maslow (1970) defined a model of human needs by providing a hierarchical framework for needs. Human beings are dominated by a number of basic needs. Physical is an early need and later to be psychological needs (Maslow, 1970 cited in Ronald and Laura, 1991: 57-58 cited in Thanutteerakul, V. 1993: 18-19). The five hierarchical of needs including:

1. Physical needs or basic needs: That human need referred to basic human needs to maintain well-being and life about physiological such as oxygen, water, drug, food, wear, rest and sleep, activity and sexuality. If all needs within this level are unsatisfied, the other higher-level needs emerge to drive the human organism.

2. The Security and Safety needs: Humans needs to be physical safe and free from the fear and anxiety that can result from a lack of security and protection.

3. Love and Belongingness needs: If the other needs have been fairly well gratified, love and belonging level of needs will emerge and become dominate. They include the understanding and acceptance of others in both giving and receiving love and feeling of belonging to other peers, families and the community.

4. The self - esteem needs: It relates to the feeling of personal worth in the needs of acquiring respect by others.

5. The needs for self – actualization: Self – actualization needs is the highest level on the hierarchy which are the needs for and individual to reach his or her potential through full development of the individual 's unique capabilities if the lower needs are fairly well met.

Rine and Montag (1976: 56-57) identified basic human needs that tend to direct human' s life. They can be categorized as:

1. Physical needs were needs for food, air, water, rest, exercise, comfortable about clothing and shelter, cleaning of body, surrounding, body temperature control and urinary system.

2. Psychological needs were need for love and belonging, self – esteem,freedom and self – actualization.

An illness that occurs in family members, especially illness in children who are developing center psychologically. They were flourishing, growing and looking forward the future. They were the hope of their parents and family. Now the parents become anxious and worry about their child. Parents will do anything that makes their child happy. The studies about needs of care-giver to care for patients is as follows:

Ragdel et al (1993: 154-161) studied caregivers of patients with cerebral vascular accidents (CVA). Two case studies are presented to illustrate the use of nursing protocols. Criteria from Caplan' s social support Theory (Caplan & Killilea, 1976) they were used to outline a plan that included input from significant others to create a plan for their loved ones who were recovering from left – side cerebral vascular accidents. The caregivers' s needs were subdivided into 3 categories:

1. Psychological support and emotional support that made families caregivers to feel useful and important to their patients.

2. Information about the patients with cerebral vascular accidents. Caregivers need to know how to care for patients, the cause of the disease and the treatment plan that made caregivers analogous to nurses.

3. Necessities of life and services.

Rawlins (1993: 213-220) defined the needs of the caregivers as identified by seven families of subjects. Family caregivers were selected for interview. Family caregivers needs were help, hope and happiness. The caregivers' s needs were divided into 3 categories:

1. The core variable that emerged was the needs for help: Caregivers needed help in direct care to the dependent person in the home.

2. The caregivers needs to be offered hope from two sources from God and from their people.

3. Caregivers needs support: The caring rituals were valued as an important link to happiness and emphasized the need for happiness.

Thanutteerakul, V. (1993: 49-51) determined the relationship between selected factors and needs of parents who cared for children with acute lymphoblastic leukemia. There were 110 parents as subjects. Their needs could be into 4 groups as follows: 1) information about the child' s illness, 2) psychological support for the parents, who care for the ill child, 3) information about how to care for the children and 4) needs for financial-social support.

Phongkampan, C. (1994: 26-70) documented the needs and received responses of mothers who had hospitalized children 256 subjects at Singburi Hospital. She studied about the needs of the mothers could be categorized into 5 groups, as follow: 1) Needs for mother role, 2) Needs for the best treatment and nursing care for the child , 3) Needs for psychological support, 4) Information needs and 5) Needs for accomplishment, received responses of physical.

Chouangsawadsak, S. (1997: 54-66) documented the needs of caregivers of patients with cerebro vascular accidents. The total sample was 120 subjects. The needed had 6 categorizes. The findings of the study are as follow: 1) Spiritual needs, 2) Psychological needs, 3) Household needs, 4) Physical of caregivers needs and 5) Information needs.

Wingate and Lakey (1989: 216-224) that they studied to identify the needs of the non-institutionalized patients with cancer as defined by patients and primary caregivers at home. The questionnaire was an open-ended and sent to the subjects by mail. When completed, it was mailed back to the researcher. The sample of subjects included: The patients group (n = 10), Primary caregivers (n = 14) and Nurses (n = 9). Categorizes of caregivers needs are as follows:

1. Information needs: Needs for knowledge, information and about diseases.

2. Household management needs: Those needs related to managing / running a household and providing care to the patients.

3. Physical needs of caregivers: Needs anything that continues, preserves, maintains or retains the primary caregivers' s body functions.

4. Psychological needs: Needs anything the continues, preserves, supports and/or develops one' s emotions thought and relationship to others.

5. Spiritual needs: Need anything that continues, preserves, supports, and/or develops the nature of man' s relationship to God.

6. Financial needs: Needs for those things that pertain to legal or financial matters.

7. Respite needs: Needs for an interval of temporary rest or relief: needs for reprieve.

8. Others needs: Those needs that did not fit in to the others categories listed.

The researcher applied the needs of cancer caregivers of Wingate and Lakey (1989: 216-224) to describe the needs of parents in caring children with congenital heart disease which had 6 dimensions including: (1) Information needs, (2) Psychological needs, (3) Physical needs, (4) Spiritual needs, (5) Household management needs and (6) Financial needs. It would be discussed in detail as follows:

**1. Information needs:** This is necessary for parents to receive information and advise about how to care for their child. One must identify the needs of parents on how to care for children with congenital heart disease. (Jamjureerak, V. 1993: 38-76).

1.1 The caring related to food and water. Because the ill child had the heart function impairment, the food preparation should select the menu that had less important on heart function but give high benefits to the body.

For the healthy child with congenital heart disease, there was no limitation on water. Thus, the parents should give sufficient water for their children following their growth development (Gidding & Rosenthal, 1984: 1369).

2.2 Exercises and playing are the important and benefit activities for all- aged children. Exercise will enhance the body development such as enhancing the muscle strength and large size. Moreover, it will relax from tension and promote the good emotional and social development (Luowhaprasittiporn, D. 1992: 6). However, exercises and play combine within the treatment and nursing care plan. Parents must observe their children. When they are playing or exercising. If the child feels exhausted they should stop exercises immediately. If not, this could be dangerous to the child (Asampinzup, U. 1997: 28).

1.3 Sleep and rest: everyone need physical and psychological relaxation from stress. This relaxation including sleeping, hobby, watching television and listening to the radio. Sleeping is the best rest for children with congenital heart diseases. It can revive the body. Children with congenital heart diseases have an abnormal circulation system. This abnormality decreases the volume of oxygen available. It is important to promote rest and sleep for the children so the body works less and decreases oxygen consumption (Asampinzup, U. 1997: 28).

1.4 Mouth and dental care: dental care is important for the children with congenital heart diseases. When infection in mouth is present it increases the risk for dental caries. It makes bacteria in to blood circulation, an infection that starts in the mouth can lead to the heart and cause endocarditis (Gidding and Rosethal, 1984: 1373). Parents must care for their child mouth and teeth. Children much brush their teeth 2 - 3 per day, in the morning, after eating and before bed. Children need to visit a dentist at least twice a year for a check up (Price, 1980: 389 cite in Asampinzup, U. 1997: 31).

1.5 Prevention of infection: children with congenital heart diseases can easily get an infection in their respiratory system and their lung to a decrease in lung capacity into lung edema. Prevention of infections are important. This children should avoid people who have colds or infections and they should not go where there are crowds (Leeleatvarawong, W. 1981: 405). An infection in the respiratory system can increase the severity of symptoms in children with congenital heart diseases. They should proper rest and diet in order to have a strong immune system to prevent diseases.

1.6 Vaccinations: infection in children with congenital heart diseases can be more severe than normal healthy children. This children should to receive complete vaccinations for protection of diseases. The schedule of vaccinations is similar to that normal healthy children (Pilliteri, 1999: 1236).

1.7 The caring about the normal elimination: parents who give care for children with congenital heart disease, should practice their child to eliminate at the same time everyday. Moreover, they should aware of the child' s constipation especially the child with cyanotic congenital heart disease which could lead to acute hypoxemia (Senasuttipan, V. 1991: 19).

1.8 Medication Management: The children with congenital heart disease would receive medication therapy at home. These medications have many side effects and should take as the doctors prescribed. Therefore, parents should know how to manage these medication for their child.

1.9 The caring about the child' s normal development: Because a child has a continuous growth development, same illness would have direct effect on the growth and development of that child. The child with congenital heart disease who has no other abnormality and has normal intelligence should be promoted the growth and development as the normal child (Price, 1980: 381-418 cite in Asampinzup, U. 1997: 31).

1.10 The caring for psychological aspect: The child with congenital heart disease would have violent emotions and aggressive behaviors. The psychological support should motivate the group activity between the ill child with their peers, and siblings. This playing or activity would be the promotion for the child to adaptation to live in society (Clare, 1985: 218-221).

Similarly, activities to care for children with congenital heart diseases are important for parents. Information, suggestions and recommendations to help meet the needs or response to needs of parents to help care for children with congenital heart diseases. This will help parents to understand they can solve crisis and promotes. They can prevent the dangerous ways of their child and the parents will feel they can take care of their child sufficiently.

### 2. Psychological Needs

The psychological support needs of the parents are the intervention to give support and cooperation with parents which parents could receive the sympathy and they are encouraged to discuss their feeling as well as assist in problem solving about caregiving to their child. The feeling of health care provider give some support caused the parents felt safe, attached and had not lonely or rejected from society. They could have relationship with their friends and are the one of family members. The psychological support could come from family members, relatives and their friends. Moreover, the health care team could support their needs by giving consult and assisting, giving information about caring patients when they have problem. Furthermore, if the parents could be participate in assisting care their ill child, the parents would feel happy relax, no anxiety and stress and, have good adaptation with confidence and could continue caring their ill child.

### 3. Physical needs

The physical needs of parents: Due to caregiving to a child with congenital heart disease, the parents would have physical fatigued from insufficient rest and sleep. The study of Kasemkitwattana,S. (1993: 87) presented that the majority of the wives (76.92 %) who were caregiving of chronic illness had health problems from the caregiving periods. The most symptoms were fatigue, insomnia, easily frighten, palpitation, loss of appetite, headache and dyspnea. Therefore, the parents who have heavy responsibilities for care of the ill child would need to maintain their health by sufficient rest and relaxation. The rest activities would be various such as reading a book, walking, or going outside. In addition, they should have time for themselves such as for self- care, exercise, check up their annual health. In conclusion, they need someone in their family members to subactivities giving care during their rest in order to relieve the stress and fatigue (Rawlins, 1991: 215). However, the child with congenital heart disease would sleep for a short period and did not at the same time. Their parents had to work up at night to look after their child leading to insufficient rest and unhealthy.

### 4. Spiritual needs

Spiritual needs are an intervention to support parents with love, sympathy, encouragement, hope and promoting self-esteem. There are several studies about the spiritual aspects as follows:

Carson (1989: 6-7) defined spirituality of individual into 6 aspects including: 1) a care of life as a person should be and have, 2) purpose in life for something or someone, 3) the feeling of touching God and a high superpower, 4) The motivation of individual to achieve the high value of love, hope, goodness and truth, 5) a special experience of life and 6) a faith in God to give happiness, life and love.

In addition, spiritual needs are the motivation for individual to have relationships with others such as the need to give love and to receive love, having faith in religion as their refugee. Moreover, they are important factor to create and maintain the continuous relationship with the highest thing and human being with forgiveness, love, hope, trust and meaning as well as purpose in life (Kaseakitwattana, S. 1993: 5).

Caregivers also need hope and need empowerment. Although hope is an anticipation about something happening in the future, it is important for the life of children and their parents. The hope of parents is to empower them to endure and to be strong to deal with crisis of their ill child' s life. If there is something changing in their child, it should be hope to be a positive way (Miller, 1983: 287-288).

If the spiritual responses for parents of the ill child is not sufficient, there would be a pressure or stress for parent, s spirituality. On the other hand, if this response is fulfil their spiritual needs, they would be in greater life satisfaction.

### 5. Household management Needs

It is necessary to manage household work, family works and caregiving activities for child continuously. In general, household activities are the role of women or mother (Meekanon, J. 1989: 9-11).

5.1 Food preparation for the family is a routine work for support daily living of all family members especially an infant, a toddle, an elderly and the ill person. The food preparation should be clean, safe and full of nutrient value especially for the ill person.

5.2 Caring for health hygiene behaviors: Women have to take care about the hygiene of family members such as bathing. Moreover, they have to do laudry, clean house and wash dishes.

5.3 Caring for ill family members: This task is to giving care for a family member who is sick by seeking-treatment, seeking-service and giving care.

5.4 To create the happiness in their family: Women have to provide the good environments in the house, create a harmony atmosphere with attention, support and create the good relationship among family members.

### 6. Financial needs

Financial needs are an important factor to support the long term of caregiving to children with congenital heart disease. The costs of caring can be overwhelming such as out of pockets expenses for non-prescription medication, special dietary needs and transport can consume a significant percentage of a family income.

