CHAPTER 4

FINDINGS AND DISCUSSION

The purpose of this chapter is to present the empirical grounding of the main research findings concerning families' practices in caring for children with CHD aged 0-3 years prior to cardiac surgery in Bangkok, Thailand. The chapter is organized into four parts as follow:

Part 1: A summary description of family context, including demographic data of the eight children and 14 key informants of eight families, and the information of hospital settings and family home settings in relation to the practices of families is presented. In addition, portraits of eight families are described, in order to provide better understand the practices of families in caring for their child within the family context.

Part 2: Perceptions of families regarding the child's illness and treatments, and discussion.

Part 3: Practices of families in caring for children with CHD aged 0-3 years prior to cardiac surgery, and discussion.

Part 1: Family Context in Caring for Children with CHD

1.1 Demographic Data and General Information of the Children in this Study

This study included an equal number of male (50 %, n=4) and female children (50 %, n=4). Children's ages ranged from three months to one year and five months old. Most of the children were infants (75%, n=6). All were Buddhist, and approximately 37% were only children. The children were diagnosed with acyanotic CHD (50 %, n=4) and cyanotic CHD (50%, n=4). At the first contact, two children with cyanotic type had received palliative surgery and waited for corrective surgery, while other six had not yet had surgery. Waiting time for the first surgery ranged from one month to 11 months depended on the children's heart defect, health condition, and weight. Prior to cardiac surgery, six of eight children (75 %) used to be admitted to the hospital due to pneumonia (50%, n=4), diarrhea (12.5%, n=1), and one child used to be hospitalized because of pneumonia and diarrhea (12.5%, n=1). Of these, more than half of the children (87.5%, n=7) relied on the universal health coverage in Thailand (the 30 baht scheme for medical cost coverage). Only one child had qualified for disabled status (spinal cord malformation). Demographic data and general information of the child's illness and treatments are presented in Table 1 and Appendix H.

Table 1

Demographic Data and General Information of the Children (n =8)

Characteristics	Number	Percentage
Sex		
Male	4	50.00
Female	4	50.00
Age		
Infant (0-12 months)	6	75.00
Toddlers (>1-3 year)	2	25.00
Range = 3 months-1.5 years		
Number of siblings		
0	3	37.50
1	2	25.00
2	1	12.50
3	1	12.50
Diagnosis		
Acyanotic CHD	4	50.00
Cyanotic CHD	4	50.00
Health care scheme		
30 baht policy	7	87.50
Disabled status	1	12.50

Table 1(*continued*)

Characteristics	Number	Percentage
Number of admission with complications		
0	2	25.00
1	3	37.50
2	2	25.00
3	1	12.50
Reasons of admissions with complications (n=6)		
Pneumonia	4	50.00
Diarrhea	1	25.00
Pneumonia and Diarrhea	1	25.00

1.2 Demographic Data and General Information of Key Informants

Fourteen key informants in eight families participated in this study. Seven families were recruited from the Hospital A and one family from the Hospital B. Demographic characteristics of the 14 key informants include information about sex, age, relationship with the child, religious, education, marital status, occupation, incomes, type of family, residence, and hometown. These demographic data and general information of the key informants are depicted in Tables 2 and Appendix I.

Table 2

The Demographic Data of the Key Informants (N=14)

Characteristics	Number	Percentage
Sex		
Male	4	28.58
Female	10	71.42
Age (yrs)		
Less than 20	1	7.14
21-30	4	28.58
31-40	8	57.16
41-50	-	-
51-60	-	-
61-70	1	7.14
Range = 18 to 63		
Relationship with a child		
Father	4	28.58
Mother	8	57.16
Grandmother (mother's side)	1	7.14
Maternal Aunt	1	7.14
Religious		
Buddhist	14	100.00

Table 2 (*continued*)

Characteristics	Number	Percentage
Marital status		
Married	13	92.86
Separated	1	7.14
Education		
No schooling	1	7.14
Primary school	7	50.00
Secondary school	4	28.58
High school	1	7.14
Vocational school	1	7.14
Occupation		
Unemployed	1	7.14
Employee	2	14.28
House-wife	3	21.44
Merchant	7	50.00
Taxi driver	1	7.14
Average Incomes (Baht/month)		
Less than 5,000	8	57.16
5,000-10,000	4	28.56
10,000-15,000	2	14.28

Table 2 (*continued*)

Characteristics	Number	Percentage
Type of Family		
Nuclear	8	57.14
Extended	6	42.86
Hometown		
Bangkok	4	28.58
Outside Bangkok	10	71.42