In addition, if one parent may have to leave their job to care their ill child, the family income will decrease. Therefore, the low or moderate family income may experience with financial problems. However, the high family income who has sufficient income and relations support, they would have financial constraint due to the long term of this illness.

**Factors influencing on the needs of parents of children with congenital heart disease.**

Every human being always has needs which are never ending in normal conditions. However, these needs will increase when they are ill (Kraejel et al, 1972 cite in Thanutteerakul, 1993: 28-29), which would be various based on their personal factors. Similarity, the parents of children with congenital heart disease also have varieties of needs depended on these following factors:

**1. Age of parents**

Age is indicator of the maturity of people from passing various experiences and trying to understand the world. Therefore, it is related to the caregiving ability for the ill child. The more maturity they are, the more suitable decision making ability about health- seeking they have. According to (Orem, 1991: 239), the capacity of people who take care of their dependent will increase following their age, which will reach the maximum ability in adulthood and will gradually decline in elderly. From passing more experiences and learning more life' s lesson, the older people could have more information sources to support their needs than the younger did. Similarity, the older parents would have more understanding, be more prudence and more cooperate with the treatment and caring than the younger did. In comparison between the behavior responses of both age group of parents (Thanutteerakul,V., 1993: 29). The younger parents always have high anxiety with the symptoms of their ill child, resistance to the treatment or accused their spouses. This presented that the parents' age would related to the coping ability. For example, the order parents who had more life' s experiences would better coping with their problems than the younger ones did. As a result, their needs would decline. Similarity to the study of Asampinzup, A. (1997: 102), age of mothers had a positive relationship with the behaviors of mothers in caring their children with congenital heart diseases. In addition, the study of Thanutteerakul, V. (1993: 52) supported that the parents' age related with the needs of parents who gave care to the children with acute leukemia.

### 2. Educational levels

Nowaday, education is an important component of promotion people in seeking indispenaible resources for their lives and their society. The more education the man have, the better health status he will. As a result, they could seek for the benefit resources in order to response their needs and their society. The needs of high education people would lower than the ones of lower education. In the same way, the parents who higher education could more easily seek for the information and support resources as well as the readiness of caring ability than the ones with lower education did. According to Dodge (cite in Newwatcharawong, P. 1983: 32), patients who had low educational level had more information need about treatment than ones who had high educational levels. Moreover, the study of Asampinzup, U. (1997: 102) presented that the mother' s educational level had a positive relationship with their caregiving behaviors for their children with congenital heart disease. The study of Phongkumpon, C. (1994: 121), also supported that mothers of the children admitted at Singburi Hospital who had high educational level had lower assistance needs from the health care team about financial problems, the ways to giving care to their child and themselves than the ones who had low educational level. She explained that the mothers in the latter group did not know and understand about the proper care giving to their ill child.

### 3. Family income

In the present society, there are many financial constraints which most family had only their income to be a financial resource. When there is a sick person in a family, the financial need would increase and cause direct impacts on that family. According to (Orem, 1991: 361), family income is a beneficial resource for look after dependent person. Therefore, the high income family would have more opportunity to seek facilitators' the beneficial component for health such as the rich nutrient diet and health- care service the lower did (Pender, 1987: 161-162). According to the study of Mitthongtha, J. (1989: 46), families who had high income could more easily cope and less stress or suffer from the costs of treatment than the low income family did. Therefore, the lower income would have more financial needs than the higher did. Particularly for a child with congenital heart disease, the long term of treatment with high expenditure would related to the need of parents to care their ill child. The study of Thanutteerakul, V. (1993: 60), supported that the families with low income had a negative relationship with the needs of parents who gave care for children with acute leukemia.

**4. Age of the ill child**

Age is an influencing factor on self-care behaviors due to the ability to integrate the well-being concept with the response ability to the health deviation ( Kozier, Erb & Oliveri, 1991: 75). According to Wong & Whaley (1995: 585), children in each age groups had individually characteristics. Moreover, children who were different in age groups would have different in the development of physical, cognitive, memory, perception and response to the illness, cognitive developmental levels about physical status, intelligent memory and response to illness. For example, infants would have fear about the separation from parents leading to loss feeling and more pain. Similarity to toddles and preschool children, they felt loss and felt as being punishment from the behavior control during their illness. It would be the result of the nature of these children in this age group who had self-center and imagine. Moreover, they would have behavior problems due to absent from school, separate from their peers and parents to hospitalization. For adolescence age group, they would lose about self-care, could not be free and loss self-image. However, they could more perceive and self-care than the younger ones. Therefore, the caregiving for children in different age group would variety. For the parents who pay attention in caring children both physical and psychosocial conditions, they had to assume heavy responsibility for care of children individually according to the age group. This leads the parents had a little time for themselves and family members (Pillitteri, 1981: 891). Children in different age groups have different developmental needs. Age of the ill child effect of the needs of parents. From studies of Srilenawat, S. (1987: 162) she found that mothers who have ill child needs the health care team care and help children more than herself, especially mothers who have younger children. These mothers have needs than mothers who have older children or adolescence. Older ill children needs some quiet time and have the capability to help care for themselves. They understand about various situations of illness better than younger children. Therefore, parents need help and advice from the health care team to give care for their ill child accordance with their age group.

### 5. Severity of Illness

Severity of the illness is an important influencing factor on the reaction of both the ill child and parents and may cause different in their coping with their illness. The more severity of the disease have, the more reaction of the parents and child would. Particularly, the complicated practice with special investigated instruments caused parents to fear and more anxiety. Moreover, the severity of illness had related with the stress level. The needs for assistance would increase (Noonan, 1981: 563-568). According to study of Phongkumpon, C. (1994: 32-36) about the need and received responses of mothers of hospitalized children in Singburi Hospital, indicated that there were the difference in the mothers, need for decreases. There, the parents who had different in perceived severity of illness would have different needs from nurses.

### 6. Numbers of admission

Numbers of admissions is a factor that effect to the stress levels of Caregivers. When admitted to the hospital the parents and child must cooperate with the health care team. Both the parents and child must trust the health care team to care for the patient. Number of admissions is relate with levels of needs of caregivers. From studies of Kachapukdee, P. (1981: 189) she found families and the ill child on their first admission in the hospital had fear and they felt uncomfortable in the hospital. They did not know the staff and they had trouble to adjust themselves. Therefore, they had needs about advice from the health care team more than groups with a high number of admissions. According to studies of Srilenawat, S. (1987: 163) found the ill child who was often admitted in the hospital could adjust oneself better than an ill child who have few admission in the hospital. The caregivers felt they needed to closely care for their child. Therefore, number of admissions effected the needs and amount of help of the health care team to parents of children with congenital heart disease.

## The importance of nurses in responding to the needs of parents of children with congenital heart disease

Because needs are necessary for living, balancing the body equilibrium, parenting stress, producing confidence and ambition to do useful things as well as a motivation for behaviors, the nurses should response to the needs of parents of children with congenital heart disease. However, the nurses as well as doctors may be neglect the needs of parents and family due to focusing only on the ill child. This may caused parents needs did not receive proper response and could produce more stress.

The health care team (nurses and doctors) want to help the patients. However, sometimes the caregivers or parents and family of the patients are forgotten. The caregivers need help and hope from the health care team too.

Nursing must respond to the individual needs of the caregivers. Nursing must provide the necessary information and education on the best way to care for the ill child.

Brue and Dracup (1978: 212-216 cite in Chaichan, P. 1997: 11-14) studied about the responses to needs of families of the patients. They categorized needs of families of patients with sever heart disease into 4 groups. This way nurses can create a special framework to care for the caregivers of patients with heart disease as follows:

1. Communicate with the family of the patients about the patients symptoms at least twice per day
2. Primary nursing care management system

3. Arrange a comfortable time to visit both day and night

4. Caregivers of the family can consult with the health care team about problems and to have the opportunity to open communication with them.

With these four aspects, nurses can create nursing care plan that best can provide care to the ill child with heart disease. When using this nursing care plan, identify crisis earlier and will decrease stress.

Ward et al., (1990: 34-42 cite in Phongkumpan, C. 1994: 20-22) studied the effect of information, knowledge, support and motivation of the families of the patients who had heart surgery. Those groups who received information and education had lower levels of stress than the groups who received in inadequate information.

Becker et al., (1977: 348-366) who focused on the important of care to the family of children. Nurses must not forget the important of supporting for the family. If nurses do not take interest in the families, they will lack knowledge and understandings about the needs of the patient.

On the other hand if nursing responds to the family of the patient, by giving information, consultation and advice about how to care for the patient, They will help the family to problems solves. This will result in decreases anxiety and stress to the family.

Therefore, the health care team should assess about the needs of the parents of the ill child and should attempt to respond to the needs. It is useful to the ill child and family.

From literature review as mentioned above, children with congenital heart disease effects not only themselves but also the parents and family both physically and psychologically. This would be the results of long term of treatment and the crisis illness which could predict. The caregiving for the ill child is a big burden for parents. They had to face with the stress, life- style change, role change and financial society problem. Therefore, parents had various dimensions of needs, it focuses on about needs and response to needs of parents of children with congenital heart disease in 6 dimensions as follows: 1) Information needs, 2) Psychological needs, 3) Physical needs, 4) Spiritual needs, 5) Household needs and 6) Financial needs.

The needs of parents and their basic factors as mention above would be different. The nurses should response according with their needs could the nurses response according with the parents needs. This is an important answer which nurses had to assess and find out in order to give holistic care for both the ill child and their parents as well as their family. Therefore, this study would explore the needs and the response to needs of parents who give care for the children with congenital heart disease. The result from this study would be a guideline for nursing care plan, advice, consult and assist parents to care their ill child, themselves, and family effectively both during hospitalization and at home. In addition, nurses could give nursing care directly to the needs of parents and make nursing care to be standard and are effective.

# CHAPTER III

# METHODOLOGY

## Research Design

This study is a descriptive research which aimed to study about needs and response to needs of parents of children with congenital heart disease and to compare the difference of parents' needs according to basic factors of parents (age, educational level and family income) and basic factors of the ill child (age, severity of illness and number of admissions).

## Population and Sampling

The population of this study was parents who take care of their children with congenital heart disease by themselves. An accidental sampling was used to select the parents whose their children were follow-up and who were admitted at the Out-Patient Department (OPD) and the In -Patient Department (IPD) in four hospitals: Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Mongkutklao Hospital and King Chulalongkorn Memorial Hospital. In this sampling there was no limitation to the parents' age, sex, marital status, educational level and family income.

**Estimate of Sample Size** (Wayne & Daniel, 1991: 154-156)

$$n = \frac{Z^2 \sigma^2}{d^2}$$

Remarks: $n$ = Sample size

$Z^2$ = Critical Value $(1.96)^2$

$\sigma^2$ = Variance of score corresponding needs of the parents $(13.40)^2$

$d^2$ = Deviation of mean score of population and sample $(2)^2$

$$n = \frac{(1.96)^2(13.40)^2}{(2)^2}$$

$$n = 172.83$$

The 180 subjects were selected by accidental sampling, all of whom were either fathers or mothers whose children were follow up and admitted in four hospitals.

**Setting**

This research investigated the needs and responses to needs of parents of children with congenital heart disease. The parents whose children were follow- up and admitted at the Out -Patient Department (OPD) and the In -Patient Department (IPD) or at the Heart clinic of children with congenital heart disease in four hospitals: Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Mongkutklao Hospital and King Chulalongkorn Memorial Hospital during June-August 2000. All hospitals in this study are government hospitals. Therefore, they are expected to provide similar services for the children with congenital heart disease and follow -up programs after discharge from the hospital. The four hospitals also provide health education of child care for the parents during the ill child' s stay at the hospital. These four hospitals are located in Bangkok, and the data collected at these four hospitals were conducted as shown in the following schedule:

| Hospital: | Day: | Time: |
|---|---|---|
| Siriraj Hospital | Tuesday | 08.00 – 12.00 A.M. |
| Queen Sirikit National Institute of Child Health | Wednesday | 08.00 – 12.00 A.M |
| King Chulalongkorn Memorial Hospital | Wednesday, Friday | 01.00 – 04.00 P.M |
| King Mongkutklao Hospital | Friday | 08.00 – 12.00 A.M. |

**Instrumentation**

The questionnaires used in collecting data consisted of two parts:

Part I: Demographic data of parents: Information concerning age, sex, marital status, religion, relationship with patient, educational level, occupation, family income, sufficiency of income, payment for treatment and duration of care for the ill child was elicited, as well as the demographic data of the ill child including age, sex, diagnosis, severity of illness and number of admissions.