The majority of informants were female (71.42%, n=10, 8 mothers, one maternal grandmother, and one mother's younger sister). They ranged in aged from 18 to 63, with a mean of 32.7 years. Most of the parent caregivers were of early adult age (28 to 35 years old), except for one teen-age mother (18 years old) and one elderly relative (63 years old). All were Buddhist and 13 (92%) were married. While one informant was illiterate, most (n = 7, 50%) had completed primary school, (six years). Four of them had secondary school and one had completed vocational certification. One informant did not work (not a house-wife) and three were housewives. Of these four stay-at-home informants, all received income from either husbands or parents. Two informants worked as employees in a candy factory, while one worked as a taxi driver. Seven of them were merchants who sold goods such as fish or used products. Of these merchants, three had their own business such as making and selling candles or silver. Fifty-seven percent of the informants (n=8) noted that they did not have enough income for their living expenses, but received

some support from other family members or borrowed from friends, neighbors, or lenders. Eight key informants (57.14%) lived in nuclear families, whereas six (43%) lived within an extended family arrangement, which had six to eleven members in the household. Informants' residences were spread throughout Bangkok, meaning that their travel time to the hospital varied widely. Study informants came from various parts of Thailand. Ten of them came from countryside, while four were from the Bangkok area.

1.3 Hospital and Home Settings

Hospital Settings

Two university hospitals in Bangkok were the first choice for hospital settings in this study because of their specializing in CHD. They provide health care services emphasizing tertiary care. There are big pediatric cardiac centers providing both medical and surgical treatments for children with CHD. At the first university hospital (Hospital A), the researcher was not a stranger here because she had graduated and worked here for sixteen years before she came to be a lecturer at the Faculty of Nursing of this university. Therefore, the researcher was familiar with her study settings even though she had never worked in an OPD setting or in the cardio clinic before. For the second university hospital (Hospital B), although the researcher had never worked there, she had been there and was familiar with the setting.

The researcher came to meet seven families at Hospital A and one at Hospital B when the parents took their children to visit the pediatric cardiologist at the cardio clinic following a schedule. Sometimes they took the child to the hospital without

an appointment because the child had a fever or upper respiratory tract infection. The researcher usually came to meet them once they arrived at the OPD and accompanied them when the child met the physician, received medications and an appointment card. They then had lunch together, before the family returned back home. To help the readers understand how the children and families spent their lives during visiting the hospitals while waiting for surgery, the researcher will portray her clinical settings as follows.

Hospital A. Hospital A is one of the largest university hospitals in Thailand, so education, research, and services are the focuses of the hospital. It is located at the west side of Choapraya River opposite the Royal palace, one of the most important places in Thailand. The hospital area is a little small when compared to the service it provides: 2,368 beds and 6,000 walk-in patients per day (Informal data, Annual Statistic Report, Department of Pediatric, Hospital A, 2008). It provides health care services emphasizing tertiary care. In reality it provides care at all levels.

There are three major buildings that provide hospital services for pediatric patients. All pediatric OPD clinics are located on the first floor of the first buildings when they come from the main street. All children who first come to receive health service will get a hospital card at a room located on the left when they enter the main entrance of the building. Pediatric patients who have an appointment card need to submit the card at this room as well. Close to the hospital card room is a privilege checking room, where parents submit their documents before their child receive treatments or admission. In addition, the pediatric pharmacy, treatment, and physical examination rooms are located on the first floor close to the main entrance.

When passing the hospital card room and continue straight, parents will meet the pediatric cardio clinic located on the right, close to another entrance of this building. In the cardio clinic, there are ten physical exam rooms serving three cardiologists, two fellows, and five pediatricians. Every Tuesday morning there are 60-80 children with cardiovascular problems. The children and their parents spend four to five hours including submitting the hospital card, meeting with a pediatric cardiologist, and receiving medications and an appointment card for the future visits.

As for the children who need further cardiac investigation including cardiac echocardiogram and/or catheterization, they will be sent to get an appointment card at the cardiac center, which is located in the other building opposite the pediatric building. Rooms for echocardiograms and cardiac catheterization are on the second floor and fourth floor of the building, respectively. After receiving those investigations, the cardiologists and surgeon will have a consideration together in order to plan for the child's further treatment. The parents will come to see the doctors to get the results. If the child needs for surgery, parents have to take the child to see a cardiac surgeon at a clinic of cardiovascular- thoracic (CVT) surgery located in the next building.