Part II: The questionnaire of needs and responses to needs of parents of children with congenital heart disease: This questionnaire was developed from Wingate and Lackey' s framework, which was based on the needs of non-institutionalized cancer patients and their primary caregivers (Wingate & Lackey, 1989: 216-224). The adapted questionnaire consisted of 43 items regarding needs and responses to needs of parents of children with congenital heart disease, which were divided into 6 dimensions as follows:

1. Information needs: 23 items (1-23)

2. Psychological needs: 4 items (24-27)
3. Physical needs: 4 items (28-31)
4. Spiritual needs: 4 items (32-35)
5. Household management needs: 4 items (36-39)
6. Financial needs: 4 items (40-43)

The answer were categorizes into 2 sections:

1. The answer concerning the needs of parents of children with congenital heart disease were categoried into 5 levels:

| | | |
|---|---|---|
| No needs | means | the parents did not have needs. |
| Low needs | means | the parents had a low level of needs. |
| Moderate needs | means | the parents had a moderate level of needs. |
| High needs | means | the parents had a high level of needs. |
| Extreme needs | means | the parents had an extreme level of needs. |

The scoring corresponding needs of each parents, item by item, were as follows:

| | | |
|---|---|---|
| No Needs | score | 1 |
| Low Needs | score | 2 |
| Moderate Needs | score | 3 |
| High Needs | score | 4 |
| Extreme Needs | score | 5 |

The interpretation of the scoring was as follows:

Average score 1.00-1.49 means the parents did not have needs.

Average score 1.50-2.49 means the parents had a low level of needs.

Average score 2.50-3.49 means the parents had a moderate level of needs.

Average score 3.50-4.49 means the parents had a high level of needs.

Average score 4.50-5.00 means the parents had an extreme level of needs.

2. The answers concerning the response to the needs of the parents of children with congenital heart disease were categorized into 2 levels:

Response to the needs means the parents received response or suggestions according to their needs.

No response to the needs means the parents did not receive response or suggestions according to their needs.

The scoring corresponding to responses to needs of each parents, item by item was as follows:

| | | |
|---|---|---|
| Response to needs | score | 1 |
| No response to needs | score | 0 |

The interpretation of the scoring was as follows:

Average score 0.00-0.33 means the parents received low response to their needs.

Average score 0.34-0.67 means the parents received moderate response to their needs.

Average score 0.68-1.00 means the parents received high response to their needs.

**Instrument Validity:**

The researcher submitted the instrument to the following 5 experts in order to test the content validity and the language of the instrument. (Appendix C):

Recommendations from the experts were then collected and the researcher revised the instruments as suggested to improve its validity..

**Questionnaire Reliability:**

After revising the instruments according, the reliability of the instrument was tested among 30 subjects who had the same demographic characteristics with the sample. The Cronbach' s alpha coefficient (Polit & Hungler, 1993: 240-252) was used to test the reliability of the instrument by the following formula:

$$\alpha = \frac{n}{n-1}\left[1 - \frac{\sum Si^2}{St^2}\right]$$

$\alpha$ = Reliability of instrument

n = Number of items in instrument

$Si^2$ = Variance of each item score

$St^2$ = Variance of total score

$\Sigma$ = The sum of scores

The questionnaire of needs of parents whose children with congenital heart disease yielded the reliability index of 0.82.

The reliability of the instrument concerning response to parents' needs was tested among 30 subjects with heterogeneous demographic characteristics similar to those of the sample, using the test for reliability by Kuder- Richardson formula 20 (KR-20) (Polit & Hungler, 1991: 372):

$$r = \frac{k}{k-1}\left[1- \frac{pq}{s^2}\right]$$

Remark r = The estimated reliability

k = The total number of items in the test

p = Proportion of subjects who receive response to needs.

q = Proportion of subjects who did not receive response to needs.

$S^2$ = The variance of the total test score

The questionnaire of the response to the needs of parents of children with congenital heart diseases yielded the reliability index of 0.89

**Data Collection**

Data were collected by the researcher. The following procedure was performed to collect data.

1. The researcher asked the Dean Faculty of Graduate studies, Mahidol University, to issue a recommendation letter to the directors of Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Mongkutklao Hospital and King Chulalongkorn' Memorial Hospital.

2. The researcher explained the objectives of the study to the chief of pediatric nurses at the Out - Patient Department (OPD) and In –Patients Department (IPD) of Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Mongkutklao Hospital and King Chulalongkorn' Memorial Hospital.

3. The researcher surveyed the list of patients from OPD cards at pediatric wards in order to identify diagnoses and collect list of patients.

4. Data were collected from the parents who were waiting for the physician in the OPD and at the pediatric wards. First, the researcher introduced herself and explained the purposes and benefits of the study to the parents, and then asked them to sign a consent form.

5. When the subjects agreed to participate in the study, the researcher brought them into a private section and started to interview them by reading each statement to the subjects and recorded a mark (/) for each answer until the questionnaire was completed. Whenever the subjects did not understand the items in the questionnaire, the researcher would provide explanation one more time.

6. After data was completely collected from the 180 subjects, the questionnaires were prepared for data analysis.

## Data Analysis

The Statistical Package for the Social Science for Windows (SPSS/FW) was used for data analysis. The level of significance set for the study was 0.05. The following procedure was then performed:

1. Frequency and percentage were used for description of demographic data of the parents and children with congenital heart disease.

2. Mean and standard deviation were used to describe the total needs and responses to needs of parents of children with congenital heart disease, both by dimensions and by items.

3. Analysis of Variance (ANOVA) was used to compare the needs of parents

of children with congenital heart disease. Categorization for parents was based on age, educational level and family income, while categorization for children was based on age, severity of illness and number of admissions. Finally, the Sheffe Test was performed to analyze the differences in the needs of each pair of groups of parents that categories by those variables.

# CHAPTER IV

# RESULTS

The results of this study were presented about needs and response to needs of parents of children with congenital heart disease. An accidental sampling was used to select the 180 parents whose children were follow-up and admitted in the Out-Patient Departments (OPD) and the In- Patient Departments (IPD) of four hospitals including Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Mongkutklao Hospital and King Chulalongkorn Memorial Hospital. The findings was presented in three parts as follows:

Part I: Demographic data of the parents and the children

Part II: The needs and response to needs of parents of children with congenital heart disease

Part III: Comparison of the needs of parents of children with congenital heart disease in basic factors.

**Part I: Demographic data of the parents and the children**

**Table 1 Number and percentage of the parents' characteristics classified by age, religion, marital status, educational level, occupation, family income, sufficiency of income, payment for treatment and duration of care. (N = 180)**

| Characteristics data | Number | Percentage |
|---|---|---|
| Relationship with ill child | | |
| Father | 31 | 17.2 |
| Mother | 149 | 82.8 |
| Age (years) | | |
| ≤ 20 | 7 | 3.9 |
| 21-40 | 150 | 83.3 |
| 41-60 | 23 | 12.8 |
| Religion | | |
| Buddhism | 175 | 97.2 |
| Christian | 1 | 0.6 |
| Islam | 4 | 2.2 |
| Marital status | | |
| Married | 161 | 89.4 |
| Divorced | 19 | 10.6 |
| Educational level | | |
| No education | 6 | 3.3 |
| Primary education | 107 | 59.4 |
| Secondary education | 40 | 22.2 |
| Diploma/Vocation certificate | 16 | 8.9 |
| Bachelors degree and higher | 11 | 6.1 |

**Table 1** (Continue)

| Characteristics data | Number | Percentage |
|---|---|---|
| Occupation | | |
| House-worker | 11 | 6.1 |
| Employee | 30 | 16.7 |
| Government officer / State enterprise | 100 | 55.6 |
| Commerce / Business person | 27 | 15.0 |
| Agriculture | 10 | 5.6 |
| Unemployed | 2 | 1.1 |
| Family income (Baht /month) | | |
| ≤ 5,000 | 100 | 55.6 |
| 5,001-10,000 | 46 | 25.6 |
| 10,001-15,000 | 13 | 7.2 |
| > 15,000 | 21 | 11.7 |
| Sufficiency of income | | |
| Adequate and savings | 40 | 22.2 |
| Adequate but no savings | 20 | 11.1 |
| Inadequate and had debt | 72 | 40.0 |
| Inadequate but no debt | 48 | 26.7 |
| Payment for treatment | | |
| Total reimbursement | 14 | 7.8 |
| Partial reimbursement | 6 | 3.3 |
| Own payment | 45 | 25.0 |
| Partially own payment | 75 | 41.7 |
| Social security | 40 | 22.2 |
| Duration of care (years) | | |
| ≤1 | 37 | 20.6 |
| 1-3 | 53 | 29.4 |
| 4-6 | 32 | 17.8 |
| 7-9 | 21 | 11.7 |
| 10-12 | 26 | 14.4 |
| 13-18 | 11 | 6.1 |

Table 1 showed that there were149 cases of mothers (82.8%). The majority of the parents (83.3 %) had age ranged from 21 to 40 years old. Most parents (97.2 %) were Buddhists and were married (89.4 %). The common educational level of the parents was primary school (59.4 %) and most parents' occupation were government officer / State enterprise (55.6 %). Their family income was lower than 5,001 Baht (55.6 %). Most parents reported that their income was inadequate and had debt (40 %). Payment for treatment of parents were partially own payment (41.7 %). The duration of care was mainly ranged from 1 to 3 years (29.4 %).

**Table 2 Number and percentage of the children's characteristics classified by age, gender, diagnosis, severity of illness and number of admissions. (N = 180)**

| Characteristic data | Number | Percentage |
|---|---|---|
| Age (years) | | |
| <1 | 37 | 20.6 |
| 1-3 | 53 | 29.4 |
| 4-6 | 32 | 17.8 |
| 7-12 | 47 | 26.1 |
| 13-18 | 11 | 6.1 |
| Gender | | |
| Boy | 81 | 45.0 |
| Girl | 99 | 55.0 |
| Diagnosis | | |
| Cyanotic type | 75 | 41.7 |
| Acyanotic type | 105 | 58.3 |
| Severity of illness | | |
| Class I | 39 | 21.7 |
| Class II | 107 | 59.4 |
| Class III | 31 | 17.2 |
| Class IV | 3 | 1.7 |
| Number of admissions | | |
| 2-7 | 155 | 86.1 |
| 8-13 | 15 | 8.3 |
| > 13 | 10 | 5.6 |

From Table 2, most children had age between 1 to 3 years old (29.4 %). The majority of the children were girls (55 %) of which diagnosis was acyanotic type

(58.3 %). The severity of illness was mostly at class II (59.4 %). The number of admissions generally ranged from 2 – 7 times (86.1 %).

**Part II: The needs and response to needs of parents of children with congenital heart diseases.**

**Table 3 Mean, standard deviation and interpretation of the mean score the needs and response to needs of parents of children with congenital heart disease by total needs and by dimensions.**

| Needs by dimensions | Needs | | | Response to the needs | | |
|---|---|---|---|---|---|---|
| | $\overline{X}$ | S.D. | interpretation | $\overline{X}$ | S.D. | interpretation |
| Total needs of parents. | 3.00 | 0.50 | Moderate | 0.50 | 0.30 | Moderate |
| 1. Financial needs | 3.50 | 0.73 | High | 0.31 | 0.23 | Low |
| 2. Spiritual needs | 3.26 | 0.84 | Moderate | 0.33 | 0.35 | Low |
| 3. Information needs | 3.17 | 0.61 | Moderate | 0.50 | 0.25 | Moderate |
| 4. Physical needs | 2.90 | 0.80 | Moderate | 0.28 | 0.36 | Low |
| 5. Household management needs | 2.60 | 0.66 | Moderate | 0.30 | 0.30 | Low |
| 6. Psychological needs | 2.58 | 0.80 | Moderate | 0.30 | 0.32 | Low |

As shown in Table 3, the total needs of parents were at a moderate level ($\overline{X}$ = 3.00, S.D = 0.50) as well as the five dimension needs including spiritual needs, information needs, physical needs, household management needs and psychological needs were at a moderate level and financial needs was at a high level.

Moreover, the response to total needs and information needs of parents were at a moderate level ($\overline{X}$ = 0.50, 0.50, S.D =0.30, 0.25, respectively). However, the response to five dimensions of needs of parents including financial needs, spiritual needs, physical needs, household management needs and psychological needs were at a low level.