Hospital B. Hospital B is was another obvious choice for the researcher's study setting, as it is one of the best hospitals in Thailand specializing in CHD treatment. It is located at the center of Bangkok, opposite the current King's palace. There are four major buildings that provide hospital services: orthopedic building, emergency building, main hospital, and the medical center building. Most OPD clinics are located on the first and second floors of the main nine-story building including a pediatric cardio clinic and a clinic of cardiovascular-thoracic (CVT) surgery.

Pediatric wards and intensive units are also in the main hospital building. The pediatric cardio unit is located on the 8th floor of the building. In the unit, there is an echocardiography room providing service every Tuesday morning.

When people enter the main entrance of the main building, they will see the hospital reception, an area for getting hospital cards, a privilege checking room, the hospital pharmacy, a small park and a small coffee shop. If they go further inside, turning to the left, they will see the OPD surgery including a CVT clinic. Close to the park is a stair to the second floor. On the second floor, a pediatric cardio clinic is on the left, holding clinic on every Monday afternoon. X-ray service is also located on the second floor.

At the pediatric OPD of both Hospitals, the spaces are big, more than 10 physical exam rooms, but the clinic spaces (3× 3 meter for one room) are the limiting factor for the number of people allowed in each room. Each examination room has one office table for a doctor and one physical exam bed. The space is so limited that there is only one seat for a parent to sit.

Hospitals' systems and processes. When parents come to the hospitals, they usually do not have a difficult time finding the main service locations. However, hospital services are another story and much more complex than those locations. After submitting an appointment card at a room of hospital card, pediatric patients will be weighed on the digital weight machine. The parents are interviewed by a nurse before being distributed to each clinic. Children and parent's privileged documents will be checked. Then the children with cardiovascular problems are sent to the cardio clinic. While waiting in front of the clinic, the children's blood pressure and oxygen saturation are taken by a practical nurse. After seeing a cardiologist, the parents

and their child go to see a nurse for suggestions, following up, and making appointments. The nurse will send the parents to get medicines at a pharmacy room. The children and parents spend four to five hours at the OPD. Nearly all parents in this study have all of their expenses covered under the 30 baht-scheme. They have to pay some for the medicines, which are not included under this scheme. Parents who do not have money need to tell a doctor or nurse to write a hospital welfare card, for the parents to be interviewed, and get financial support from the hospitals. However, hospital welfare has its own policy.

For children who need to be investigated with an echocardiogram, the parents must submit the appointment card at the counter in front of the echocardiogram room an hour before the appointment, as the child will be fed with some sedative medicine before the investigation. The children and their parents spend three to four hours here. Children who need cardiac catheterization would be admitted to the hospital for three days, one day before and two days after the investigation. After those investigations, the cardiologists and surgeon will have a meeting together in order to plan the child's further treatments. One week later, the parents come back to see a cardiologist at the cardio clinic to receive the final consideration of the meeting. If the child is considered to receive cardiac surgery, the parents will get an appointment card for CVT-surgery clinic, and then take the child to see the surgeon a week later. After seeing the surgeon, most parents will get a date on which they had to take the child to the hospital for surgery. At Hospital A, some parents do not get an appointed date, and have to wait for a phone call from an officer of the CVT surgery clinic. Sometimes the day for surgery will be another month or two away, perhaps even three

or more. According to the interviews, this uncertain period is a difficult time for the parents.

Based on the researcher's interviews and observation, parents who came to OPDs and CVT surgery clinics of Hospital A and Hospital B did not receive health education regarding caring for the child while waiting for surgery, neither from nurses nor from a health education program via a television of hospitals. According to key informants' information, nurses usually inform them about the children's following up schedule. The information regarding preparing the child for surgery, however, was described by an officer of the CVT-surgery clinics. It appears that a pharmacist explained the parents about dosage of medications rather than about side effects or which symptoms should be observed after taking medications. Parents did not have a chance to talk with a nurse about their child's care, particularly the practices of care for the child prior to surgery. Conversely, parents whose children were admitted in the hospital due to complications or cardiac catheterization would receive health information regarding the child's care provided by a nurse in the pediatric wards.

Home settings

The researcher spent thirteen months, several times a week, visiting eight families. Families lived in various parts of Bangkok, in seven Bangkok districts, including Bangkok Noi, Bangkok Yai, Pasrichareon, Thonburi, Sai Mai, Prakanong, and Huay Khwang. It took one to three hours to travel from each informant's home to the hospital by public transportation, but only 30 minutes to two hours if going by taxi.