**Table 4 Mean, standard deviation and interpretation of the mean score of the information needs and response to needs of the parents of children with congenital heart disease classified by items (N=180).**

| Information needs | Needs | | | Response to the needs | | |
|---|---|---|---|---|---|---|
| | $\bar{X}$ | S.D | interpretation | $\bar{X}$ | S.D | interpretation |
| Total information needs | 3.17 | 0.61 | Moderate | 0.50 | 0.30 | Moderate |
| By items | | | | | | |
| 1. Treatment for the ill child | 3.62 | 0.88 | High | 0.70 | 0.46 | High |
| 2. How to care when the ill child had cyanosis | 3.60 | 1.05 | High | 0.61 | 0.49 | Moderate |
| 3. Severity of heart disease | 3.57 | 0.84 | High | 0.66 | 0.47 | Moderate |
| 4. How to prevention of the infection in oral cavity | 3.55 | 0.97 | High | 0.56 | 0.50 | Moderate |
| 5. Suggestion about to proper dental care and follow up with dentist | 3.49 | 0.97 | Moderate | 0.58 | 0.50 | Moderate |
| 6. Knowledge about drugs (dose, time and method) | 3.48 | 0.94 | Moderate | 0.74 | 0.44 | High |
| 7. Suggestion about how to care the ill child with specific symptoms | 3.41 | 1.16 | Moderate | 0.30 | 0.46 | Low |
| 8. Prevention of infection in respiratory system | 3.40 | 1.05 | Moderate | 0.66 | 0.48 | Moderate |
| 9. Suggestion about nutrition and dietary pattern | 3.36 | 0.93 | Moderate | 0.64 | 0.48 | Moderate |
| 10.Suggestion about how to care the ill child when they had behavioral changed | 3.34 | 1.17 | Moderate | 0.23 | 0.42 | Low |

**Table 4** (continue )

| Information needs | Needs | | | Response to the needs | | |
|---|---|---|---|---|---|---|
| | $\bar{X}$ | S.D | Interpretation | $\bar{X}$ | S.D | Interpretation |
| 11. How to care the ill child who had the fever | 3.31 | 0.98 | Moderate | 0.71 | 0.45 | High |
| 12. How to promote child development | 3.27 | 1.02 | Moderate | 0.56 | 0.50 | Moderate |
| 13. Suggestion about appropriate drinking of water | 3.26 | 0.89 | Moderate | 0.63 | 0.48 | Moderate |
| 14. Suggestion about appropriate exercise | 3.04 | 1.00 | Moderate | 0.54 | 0.50 | Moderate |
| 15. Suggestion about rest and sleep | 3.03 | 1.00 | Moderate | 0.53 | 0.50 | Moderate |
| 16. Promoting the ill child in social activity with other persons | 3.01 | 0.95 | Moderate | 0.24 | 0.43 | Low |
| 17. Promotion to the ill child has activity | 2.99 | 0.99 | Moderate | 0.27 | 0.44 | Low |
| 18. Suggestion about how to decrease of stress | 2.98 | 1.13 | Moderate | 0.24 | 0.43 | Low |
| 19. Suggestion about daily activity in the ill child | 2.83 | 1.00 | Moderate | 0.46 | 0.50 | Moderate |
| 20. How to care about elimination of urine and feces | 2.76 | 1.04 | Moderate | 0.49 | 0.50 | Moderate |
| 21. Suggestion about vaccination | 2.67 | 1.10 | Moderate | 0.88 | 0.32 | High |
| 22. How to care the ill child when they had convulsion, or unconscious | 2.45 | 1.06 | Low | 0.16 | 0.36 | Low |
| 23.How to care the ill child when they had edema | 2.31 | 1.30 | Low | 0.19 | 0.40 | Low |

As Shown in Table 4, the total information needs were at a moderate level and the total response to parents needs were at a moderate level. The parents' needs were at a high level in four items as follows: 1) Treatment for the ill child, 2) How to care when the ill child had cyanosis, 3) Severity of heart disease and 4) How to prevention of the infection in oral cavity. The response of needs of parents were at a high level in 4 items such as 1) Treatment for the ill child, 2) Knowledge about drugs, 3) How to care the ill child who had the fever, 4) Suggestion about vaccination.

**Table 5 Mean, standard deviation and interpretation of the mean score of household management needs and response to needs of the parents of children with congenital heart disease classified by items. (N = 180).**

| Household management needs | Needs | | | Response to the needs | | |
|---|---|---|---|---|---|---|
| | $\bar{X}$ | S.D | Inter-pretation | $\bar{X}$ | S.D | Inter-pretation |
| Total household management needs | 2.60 | 0.66 | Moderate | 0.30 | 0.32 | Low |
| By items | | | | | | |
| 1. Suggestion about follow up planning | 2.94 | 1.10 | Moderate | 0.49 | 0.50 | Moderate |
| 2. Suggestion about dietary management | 2.87 | 0.99 | Moderate | 0.28 | 0.45 | Low |
| 3. Suggestion about home cleaning | 2.64 | 0.97 | Moderate | 0.30 | 0.46 | Low |
| 4. Suggestion about the supportive organization for caring | 1.87 | 1.13 | Low | 0.09 | 0.29 | Low |

As Shown in Table 5, The total household management needs were at the moderate level and the response to parents needs were at the moderate level including suggestion about follow up planning, suggestion about dietary management and suggestion about home cleaning. However, the need about the suggestion about the supportive organization for caring was at a low level. For the response to needs of parents were at a low level, except response to needs in suggestion about follow up planning were at the moderate level.

**Table 6 Mean, standard deviation and interpretation of the mean score of physical needs and response to needs of the parents of children with congenital heart disease classified by items (N = 180).**

| Physical Needs | Needs | | | Response to the needs | | |
|---|---|---|---|---|---|---|
| | $\bar{X}$ | S.D | Inter-Pretation | $\bar{X}$ | S.D | Inter-pretation |
| Total physical needs | 2.90 | 0.80 | Modertate | 0.28 | 0.36 | Low |
| By items | | | | | | |
| 1. Suggestion about annual physical examination | 3.20 | 0.95 | Moderate | 0.38 | 0.49 | Moderate |
| 2. Suggestion about exercise | 2.87 | 0.99 | Moderate | 0.28 | 0.45 | Low |
| 3. Suggestion about self care management | 2.86 | 1.01 | Moderate | 0.18 | 0.39 | Low |
| 4.Suggestion about rest and sleep | 1.87 | 1.13 | Low | 0.29 | 0.46 | Low |

As Shown in Table 6, the total mean score of physical needs of parents were at the moderate level, and the mean scores of response of physical needs of the parents were at a low level. The physical needs, by items, such as suggestion about annual physical examination, exercise and self care management were at the moderate level, while needs in suggestion about rest and sleep were at a low level. However, the parents had moderate response in suggestion about exercise, self care management ,and rest and sleep.

**Table 7 Mean, standard deviation and interpretation of the mean score of psychological needs and response to needs of the parents of children with congenital heart disease classified by item. (N = 180)**

| Psychological needs | Needs | | | Response to the needs | | |
|---|---|---|---|---|---|---|
| | $\bar{X}$ | S.D | Inter-pretation | $\bar{X}$ | S.D | Inter-pretation |
| Total psychological needs | 2.58 | 0.80 | Moderate | 0.30 | 0.32 | Low |
| By items | | | | | | |
| 1. Psychological support from doctors and nurses in caring the ill child. | 3.66 | 1.03 | High | 0.37 | 0.48 | Moderate |
| 2. Needs more time in asking about problems in child care. | 3.59 | 0.99 | High | 0.31 | 0.46 | Low |
| 3. Psychological support from the family members. | 2.91 | 1.12 | Moderate | 0.31 | 0.46 | Low |
| 4. Need cooperated and assistance in caring the ill child from family members. | 2.88 | 1.17 | Moderate | 0.33 | 0.47 | Low |

As shown in Table 7, the mean score of the total psychological needs were at a moderate level, the mean scores of response of psychological needs of parents were at a low level. The psychological needs, by items, the parents had high needs in psychological support from the doctors and nurses, more time in asking about problems in child care. However, the moderate response to needs were psychological support from the doctors and nurses.

**Table 8 Mean, standard deviation and interpretation of the mean score of spiritual needs and response to needs of the parents of children with congenital heart disease classified by item (N=180).**

| Spiritual needs | Needs | | | Response to the needs | | |
|---|---|---|---|---|---|---|
| | $\bar{X}$ | S.D | Inter-pretation | $\bar{X}$ | S.D | Inter-pretation |
| Total spiritual needs | 3.26 | 0.84 | Moderate | 0.33 | 0.35 | Low |
| By items | | | | | | |
| 1. Truth about illness. | 3.61 | 1.13 | High | 0.26 | 0.44 | Low |
| 2. How to strengthen the relationship between father and mother. | 3.22 | 0.97 | Moderate | 0.17 | 0.37 | Low |
| 3. Religious activity | 1.88 | 1.05 | Low | 0.37 | 0.48 | Moderate |
| 4. Caring the ill child with holy belief | 1.69 | 0.95 | Low | 0.37 | 0.48 | Moderate |

As shown in Table 8, the total means score of spiritual needs of parents were at a moderate level. The spiritual needs, by items, The parents needed a high level in truth about illness and moderate level in how to strengthen the relationship between father and mother, while items about religious activity and holy belief in a low level. For the response to needs of the parents, they receive responses about Religious activity and holy belief in a moderate level and the mean scores of spiritual needs of the parents were at a low level.

**Table 9 Mean, standard deviation and interpretation of the mean score of financial needs and response to needs of the parents of children with congenital heart disease classified by item (N=180).**

| Financial needs | Needs | | | Response to the needs | | |
|---|---|---|---|---|---|---|
| | $\overline{X}$ | S.D | Interpretation | $\overline{X}$ | S.D | Interpretation |
| Total financial needs | 3.50 | 0.73 | Moderate | 0.31 | 0.23 | Low |
| By items | | | | | | |
| 1. Helping about hospital expense | 3.69 | 0.95 | High | 0.77 | 0.42 | High |
| 2. Information about financial | 3.56 | 1.12 | High | 0.13 | 0.34 | Low |
| organization | 3.40 | 1.02 | Moderate | 0.11 | 0.39 | Low |
| 3. Other expense of the family | | | | | | |
| 4. Information about medical service | 3.34 | 0.98 | Moderate | 0.23 | 0.42 | Low |

As shown in Table 9, the total mean score of the financial needs of parents were at a moderate level, The financial needs, by items, the parents need in a high level were helping about hospital expense and information about financial organization. For the response to needs of the parents in a high level in helping about hospital expense, while the other in a low level.

## Part III Comparison of the needs of parents of children with congenital heart diseases which had the difference in basic factors.

**Table 10 Comparison of the needs of parents of children with congenital heart disease in total needs and each dimensions distributed by age of parents by ANOVA.**

| Group of age of the parents | n | $\overline{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Total needs.** | | | | | |
| 20 years and younger | 7 | 3.16 | 0.25 | | |
| 21-40 years | 150 | 3.00 | 0.26 | 2.36 | 0.97 ns |
| 41-60 years | 23 | 3.00 | 0.21 | | |
| **Information needs.** | | | | | |
| 20 years and younger | 7 | 3.37 | 0.45 | | |
| 21 – 40 years | 150 | 3.20 | 0.63 | 1.67 | 0.19 ns |
| 41-60 years | 23 | 3.00 | 0.45 | | |
| **Psychological needs** | | | | | |
| 20 years and younger | 7 | 2.90 | 1.02 | | |
| 21 – 40 years | 150 | 2.60 | 0.79 | 0.80 | 0.45 ns |
| 41-60 years | 23 | 2.50 | 0.84 | | |
| **Physical needs** | | | | | |
| 20 years and younger | 7 | 3.07 | 1.12 | | |
| 21 – 40 years | 150 | 2.92 | 0.79 | 0.88 | 0.42 ns |
| 41-60 years | 23 | 2.71 | 0.73 | | |

Table 10 (continued)

| Group of age of the parents | n | $\bar{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Spiritual needs** | | | | | |
| 20 years and younger | 7 | 3.54 | 0.85 | | |
| 21 – 40 years | 150 | 3.26 | 0.84 | 0.43 | 0.66 ns |
| 41-60 years | 23 | 3.21 | 0.84 | | |
| **Household needs management** | | | | | |
| 20 years and younger | 7 | 2.75 | 0.63 | | |
| 21-40 years | 150 | 2.58 | 0.63 | 0.55 | 0.65 ns |
| 41-60 years | 23 | 2.71 | 0.82 | | |
| **Financial needs** | | | | | |
| 20 years and younger | 7 | 3.32 | 0.70 | | |
| 21-40 years | 150 | 3.49 | 0.74 | 0.48 | 0.62 ns |
| 41-60 years | 23 | 3.61 | 0.69 | | |

ns = no significant

As shown in Table 10, there were no significantly difference level (p > .05). in total and all dimensions needs of the parents who were different in age groups.

**Table 11 Comparison of the needs of parents of children with congenital heart disease in total needs and each dimensions distributed by educational levels by ANOVA.**

| Group of educational level | n | $\overline{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| Total needs | | | | | |
| No education | 6 | 3.04 | 0.19 | | |
| Primary education | 107 | 3.03 | 0.27 | | |
| Secondary education | 40 | 2.90 | 0.23 | 0.21 | 0.81 ns |
| Vocation certification / Diploma | 16 | 3.17 | 0.32 | | |
| Bachelors degree and higher | 11 | 2.86 | 0.25 | | |
| Information needs | | | | | |
| No education | 6 | 3.16 | 0.77 | | |
| Primary education | 107 | 3.12 | 0.53 | | |
| Secondary education | 40 | 3.08 | 0.59 | 3.47 | 0.009 ** |
| Vocation certification/ Diploma | 16 | 3.69 | 0.83 | | |
| Bachelors degree and higher | 11 | 3.16 | 0.70 | | |
| Psychological needs | | | | | |
| No education | 6 | 2.57 | 0.74 | | |
| Primary education | 107 | 3.12 | 0.81 | | |
| Secondary education | 40 | 3.08 | 0.65 | 0.92 | 0.45 ns |
| Vocation certification / Diploma | 16 | 3.69 | 0.65 | | |
| Bachelors degree and higher | 11 | 2.70 | 0.77 | | |
| Physical needs | | | | | |
| No education | 6 | 2.63 | 0.65 | | |
| Primary education | 107 | 2.91 | 0.79 | | |
| Secondary education | 40 | 2.77 | 0.70 | 0.97 | 0.42 ns |
| Vocation certification / Diploma | 16 | 3.00 | 1.12 | | |
| Bachelors degree and higher | 11 | 3.23 | 0.71 | | |

**Table11** (contined)

| Group of educational level | n | $\overline{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| Spiritual needs | | | | | |
| No education | 6 | 3.33 | 0.97 | | |
| Primary education | 107 | 2.91 | 0.79 | | |
| Secondary education | 40 | 2.77 | 0.70 | 0.68 | 0.61 ns |
| Vocation certification / Diploma | 16 | 3.00 | 1.12 | | |
| Bachelors degree and higher | 11 | 3.23 | 0.71 | | |
| Household needs management | | | | | |
| No education | 6 | 2.58 | 0.30 | | |
| Primary education | 107 | 2.65 | 0.64 | | |
| Secondary education | 40 | 2.52 | 0.69 | 0.48 | 0.75 ns |
| Vocation certification / Diploma | 16 | 2.64 | 0.83 | | |
| Bachelors degree and higher | 11 | 2.43 | 0.62 | | |
| Financial needs | | | | | |
| No education | 6 | 4.04 | 0.49 | | |
| Primary education | 107 | 3.65 | 0.62 | | |
| Secondary education | 40 | 3.29 | 0.73 | 8.56 | 0.000 *** |
| Vocation certification / Diploma | 16 | 3.42 | 0.92 | | |
| Bachelors degree and higher | 11 | 2.57 | 0.70 | | |

ns = no significant * $p< .05$ , **$p<0.01$, ***$p< 0.001$

As shown in Table 11, the parents who differences in educational level had significantly differences level ($p<0.01$) in mean score in information needs ($p<0.01$) and of financial needs ($p<0.001$)where as the other need dimensions were not significantly difference.

**Table 12 Comparison of the mean score of information needs of the parents who had difference in educational level.**

| Educational level of parents | $\bar{X}$ | No Ed. | Primary Ed. | Secondary Ed. | Vocation-certification / Diploma | Bachelors degree and higher |
|---|---|---|---|---|---|---|
| -No education | 3.16 | - | - | - | - | - |
| -Primary education | 3.12 | $0.04^{ns}$ | - | - | - | - |
| -Secondary education | 3.08 | $0.08^{ns}$ | $0.04^{ns}$ | - | - | - |
| -Vocation certification /Diploma | 3.69 | $-0.53^{ns}$ | -0.57* | -0.60* | - | - |
| -Bachelors degree and higher | 3.16 | $0.00^{ns}$ | $-0.04^{ns}$ | $-0.08^{ns}$ | $0.53^{ns}$ | - |

*p < .05; ns = no significant

As shown in Table 12, the mean score of information needs of parents who have educational level in primary and secondary education were less than those of parents who had educational level in high vocation certification / diploma at the significant level of .05 (p<0.05).

**Table 13 Comparison of the mean score of financial needs of the parents who had differences in educational level.**

| Educational level of parents | $\bar{X}$ | No Ed. | Primary education | Secondary education | Vocation-certification / Diploma | Bachelors degree and higher |
|---|---|---|---|---|---|---|
| -No education | 4.04 | - | - | - | - | - |
| -Primary education | 3.65 | 0.39$^{ns}$ | - | - | - | |
| -Secondary education | 3.29 | 0.75$^{ns}$ | 0.36$^{ns}$ | - | - | - |
| -Vocation certification /Diploma | 3.42 | 0.62$^{ns}$ | 0.23$^{ns}$ | -0.13$^{ns}$ | - | - |
| -Bachelors degree and higher | 2.57 | 1.47*** | 1.08*** | 0.72* | 0.85* | - |

ns = no significant *p < .05; **p< .01 ***p < .001

As shown in Table 13, the mean score of the financial needs of parents who had educational level in no education, primary education, secondary education and vocation certification / diploma were more than those of parents who had educational level in bachelors degree and higher at the significant level of .001, .01 and .05, respectively.

**Table 14 Comparison of the needs of parents of children with congenital heart disease in total needs and each dimensions distributed by family income by ANOVA.**

| Family income (Baht/month) | n | $\bar{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Total needs.** | | | | | |
| ≤ 5,000 | 100 | 3.13 | 0.93 | | |
| 5,001-10,000 | 46 | 2.90 | 0.94 | 0.13 | 0.94 ns |
| 10,001-15,000 | 13 | 2.85 | 0.98 | | |
| >15,000 | 21 | 2.71 | 0.94 | | |
| **Information needs** | | | | | |
| ≤ 5,000 | 100 | 3.30 | 0.52 | | |
| 5,001-10,000 | 46 | 3.05 | 0.69 | 3.47 | 0.009 ** |
| 10,001-15,000 | 13 | 2.83 | 0.69 | | |
| > 15,000 | 21 | 2.99 | 0.64 | | |
| **Psychological needs** | | | | | |
| ≤ 5,000 | 100 | 2.66 | 0.81 | | |
| 5,001-10,000 | 46 | 2.51 | 0.74 | 0.94 | 0.42 ns |
| 10,001-15,000 | 13 | 2.33 | 0.92 | | |
| > 15,000 | 21 | 2.51 | 0.85 | | |
| **Physical needs** | | | | | |
| ≤ 5,000 | 100 | 2.94 | 0.79 | | |
| 5,001-10,000 | 46 | 2.80 | 0.86 | 0.39 | 0.76 ns |
| 10,001-15,000 | 13 | 2.83 | 0.83 | | |
| > 15,000 | 21 | 2.95 | 0.71 | | |
| **Spiritual needs** | | | | | |
| ≤ 5,000 | 100 | 3.45 | 0.78 | | |
| 5,001-10,000 | 46 | 2.96 | 0.89 | 4.58 | 0.004** |
| 10,001-15,000 | 13 | 2.98 | 0.82 | | |
| > 15,000 | 21 | 3.19 | 0.77 | | |

**Table 14** (continued)

| Family income (Bath/month) | n | $\bar{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Household needs management** | | | | | |
| ≤ 5,000 | 100 | 2.72 | 0.57 | | |
| 5,001-10,000 | 46 | 2.47 | 0.77 | 2.75 | 0.044* |
| 10,001-15,000 | 13 | 2.54 | 0.56 | | |
| > 15,000 | 21 | 2.37 | 0.76 | | |
| **Financial needs** | | | | | |
| ≤ 5,000 | 100 | 3.72 | 0.57 | | |
| 5,001-10,000 | 46 | 3.38 | 0.68 | 12.63 | 0.000*** |
| 10,001-15,000 | 13 | 3.37 | 0.97 | | |
| > 15,000 | 21 | 2.77 | 0.85 | | |

ns = no significant, *$p< .05$, **$p< .01$, ***$p< .001$,

As shown in Table 14, the parents who had differences in family income had differences in mean score in information needs, spiritual needs, household management needs and financial needs at significant level of .05 ($p< .01$, $p<.01$, $p< .05$ and $p< .001$, respectively), where as the other need dimensions were not significantly difference.

**Table 15 Comparison of the mean score of spiritual needs of the parents who had differences in family income.**

| Family Income (Baht/Month) | $\bar{X}$ | ≤ 5,000 | 5,001-10,000 | 10,001-15,000 | > 15,000 |
|---|---|---|---|---|---|
| ≤ 5,000 | 3.45 | - | - | - | - |
| 5,001-10,000 | 2.96 | $0.50^{**}$ | - | - | - |
| 10,001-15,000 | 3.02 | $0.43^{ns}$ | $-0.06^{ns}$ | - | - |
| > 15,000 | 3.19 | $0.26^{ns}$ | $-0.23^{ns}$ | $-0.17^{ns}$ | - |

ns = no significant **p < .01

As shown in Table 15, the mean score of spiritual needs of parents who had family income ≤ 5,000 baht /month were more than those of parents who had family income between 5,001-10,000 baht / month at the significant level of .01 (p < .01).

**Table 16 Comparison of the mean score of financial needs of the parents who had differences in family income.**

| Family Income (Bahts/Month) | $\bar{X}$ | ≤5,000 | 5,001-10,000 | 10,001-15,000 | > 15,000 |
|---|---|---|---|---|---|
| ≤ 5,000 | 3.72 | - | - | - | - |
| 5,001-10,000 | 3.38 | $0.34^{*}$ | - | - | - |
| 10,001-51,000 | 3.37 | $0.35^{*}$ | $-0.04^{ns}$ | - | - |
| > 15,000 | 2.77 | $0.95^{***}$ | $0.60^{**}$ | $0.64^{**}$ | - |

ns = no significant, *p <.05, **p < .01 , ***p< .001

As shown in Table 16, the mean scores of financial needs of parents who had family income ≤5,000 baht /month were more than those who had family income between 5,001 - 10,000 baht /month and higher, and 10,001-15,000 baht/month than 15,000 baht /month at the significant level of .05 ($p < .05$, $p< .05$ and $p< .001$, respectively). Moreover, the mean scores of financial needs of parents who had family income between 5,001 - 10,000 baht /month were more than those who had family income upper than 15,000 baht /month at the significant level of .01 ($p < .01$).

**Table 17 Comparison of the total needs of parents of children with congenital heart disease in total needs and each dimensions distributed by age of the ill child by ANOVA.**

| Age of the ill child (years) | n | $\overline{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Total needs** | | | | | |
| < 1 year | 37 | 3.04 | 0.89 | | |
| 1-3 years | 53 | 3.00 | 0.95 | | |
| 4-6 years | 32 | 2.95 | 0.92 | 0.91 | 0.46 ns |
| 7-12 years | 47 | 3.01 | 0.99 | | |
| 13-18 years | 11 | 3.03 | 0.97 | | |
| **Information needs** | | | | | |
| < 1 year | 37 | 3.18 | 0.65 | | |
| 1-3 years | 53 | 3.20 | 0.57 | | |
| 4-6 years | 32 | 3.08 | 0.64 | 0.186 | 0.95 ns |
| 7-12 years | 47 | 3.15 | 0.62 | | |
| 13-18 years | 11 | 3.22 | 0.80 | | |

**Table 17** (continued)

| Age of the ill child (years) | n | $\bar{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Psychological needs** | | | | | |
| < 1 year | 37 | 2.70 | 0.78 | | |
| 1-3 years | 53 | 2.60 | 0.74 | | |
| 4-6 years | 32 | 2.39 | 0.82 | 0.79 | 0.53 ns |
| 7-12 years | 47 | 2.61 | 1.12 | | |
| 13-18 years | 11 | 2.70 | 1.12 | | |
| **Physical needs** | | | | | |
| < 1 year | 37 | 3.00 | 0.83 | | |
| 1-3 years | 53 | 2.86 | 0.73 | | |
| 4-6 years | 32 | 2.90 | 0.74 | 0.46 | 0.76 ns |
| 7-12 years | 47 | 2.83 | 0.62 | | |
| 13-18 years | 11 | 3.03 | 1.18 | | |
| **Psychological needs** | | | | | |
| < 1 year | 37 | 3.27 | 0.82 | | |
| 1-3 years | 53 | 3.18 | 0.80 | | |
| 4-6 years | 32 | 3.20 | 0.89 | 0.79 | 0.53 ns |
| 7-12 years | 47 | 3.36 | 0.88 | | |
| 13-18 years | 11 | 3.30 | 1.08 | | |
| **Household manage needs** | | | | | |
| < 1 year | 37 | 2.57 | 0.67 | | |
| 1-3 years | 53 | 2.49 | 0.63 | | |
| 4-6 years | 32 | 2.71 | 0.65 | 0.89 | 0.47 ns |
| 7-12 years | 47 | 2.67 | 0.65 | | |
| 13-18 years | 11 | 2.75 | 0.89 | | |
| **Financial needs** | | | | | |
| < 1 year | 37 | 3.57 | 0.66 | | |
| 1-3 years | 54 | 3.44 | 0.71 | | |
| 4-6 years | 36 | 3.38 | 0.70 | 0.58 | 0.68 ns |
| 7-12 years | 44 | 3.63 | 0.85 | | |
| 13-18 years | 11 | 3.35 | 0.60 | | |

ns = no significant

As Shown in Table 17, there were no significantly difference ($p > .05$) in total and all dimensions needs of the parents who had children with different age groups.

**Table 18 Comparison of the needs of parents of children with congenital heart disease in total needs and each dimension distributed by severity of illness analysis by ANOVA.**

| Class of severity of illness | n | $\bar{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Total needs** | | | | | |
| I | 39 | 3.00 | 0.88 | | |
| II | 107 | 3.00 | 0.96 | 2.37 | 0.07 ns |
| III | 31 | 3.06 | 0.90 | | |
| IV | 3 | 3.00 | 1.20 | | |
| **Information needs** | | | | | |
| I | 39 | 3.07 | 0.62 | | |
| II | 107 | 3.19 | 0.61 | 0.59 | 0.62 ns |
| III | 31 | 3.19 | 0.63 | | |
| IV | 3 | 3.45 | 0.31 | | |
| **Psychological needs** | | | | | |
| I | 39 | 2.56 | 0.90 | | |
| II | 107 | 2.57 | 0.80 | 0.05 | 0.99.ns |
| III | 31 | 2.62 | 0.75 | | |
| IV | 3 | 2.67 | 0.63 | | |
| **Physical needs** | | | | | |
| I | 39 | 2.81 | 0.96 | | |
| II | 107 | 2.91 | 0.74 | 0.33 | 0.81 ns |
| III | 31 | 2.88 | 0.82 | | |
| IV | 3 | 2.67 | 0.89 | | |
| **Spiritual needs** | | | | | |
| I | 39 | 3.19 | 0.79 | | |
| II | 107 | 3.24 | 0.87 | 0.68 | 0.61 ns |
| III | 31 | 3.40 | 0.80 | | |
| IV | 3 | 3.50 | 0.87 | | |

**Table 18** (continued)

| Class of severity of illness | n | $\overline{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Household needs management** | | | | | |
| I | 39 | 2.50 | 0.70 | | |
| II | 107 | 2.59 | 0.65 | 2.04 | 0.11 ns |
| III | 31 | 2.69 | 0.57 | | |
| IV | 3 | 3.50 | 0.80 | | |
| **Financial needs** | | | | | |
| I | 39 | 3.47 | 0.85 | | |
| II | 107 | 3.46 | 0.68 | 0.84 | 0.47 ns |
| III | 31 | 3.61 | 0.78 | | |
| IV | 3 | 4.00 | 0.43 | | |

ns = no significant

As shown in Table 18, there were no significantly difference (p> .05) in total and all dimensions needs of the parents who had children with different severity of illness.

**Table 19 Comparison of the needs of parents of children with congenital heart disease who had differences in numbers of admissions by ANOVA.**

| Number of admissions | n | $\overline{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Total needs** | | | | | |
| 2-7 times | 155 | 3.00 | 0.25 | | |
| 8-13 times | 15 | 2.90 | 0.21 | 0.51 | 0.60 ns |
| 14 times and over | 10 | 3.09 | 0.38 | | |
| **Information needs** | | | | | |
| 2-7 times | 155 | 3.17 | 0.62 | | |
| 8-13 times | 15 | 3.05 | 0.64 | 0.35 | 0.71 ns |
| 14 times and over | 10 | 3.23 | 0.42 | | |
| **Psychological needs** | | | | | |
| 2-7 times | 155 | 2.56 | 0.82 | | |
| 8-13 times | 15 | 2.65 | 0.71 | 0.49 | 0.62 ns |
| 14 times and over | 10 | 2.80 | 0.65 | | |
| **Physical needs** | | | | | |
| 2-7 times | 155 | 2.91 | 0.81 | | |
| 8-13 times | 15 | 2.65 | 0.78 | 0.61 | 0.54 ns |
| 14 times and over | 10 | 2.98 | 0.53 | | |
| **Spiritual needs** | | | | | |
| 2-7 times | 155 | 3.27 | 0.84 | | |
| 8-13 times | 15 | 3.08 | 0.95 | 0.39 | 0.69 ns |
| 14 times and over | 10 | 3.33 | 0.64 | | |

ns = no significant

**Table 19** (continued)

| Number of admissions | n | $\bar{X}$ | S.D | F | P. value |
|---|---|---|---|---|---|
| **Household management needs** | | | | | |
| 2-7 times | 155 | 2.58 | 0.66 | | |
| 8-13 times | 15 | 2.70 | 0.64 | 1.15 | 0.32 ns |
| 14 times and over | 10 | 2.88 | 0.62 | | |
| **Financial needs** | | | | | |
| 2-7 times | 155 | 3.55 | 0.71 | | |
| 8-13 times | 15 | 2.17 | 0.77 | 2.45 | 0.09 ns |
| 14 times and over | 10 | 3.25 | 0.92 | | |

ns = no significant

As Shown in Table 19, there were no significantly different (p> .05) in all needs of the parents who had children with different numbers of admissions.

# CHAPTER V

# DISCUSSION

This research aimed to explore the needs and response to needs of parents of children with congenital heart disease. The subjects were 180 fathers or mothers of children with congenital heart disease whose their children were follow-up and who were admitted at the OPD or/and the IPD at Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Mongkutklao Hospital and King Chulalongkorn Memorial Hospital. The discussion is divided into 2 parts as follows:

1. Needs and response to needs of parents of children with congenital heart disease
2. Factors that effecting needs and response to needs of parents of children with congenital heart disease

## 1. Needs and response to needs of parents of children with congenital heart disease

In this study, the total mean score of needs of parents of children with congenital heart disease was at a moderate level ($\overline{X}$ = 3.00, S.D = 0.50) according to the total mean score of response to needs of parents of children with congenital heart disease was at a moderate level ($\overline{X}$=0.50, S.D = 0.30, Table 3). For the needed by dimension, the financial needs of parents was at a high level and the other five dimensions were at a moderate level. The details of 6 needs dimensions from high to low level in from high to low level as follows:

1.1 Financial needs. The mean score of financial needs of parents was at a high level ($\overline{X}$=3.50, S.D=0.73) but the mean score of response to needs was at a low level ($\overline{X}$=0.31, S.D =0.23; Table 3). It can be explained that the costs of treatment was a financial burden and constraint for the parents because the children with congenital heart disease needed a long -term therapy with high expenditures of treatment. Moreover, 55.6 % of parents had family income ≤5,000 baht which was insufficient for the treatment, and 40 % of them were inadequate and had debt (Table 1). Therefore, parents' financial needs were higher than other needs. This was consistent with the study of Jackson, et al (1980: 851) which found that caregivers needed financial support because they lost their jobs, were unemployed and faced with financial problems of covering payment for the treatment. According to Douglas (1993: 158), parents spent their time to visit and took care for the ill child; as a result, they lost their work and income

When analyzing by items (Table 9), it was found that the financial needs of the parents in high level were helping about hospital expense and information about financial organization but response to these needs was at a high level and low level respectively. It meant that they need the financial support for the hospital expense, and the expenditure in hospitalization and medical expense of the children with congenital heart disease are vary high. The other reasons would be all the ill children were admitted in a government hospital which had financial support for the parents who had low income (41.7 %; Table 1) and sometimes the health care team did not give complete assessment about needs of the parents and not provide helpful information. So, the parents seek for financial support from other financial organization. besides the economic crisis caused financial needs to increase even more.

1.2 Spiritual needs: The mean score of spiritual needs of parents was at a moderate level ($\bar{X}$ =3.26, S.D = 0.84), but the mean score of response to the needs was at a low level ($\bar{X}$=0.33, S.D=0.35; Table 3). Spiritual needs motivate people to create a relationship with other people, to love other people and to have faith in religion. Moreover, these needs are necessary factors to produce and maintain continuous relationships with superhuman and humans to foster love, forgiveness, trust and goal of life (Kaseamkitwattana, S. 1993: 5). For the spiritual needs by items, parents had the needs to know the truth about illness of their child at a high level ($\bar{X}$= 3.61, S.D=1.13). While, the response to their needs was at a low level ($\bar{X}$=0.26, S.D=0.44; Table 8). The explanation is that in general, the doctors who had responsibilities to inform the parents about the prognosis and therapeutic plan, and the nurses had responsibilities in health education teaching and mental support. However, doctors or nurses have no time to do others about discharge. The parents want this information to create their hope or even to face with the crisis in the future with confidence, Therefore, they feel that this is important (Miller, 1983: 287-288).

1.3 Information needs: The mean score of information needs was at a moderate level ($\bar{X}$ = 3.17, S.D = 0.61) and the response to their need was also at a moderate level ($\bar{X}$ =0.50, S.D=0.25; Table 3). The reasons would be come from the nature of congenital heart disease which is a chronic illness. The parents have to take care of their child continuously for a long time. Therefore, they receive many advice and health education from the others and gain experiences from caring for their ill child. Moreover, there are 4 items in the questionnaire which were at a high level as follows: treatment for the ill child, how to care when the ill child had cyanosis, severity of heart disease and how to prevention of the infection in oral cavity but there are 3 items which wee at a high level while the response to these needs was at a moderate level as follows: how to care when the ill child had cyanosis, severity of heart disease and how to prevention of the infection in oral cavity. One possible explanation is that the various and changing symptoms of congenital heart disease are based on their conditions which are sometimes stable and sometimes acute, especially for the ill children with cyanotic type. Therefore, these parents would have more needs for information and should receive more advice than the others. Although the parents have had experienced and advice to take care of their ill child, they still need further knowledge, information and help continuously in order to foster their strength and ability to continue caregiving in their environment. This finding is consistent with the study of Carbery (1995: 807) which suggested that the most information and knowledge needs of alzheimer caregivers were the information about symptoms and signs of the disease, treatment, and modern methods on how to care for the ill person. Moreover, Smitherman et al (1991: 648-649 cite in Chouangsawadsak, S. 1998) documented that parents of the ill children were concerned about their child' s health status and needed help from the health care team.

1.4 Physical needs: The mean score of physical needs of parent was at a moderate level ($\overline{X}$=2.90, S.D=0.80), but the mean score of response to their needs was at a low level ($\overline{X}$=0.28, S.D=0.36; Table 3). It can be explained that the health care team was a perceived by individuals as responsible for promoting and maintaining their well-being. However, caregivers such as parents of the ill children have responsibilities to take care of them for a long time with all their hearts and effort. The many activities of caregiving begin since the children wake up in the morning until they go to at night sleep which deteriorates the parents' health. The result also showed that 29.4 % of parents had taken care of their ill child for 1 to 3 years (Table 2). The prolonged duration of caregiving made caregivers exhausted, fatigued, and stressed (May, 1993: 270). Parents have needs about their own health. The analysis of each item revealed that the parents had 3 needs at a moderate level but response to these needs at a low level were suggestion about exercise and suggestion about self care management. It would have resulted from the fact that the health care team focused their care on the ill children more than on the family. In addition, the parents' concern focused only on giving care to their ill children but not on their own health and their family. Moreover, some parents had to earn more money for payment of treatment of their ill child. Similarly, the study of Harrington, Lackey & Gastes (1996; 118-125), about needs of cancer caregivers illustrated that although caregivers gave important to their own health or own activities, they gave their priority concern to their child' s health. The study of Chouangsawadsak, S. (1998, 59) also documented that the needs of cerebral vascular accident caregivers and caregiving to their own health were at a moderate level. It would be the result of the experience during the crisis of their ill children which focused they to adjust there own needs. Moreover, their own health was normal so they want to give the best care and priority to their ill children.

1.5 Household management needs: The mean score of household management needs of parents was at a moderate level ($\overline{X}$=2.60, S.D=0.66), but the mean scores of the response to their needs was at a low level ($\overline{X}$=0.30, S.D=0.30; Table 5). It would be characteristic of household management needs included activities such as preparing food and cleaning of the house. When there was some one in family had sick, there would be someone to bring them to go to see the doctors and follow up that the people who took this responsibility generally were women (Meekanon, J et al., 1988: 9-11). The analysis of each items revealed that the parents needs had 3 needs at a moderate level as follows: suggestion about follow –up planing, suggestion about dietary management and suggestion about home cleaning but the response to these needs was at a low level as follows: suggestion about dietary management and suggestion about home cleaning. Therefore, the health care team advice always incomplete and they focused only giving care to the ill child than the parents. Although the parents had experiences and ability to manage these activities, it was better to facilitate the good management and to prepare the substitute caregivers. The caregiving to children with congenital heart disease had to pay careful attention because there would cause some serious problems to patients. This was consistency with the study of Periad & Ames (1993: 86-88), that presented the cerebro vascular accidents' caregivers was always changing such as less time to do various activities, stopping some activities and being more careful about some activities, because they always spent all their times for caregiving to their ill child.

1.6 Psychological needs. The mean score of psychological needs was at a moderate level ($\bar{X}$=2.58, S.D=0.80) but the mean score of response to their needs was at a low level ($\bar{X}$=0.30, S.D=0.32; Table 3). The possible explanation that the psychological needs were the basic needs of human to be healthy (Dickeman, et al., 1980: 563). It was encouraged performance for the parents to receive help, co-operation, being worry, someone to listen and understand and help in decision making (Wingate & Lackey, 1989: 221). These psychological supports always came from their family members, relatives, friends, the health care team and the other parents of the ill child. These supports included advice, consultation and help about caregiving to their ill child and when they had problems in caring to decrease their fear and isolation (Ladebauche, 1992: 218 cite in Ke, L.1998: 71). From the finding 17.2 % (Table 1) of the parents their spouses, relatives or other family members support. It would be the result of the Thai culture that always had a good relationship, generosity, and support among family members. Although nowadays the Thai family change from extend family to nuclear family. When there was someone in the family get sick, the other members would take part the responsibility and help each other (Suphap, S. 1995: 9-11). The items which showed the parents needs was at a high level included psychological support from doctors and nurses in caring the ill child ($\overline{X}$=3.66, S.D=1.03) and need more time in asking about problems in child care ($\overline{X}$=3.59, S.D=0.99; Table 7) but the response to parents needs was at a moderate level and low level, respectively. This showed that they needed help from other people and society especially from the health care team (Phanishakul, K. 1994: 82) which they expected in accuracy information.

However, the results indicated that the majority of the parents had mean score of response to their needs at a low level (Table 7). It would be that doctors or nurses had insufficient time for giving consultation to them, especially at a government hospitals which had many clients and insufficient health personel.

### 2. Factors were effecting needs of parents of children with congenital heart disease

The hypothesis of this study was to compare the needs of parents of children with congenital heart disease according to their age, educational level and family income as well as the children' s age, severity of illness and number of admissions.

In this findings, the total six factors had no different in the total needs of parents of children with congenital heart disease. However, there were 2 factors (educational level and family income) effecting to the needs of parents of children with congenital heart disease with a significant different level ($p< .05$), which would be discussed in detail as follow:

**Educational Level**: From the finding, the educational level did not different in the total needs of the parents. However, there were significantly different in the information needs and financial needs dimensions in parents who had different educational level ($p< 0.01$ and $p< .001$, respectively). The findings illustrated that the parents who had primary and secondary educational level had more information needs than those who had vocation certificate or diploma. This finding was partially supported the hypothesis. This finding also was consistency with the concept that people who had high education could perceive and understand about the new information, want only practical and useful information as well as seek the resources better than those with low educational level (Muhienkamp & Sayles,1986: 366). This results was consistency with the study of Leesuwan, W., et al (1993: 82). That presented that the high educational level parents had more understanding and perception about the disease, had more interested during facing the children' s illness and had more seeking information especially asking the doctors and nurses about their child' s symptoms than the low educational ones. In this studies found that the parents who had no education and primary education needed financial more than the parents who had educational level in bachelor, degree and higher because the parents who had low education had occupation with low income and lack of to work in good occupation. This finding was consistency with the study of Pongkampan, C. (1994: 121) about the needs and the response to needs of mothers of children who were admitted in Singburi Hospital. She studied the needs and response to needs of parents whose children were admitted in Singburi Hospital. She found that, the mothers who had low educational level had greater needs than those who had higher educational level. They had more economic problems and had to find the money for family expenditure.

**Family income**: From the finding, the parents who had different family income did not have difference in the total needs of these parents significantly ($p > .05$). It would be that the result of the majority of parents (55.6 %) who had lower incomes ≤ 5,000 baht; Table 1). Therefore, the total needs were not different. However, the parents who had family income between ≤ 5,000 baht, had more spiritual needs than those of parents who had family income between 5, 001 – 10,000 baht significantly different ($p< 0.01$). This showed that parents who received the economic impact from lack of income, unemployment or using the majority of their time for caregiving having low family income had more spiritual needs than those who have high family income. The burden of caregiving and financial problems caused the anxiety stress, exhausted, fatigued and powerlessness. Consequently, the spiritual needs were necessary for them to encourage, support, empower and increase hope to enhance their patience and strength to face with various crisis during their cargiving (Miller, 1983: 287-288). Moreover, the parents who had family income between ≤ 5,000 baht and between 5,001-10,000 baht had more financial needs than those whose family income was 15,000 bath or higher statistically significant ($p < 0.001$ and 0.01, respectively; Table 16). This result was consistency with the study of Orem (1991: 361) that presented that family income was a financial resource especially when there someone in the family sick and increase economical problems in that family. According to the concept of Pender (1987: 161-162), people with high family incomes would have better opportunities about facilitating the benefit things for their health and seeking appropriate health care than those with low incomes. Therefore, the parents with low income had high financial needs in order to maintain their balance and function in their normal life. The study of Mitthongtha, J. (1989: 46) also illustrated that the family with high income could easily adjust and have less trouble from treatment cost whereas the low family income had high financial needs to support. Moreover, Phongkampan, C. (1994: 129), she found that mothers of the children admitted in Singburi Hospital who had a low family income had greater financial needs than those who had a high family income.

The age of the parents, age of the ill child, severity of illness and number of admissions to the hospital did not have affecting to the needs of parents of children with congenital heart disease significantly different ($p > .05$).
This discussion was as follows.

**Age of parents:** From the hypothesis, the parents' needs of children with congenital heart disease would have difference in parents who had different age. The result did not support this hypothesis that is 83.3 percent of parents had age range 21 to 40 years old whereas 12.8 percent were between 41 to 60 years old (Table 1). This accounts for the development of these age range were similar in the capacity development, the experiences the problem solving ability and the decision making.

Therefore, the age of parents did not influence on their needs. This result was agree with the study of Chouangsawadsak, S. (1998: 62-63),
she found that age did not have a relationship with the needs of cerebro-vascular accident caregivers of the patients the study of Oberst et al (1991: 71-78) also presented that the of cancer caregivers at home had no relationship with the quality of caregivers' needs and burden of caregiving.

**Age of the ill child**: From the hypothesis, the needs of parents who had children with congenital heart disease with different age would have a difference in parents' needs. However, the results showed that there was no statistical significance different (p > .05) which did not support this hypothesis. It would be explained that the result of a little distribution of the subjects. Those were 29.4 % of parents had ill child age ranged 1 to 3 (Table 2). Those parents had experience in caring for their sick children because the majority of children (86.1 %) were used to admit in the hospital for 2 to 7 times. (Table 2). For these reasons, the parents had many opportunities receive knowledge and practice their caregiving skill from the health care team. On the other word, this practice could adapt and adjust their life-style and their family to continue their function in the same period of caregivig their children. Therefore, there was no difference in the needs of parents.

**Severity of illness**: From the hypothesis the parents' needs who had children with congenital heart disease would be different according to the severity of illness. However, the results did not support this hypothesis. The parents who had children with difference in severity of illness did not have difference in their needs significantly (p > .05). The one explanation was that the majority of children had functional classification at class I and II (21.7 % and 59.4 %, respectively; Table 2).

The children in these classification had normal activity unless they had exerted activities. Moreover, if they stopped the activities for a few minute and relax, then they normal activities. Therefore, the children did not pose to serious symptoms or require close caregiving. Moreover, 29.4 % of parents had the experience of caregiving their ill child about 1 to 3 years (Table 2). In addition, the majority of parents (86.1 %) had the ill child admitted in the hospital about 2 to 7 times. The prolong duration of caring for their ill child provided parents to have the opportunity to meet the health care team, receive knowledge and increase experiences in caregiving. Therefore, the parents had no difference in their needs.

**Number of admissions**: From the hypothesis, the needs of parents whose children with congenital heart disease would be different according to the number of admissions to the hospital. The results showed no differences among parents' needs ($p > .05$). This finding did not support this hypothesis. It would be that the majority 86.1 % (Table 2) had a child who admitted for several times (2 to 7 times). There for parents had more opportunity to meet the health care team, receive knowledge and increase their experiences in caring for their ill child. Similar to the study of Zarit, Reever & Bach-Peterson (1980: 649-655) the duration and the number of caring the old patients did not related to the burden and discomfort feeling of caregivers.

From the finding, there were two factors that had influence on the parents' needs of children with congenital heart disease. These were the educational level and family income. The difference in educational level and family income caused a difference in the needs of the parent at statistically significant level .05 ($p< .05$).

# CHAPTER VI

# CONCLUSION AND SUGGESTIONS

## Summary of the study

This research is a descriptive which aimed to study about needs and response to the needs of parents of children with congenital heat disease. Subjects are fathers or mothers of children with congenital heat disease whose children were follow -up and who were admitted at the Out -Patient Department (OPD) and the In- Patient Department (IPD) of children with congenital heart diseases in four hospitals: Siriraj Hospital, Queen Sirikit National Institute of Child Health, King Mongkutklao Hospital and King Chulalongkorn Memorial Hospital, during June – August 2000. There were 180 subjects. Questionnaires were used in this research which comprises of 2 parts as follows: Part I Demographic data of the parents and basic data of the ill child. Part II Questionnaire of the needs and response to the needs of parents of children with congenital heart disease. Data was analyzed by using mean, standard deviation, ANOVA and Sheffe Test.

## Results

1. There were 180 cases of parents who completed the demographic data. The majority of the parents were mothers (82.8%). The age of the parents was 83.3 %, with the age range from 21 to 40 years old. Most of the parents (97.2 %) were Buddhists, and were married (89.4 %). The common educational level of the parents was primary education (59.4 %) and parents' occupation were government officer (55.6 %), the parents had a monthly family income of ≤ 5,000 Baht. Most of the

parents reported that their income was inadequate and had debt (40 %). Payment of treatment of parents were partially own payment (41.7 %). The duration of care were mainly range from 1 to 3 years (29.4 %).

2. Most of the children' s age were range from 1 to 3 years old (29.4 %). The majority of the children were girls (55 %) which were diagnosed as acyanotic heart diseases (58.3 %). The severity of illness was mostly at class II (59.4 %). The number of admissions ranged from 2–7 times (86.1 %).

3. The needs and response to the needs of parents of children with congenital heart diseases

3.1 The total needs of the parents was at a moderate level as well as the fifth dimensions needs including spiritual needs, information needs, physical needs, household management needs and psychological needs were at a moderate level and financial needs was at a high level. The needs in 6 dimensions from high to low level were as follows:

3.1.1 Financial needs: the financial needs of parents were at a high level included helping about hospital expense and information about financial organization.

3.1.2 Spiritual needs: the spiritual needs of parents at a high level was they wanted to know the truth about illness.

3.1.3 Information needs: the information needs of parents were at a high level included treatment for the ill child, how to care when the ill child had cyanosis, severity of heart disease, how to prevention of the infection in oral cavity.

3.1.4 Physical needs: the physical needs of the parents at a moderate

Level were suggestion about annual physical examination, exercise and self care management.

3.1.5 Household management needs: the household management needs of parents at a moderate level were suggestion about follow- up planing, dietary management and home cleaning respectively.

3.1.6 Psychological needs: the psychological needs of parents at a high level were psychological support from doctors and nurses in caring the ill child. and need more time in asking about problems in child care.

3. 2 The total of response to the needs of the parents was at moderate level. However, For the response to needs in dimensions, the result found that the parents received response to financial needs, spiritual needs, physical needs, household management needs and psychological needs at a low level but information needs was at a moderate level. The response to needs in 6 dimensions from high to low level were as follows:

3.2.1 Information needs: the total of response to needs of the parents was at a moderate level and the response to needs of the parents by items was at a high level including treatment for the ill child, knowledge about drugs, how to care the ill child with had fever and suggestion about vaccination.

3.2.2 Spiritual needs: the total of response to needs of the parents was at a low level and the response to needs of the parents by items was at a moderate level including religious activity in ward and caring the ill child with holy belief.

3.2.3 Financial needs: the total of response to the needs of the parents was at a low level and the response to the needs of the parents by items was at a high level including helping about hospital expense.

3.2.4 Psychological needs: the total of response to needs of parents was at a low level and the response to needs of parents by items was at a moderate level, including psychological support from doctors and nurses in caring the ill child.

3.2.5 Household management needs: the total of response to needs of parents was at a low level and the response to needs of parents by items was at a moderate level, including suggestions about follow –up planing.

3.2.6 Physical needs: the total of response to needs of parents was at a low level and the response to needs of parents by items was at a moderate level including suggestion about annual physical examination.

4. There are 2 factors that influencing on the needs of the parents of children with congenital heart disease. Educational level and family income were significant factors influencing on the needs of parents of children with congenital heart disease. Educational level was a significant factor influencing on the needs of parents of children with congenital heart disease, Thus is statistically significant in information needs ($p < .01$) and financial needs ($p<0.001$). In addition, family income was a significant factor influencing to the needs of parents of children with congenital heart disease, then is a statistically significant in information needs ($p<0.01$), spiritual needs ($p<0.01$), household management needs ($p<0.05$), and financial needs ($p<.001$).

## Implications and Recommendations.

### Implications of Research Findings.

### Implications for nursing practice

In caring for children with congenital heart diseases and their parents, the health care team should be listened to the parents about what needs they have. Therefore the health care team can provide care and support for the child and their parents by:

1. The health care team should properly assess the needs of parents. Nurses should develop a nursing assessment form in order to get complete information about the needs of the parents.

2. To deliver about consultation, knowledge and problems of the parents such as financial problems, information how to care their ill child. The health care team should have enough time for the parents about to talk with before their children were discharge from the hospital.

3. The health care team should be aware of the difference of the parents. They must co-operate with them for improving the nursing care plan, these are according to the needs of the parents who were different about age, educational level, family income, and whose ill child who were different about severity of illness and number of admissions.

4. To inform about financial support organization that can help the parents when they have a problems about treatment expenditure or the expense. The health care team should establish the information unit for the parents to be the center for consultation and this would made the parents more confidence and increase psychological support.

## Implications for Future Studies

1. The researcher should study in the other hospital that those have different about health service or different diseases and the nurse must study deep into

intervention research about the different of educational level and family in come of parents of children with congenital heart disease.

2. Nurses should demonstrate the role of health education more at present. The nurses can educate parents of children with congenital heart disease both as a individual or as a group. The appropriate time in giving health education for the parents is when their ill child with congenital heart diseases is waiting for the doctor or when the children with congenital heart disease were admitted in ward.

3. The further study on the topic of supportive education nursing system on parents needs in caring for children with congenital heart disease should be continued in clinical setting. It due to congenital heart disease is considered as a major problem of children particularly in children has shown its higher mortality rated. This strategy certainly enable the nurses to realize what the extent of parents needs in caring for children with congenital heart disease as well as to be recognized all existing problems encountered by the parents. As a result, nurse will be capable to adjust the parents needs on children care to be more suitable and effective.

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# APPENDIX

# APPENDIX A

# LIST OF EXPERTS

# APPENDIX A

## LIST OF EXPERTS

The experts who had validated the questionnaires of the needs and response to needs of parents of children with congenital heart disease are as follows:

1. Assoc. Prof. Doungmanee Louwhaprasittipon, M.D.
   Department of Pediatric, Faculty of Medicine, Mahidol University.
2. Assoc. Prof. Wilai Leesuwan
   Department of Nursing, Faculty of Medicine Ramathibodi Hospital.
3. Assoc. Prof. Srisombun Musisukon, M.S. (Nursing)
   Department of Pediatric Nursing, Faculty of Nursing, Mahidol University.
4. Miss. Nuananong Bunjaroonsilp, Ph.D
   Department of Pediatric Nursing, Faculty of Nursing, Mahidol University.
5. Miss. Suphattra Molanon, B.N.
   Head of Ananthamahidol VII unit, Pediatric Nursing Department, Siriraj Hospital.

# APPENDIX B

# CONSENT FORM

## คำชี้แจงและการพิทักษ์สิทธิ์ของบิดา-มารดาผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิด เพื่อขอความร่วมมือในการเข้าร่วมการวิจัย

ดิฉัน นางสาวจารุวรรณ สว่างศรี เป็นนักศึกษาพยาบาลศาสตรมหาบัณฑิต คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล กำลังศึกษาวิจัยเกี่ยวกับความต้องการและการได้รับการตอบสนองความต้องการของบิดา-มารดา ในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด

ถ้าท่านยินดีเข้าร่วมในการวิจัยครั้งนี้ ดิฉันขอความกรุณาให้ท่านตอบแบบสัมภาษณ์เกี่ยวกับข้อมูลพื้นฐานของบิดาหรือมารดาและเด็กป่วย และแบบสัมภาษณ์ความต้องการและการได้รับการตอบสนองความต้องการของบิดา-มารดา จึงขอความร่วมมือในการตอบแบบสัมภาษณ์นี้ให้ตรงกับความเป็นจริงของท่านให้มากที่สุดเท่าที่จะเป็นไปได้ คำตอบที่ได้จะสรุปออกมาเป็นภาพรวม นำมาวิเคราะห์ทางการศึกษาตามวัตถุประสงค์ที่กำหนดไว้เท่านั้น ซึ่งจะใช้เวลาประมาณ 25-30 นาที หากท่านมีข้อสงสัยประการใดเกี่ยวกับงานวิจัยครั้งนี้ ดิฉันยินดีตอบให้ท่านเข้าใจ และไม่ว่าท่านจะเข้าร่วมในการวิจัยครั้งนี้หรือไม่ก็ตาม บุตรของท่านยังคงได้รับการรักษาพยาบาลจากเจ้าหน้าที่ของโรงพยาบาลตามปกติ ท่านมีสิทธิ์ที่จะตอบรับหรือปฏิเสธการเข้าร่วมในการวิจัยและท่านยังมีสิทธิ์ยกเลิกการเข้าร่วมการวิจัยครั้งนี้ได้ตลอดเวลา โดยไม่มีผลต่อการรักษาพยาบาลผู้ป่วยหรือผลกระทบใด ๆ

ขอขอบพระคุณ

( นางสาวจารุวรรณ สว่างศรี )

**สำหรับผู้เข้าร่วมการวิจัย**

ข้าพเจ้าได้รับการอธิบายตามรายละเอียดข้างบนมีความเข้าใจและยินดีเข้าร่วมการวิจัย

ลงชื่อ.............................................

(.............................................)

วันที่......เดือน..................พ.ศ..........

# APPENDIX C

# INSTRUMENTS

## แบบสัมภาษณ์ความต้องการและการได้รับการตอบสนองความต้องการของบิดาหรือมารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด

**คำชี้แจง** แบบสัมภาษณ์นี้ มีวัตถุประสงค์เพื่อสำรวจความต้องการและการได้รับการตอบสนองความต้องการของบิดา-มารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด ประกอบด้วยแบบสัมภาษณ์ 2 ส่วน ดังนี้

**ส่วนที่ 1** แบบสัมภาษณ์ข้อมูลพื้นฐานของบิดาหรือมารดาและบุตรโรคหัวใจพิการแต่กำเนิด

**ส่วนที่ 2** แบบสัมภาษณ์ความต้องการและการได้รับการตอบสนองความต้องการของบิดาหรือมารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด

เลขที่แบบสัมภาษณ์

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|---|---|---|
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ชื่อ...................................นามสกุล...................................

วันที่สัมภาษณ์..........................................................................

ส่วนที่ 1 แบบสัมภาษณ์ข้อมูลพื้นฐานของบิดาหรือมารดา และบุตรโรคหัวใจพิการแต่กำเนิด

คำชี้แจง ผู้สัมภาษณ์จะสัมภาษณ์ตามแบบสอบถามและทำเครื่องหมาย (/) ลงหน้าข้อความที่ตรงกับคำตอบของบิดา-มารดา

**I ข้อมูลพื้นฐานของบิดาหรือมารดา**

1. มีความสัมพันธ์กับบุตรป่วยโดยเป็น

[ ] บิดา [ ] มารดา

2. อายุ .........ปี

3. ศาสนา

[ ] พุทธ [ ] คริสต์

[ ] อิสลาม [ ] อื่น ๆ......................

4. สถานภาพสมรส

[ ] คู่และอยู่ด้วยกัน [ ] หม้าย, หย่า หรือแยกกันอยู่

5. ระดับการศึกษา

[ ] บิดาจบการศึกษาชั้น............................

[ ] มารดาจบการศึกษาชั้น.........................

6. อาชีพ

6.1 อาชีพของบิดา

[ ] ทำงานบ้าน [ ] เกษตรกรรม

[ ] ค้าขาย [ ] รับราชการ/ รัฐวิสาหกิจ

[ ] รับจ้าง [ ] อื่นๆ ระบุ............

6.2 อาชีพของมารดา

[ ] ทำงานบ้าน [ ] เกษตรกรรม

[ ] ค้าขาย [ ] รับราชการ/ รัฐวิสาหกิจ

[ ] รับจ้าง [ ] อื่นๆ ระบุ............

1. รายได้ของครอบครัว เฉลี่ยต่อเดือน รวมจำนวน ...............................บาท

**ส่วนที่ 2** แบบสัมภาษณ์ความต้องการและการได้รับการตอบสนองความต้องการของบิดาหรือมารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด

**คำชี้แจง** แบบสัมภาษณ์นี้ ต้องการทราบความต้องการและการได้รับการตอบสนองความต้องการของบิดาหรือมารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด

**1. ความต้องการและการได้รับการตอบสนองความต้องการของบิดาหรือมารดาในการดูแลสุขภาพบุตรโรคหัวใจพิการแต่กำเนิด แบ่งเป็นความต้องการ 6 ด้าน จำนวน 43 ข้อ คือ**

| | | | | |
|---|---|---|---|---|
| 1. ด้านข้อมูลในการดูแลบุตรป่วย | 23 | ข้อ | ได้แก่ข้อ | 1-23 |
| 2. ด้านการจัดการภายในบ้าน | 4 | ข้อ | ได้แก่ข้อ | 24-27 |
| 3. ด้านการดูแลสุขภาพร่างกาย | 4 | ข้อ | ได้แก่ข้อ | 28-31 |
| 4. ด้านการประคับประคองจิตใจ | 4 | ข้อ | ได้แก่ข้อ | 32-35 |
| 5. ด้านการเสริมสร้างพลังทางจิตวิญญาณ | 4 | ข้อ | ได้แก่ข้อ | 36-39 |
| 6. ด้านการเงิน | 4 | ข้อ | ได้แก่ข้อ | 40-43 |

ในการตอบแบบสัมภาษณ์ ขอให้ผู้ถูกสัมภาษณ์ตอบให้ตรงกับความเป็นจริงให้มากที่สุดเท่าที่จะเป็นไปได้ เพราะไม่มีคำตอบใดถูกหรือผิด เนื่องจากแต่ละท่านย่อมมีความต้องการแตกต่างกัน คำตอบที่ได้จะเป็นการสรุปออกมาในภาพรวม นำมาใช้วิเคราะห์ทางการศึกษาตามวัตถุประสงค์ที่กำหนดไว้เท่านั้น เมื่อผู้วิจัยอ่านข้อความให้ท่านฟังแล้ว โปรดพิจารณาว่าท่านมีความต้องการและเคยได้รับการตอบสนองความต้องการตรงกับข้อความนั้นหรือไม่และมากน้อยเพียงใด โดยผู้วิจัยจะเป็นผู้ทำเครื่องหมาย (/) ลงในช่องที่ตรงกับความต้องการและการได้รับการตอบสนองความต้องการของท่าน

**2. ระดับความต้องการและการได้รับการตอบสนองความต้องการของบิดาหรือมารดา มีดังนี้**

**ระดับความต้องการ แบ่งเป็น 5 ระดับ ดังนี้**

| | | |
|---|---|---|
| มีความต้องการมากที่สุด | หมายถึง | บิดาหรือมารดามีความคิดเห็นว่าข้อความนั้นตรงกับที่ตนเองต้องการมากที่สุด |
| มีความต้องการมาก | หมายถึง | บิดาหรือมารดามีความคิดเห็นว่าข้อความนั้นตรงกับที่ตนเองต้องการมาก |
| มีความต้องการปานกลาง | หมายถึง | บิดาหรือมารดามีความคิดเห็นว่าข้อความนั้นตรงกับที่ตนเอง ต้องการปานกลาง |
| มีความต้องการเล็กน้อย | หมายถึง | บิดาหรือมารดามีความคิดเห็นว่าข้อความนั้นตรงกับที่ตนเอง ต้องการเป็นส่วนน้อย |

| | | |
|---|---|---|
| ไม่มีความต้องการ | หมายถึง | บิดาหรือมารดามีความคิดเห็นว่าข้อความนั้นไม่ตรงกับที่ตนเองต้องการ |

3. **การได้รับการตอบสนองความต้องการ** แบ่งออกเป็น 2 ระดับ ได้แก่

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|---|---|---|
| ได้รับ | หมายถึง | บิดาหรือมารดาเคยได้รับคำแนะนำให้ปฏิบัติหรือได้รับความช่วยเหลือตรงตามข้อความนั้น |
| ไม่ได้รับ | หมายถึง | บิดาหรือมารดาไม่เคยได้รับคำแนะนำให้ปฏิบัติหรือไม่เคยได้รับความช่วยเหลือตรงตามข้อความนั้น |

| ข้อ | ข้อมูลที่บิดา-มารดาต้องการ | ระดับความต้องการ | | | | | การได้รับการตอบสนองความต้องการ | |
|---|---|---|---|---|---|---|---|---|
| | | มากที่สุด | มาก | ปานกลาง | เล็กน้อย | ไม่ต้องการ | เคยได้รับ | ไม่เคยได้รับ |
| | **1. ด้านข้อมูลในการดูแลบุตร** | | | | | | | |
| 1 | ความรุนแรงของโรคหัวใจของบุตร | | | | | | | |
| 2 | การรักษาที่บุตรควรจะได้รับ | | | | | | | |
| 3 | ความรู้เกี่ยวกับยาโรคหัวใจและคำแนะนำในการให้ยาบุตร ( ขนาด เวลา และวิธีการให้ยา) | | | | | | | |
| 4 | คำแนะนำเกี่ยวกับอาหารสำหรับบุตรโรคหัวใจพิการแต่กำเนิด | | | | | | | |
| 5 | คำแนะนำเกี่ยวกับการดูแลให้บุตรได้รับน้ำดื่มในปริมาณที่เหมาะสมกับภาวะของโรค | | | | | | | |
| 6 | คำแนะนำเกี่ยวกับการดูแลเรื่องการพักผ่อนนอนหลับของบุตร | | | | | | | |
| 7 | คำแนะนำเกี่ยวกับการออกกำลังกายที่เหมาะสมของบุตร | | | | | | | |
| 8 | คำแนะนำเกี่ยวกับการทำกิจวัตรประจำวันของบุตร | | | | | | | |
| 9 | การทำความสะอาดฟัน ช่องปากและคำแนะนำเกี่ยวกับการพาบุตรไปพบทันต-แพทย์ | | | | | | | |
| 10 | การป้องกันการติดเชื้อในช่องปากและฟัน | | | | | | | |
| 11 | การดูแลเรื่องการขับถ่ายปัสสาวะและการขับถ่ายอุจจาระ | | | | | | | |
| … | | | | | | | | |
| 43 | ..........................................<br>.. | | | | | | | |

# BIOGRAPHY

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| NAME | MISS JARUWAN SAWANGSRI |
| DATE OF BIRTH | 17 APIRL, 1973 |
| PLACE OF BIRTH | SURHANBURI PROVINCE, THAILAND |
| INSTITUTIONS ATTENDEND | 1992-1996 THE DEGREE OF DIPLOMA OF NURSING PRAPOKKLAO COLLAGE OF NURSING<br>1998-2001 MASTER DEGREE OF NURSING SCIENCE (MATERNAL AND CHILD NURSING) |
| RESEARCH GRANT | SUPPORTED BY PRINCESS MUNDHAROBH KAMALASNA FOUNDATION |
| POSITION & OFFICE | 1996- PRESENT: PEDIATRIC NURSING DEPARTMENT SRITHUNYA COLLAGE OF NURSING |