As all families were living in Bangkok, the capital of the country, there were many main roads between the hospitals and those eight families' homes. Some of these roads were small local roads, made of concrete, which cars, mini buses, and motorcycles could run through. Many times the researcher employed a motorcycle to take her to the families' homes. Sometimes the researcher took a mini bus and then walked to the houses. Their residence spread throughout Bangkok, meaning that travel time from the researcher's home to each informant's home varied widely, range from two hours to three hours by public transportation.

Among eight families, six resided in rental rooms, apartments, commercial buildings, or homes located in areas that had a lot of houses. Only one family lived in a slum area, crowded and surrounded by garbage and used things, whereas one family had their own house built on the land of the Bangkok Metropolitan Association. All of the families' homes were mostly surrounded by other houses, commercial buildings, dormitories, department stores, or convenience stores, and schools. Buddhist temples and health service stations such as government health service stations, clinics, and hospitals were also found nearby.

The houses of the families in this study were not modern. Rental houses were made of wood, concrete, or both, with a difference in size varying from 15 to 60 square meters. The family's accommodations were single rental rooms, single houses, row houses, commercial houses with single or double floors, and no fences. Only one house had a space surrounding the house that was covered with small trees and also was used for multiple purposes such as washing and bathing the child. Regarding the environment in the houses, most families could not divide for bedrooms, rest rooms, and a kitchen due to limited space. Nevertheless, there was

good ventilation in the houses. Among eight families, only one had separated kitchens and bed rooms. One family was an exception because its home was of a commercial building style composed of three floors, with the first floor used for working. None of the families had beds in their house; rather, they used mattresses for sleeping.

Additionally, every family had public utilities, both water and electricity. Each family also had appliances depending on the economic status of each one. Most families had at least one type of appliance, such as a radio, television, refrigerator, or gas oven. Types, numbers, and quality of these appliances depended on the economic status of the family. However, washing machines, microwave ovens, personal computers, and so forth were not found. Only one family had a pick-up car, as the father used it to sell mackerel.

Furthermore, in every setting could be seen the shrine of the household god or spirit house, which was made of wood or concrete and located in any area inside the fence of the house. Family members believed that it was a house of god who protected everyone in the house from bad things and illness. As the result, they always worshiped at it with food, dessert, fruits, beverage, and flowers on the Buddhist holly days in order to show their respect. In addition to a shrine for a god, one family had a shrine for ancestors in the home. One member of this family said that it was a living place for the relations (e.g. the soul of grandmother or grandfather), who had passed away. Even though they had died, they still protected and took care of their children to live happily and safely. Every Buddhist holy day, family members gave some food, dessert, beverage, and flowers. Once a year, they also performed a special worship to their ancestors who had passed away. Two families

strictly performed this worship because of the belief that if they did not do it, sorrows might happen to the family members. For the other 12 families, they only mentioned about it, but they rarely performed this worship. In Chinese families' homes, there was a Chinese spirit house of red colour located on the floor inside the homes. Family members worshipped with food, fruits, dessert, flowers, and tea. In addition to the spirit house, there were images on the wall of our King Bhumibol, Queen Sirikit, and/or the Thai royal family, and also of parents, either still alive or passed away.

1.4 The Portrait of Each Family

The following part will present eight case studies to portray worldview of each family. The members of all families expressed the desire to open their names. However, the researcher assigns the pseudonyms to each member to make their story more readable and clarify relationships among family members. The researcher will offer a general description of who they were and where they lived before explaining their perceptions regarding the child's illness and treatment. Finally, the researcher will describe their daily practices relating to caring for the child with CHD.

Family 1 (Pim's Family)

There were four people in this family unit: Pim, father, mother, and one elder sister. The researcher first met Pim when her parents took her to see the doctor following up as schedule at a pediatric cardio clinic, Hospital A. Pim was an eleven month-old girl. She was a healthy newborn, 3,395 grams at birth and grew up very

well. When Pim was five months old, mother found that Pim had strong and rapid heart beats, looked sick, pale, and was smaller comparing with other children. Mother then took Pim to a private clinic, and the doctor informed that Pim might have heart disease and suggested the mother to take Pim to the hospital for further investigation. After taking Pim to see doctor at Hospital A, the parents were told that Pim had CHD, and took oral medications. When she was nine months old, Pim was admitted to the hospital due to pneumonia and congestive heart failure. During her first admission, Pim had an echocardiogram, and physicians found that Pim had patent ductus arteriosus (PDA), which could be cured by a surgery.

Pim's parents were workers with primary school education. Their hometown was in the north-east region. They worked at the snack factory 6 days a week and got 190-300 baht per day for their wages. Even though parents usually worked part-time, their wages were not enough for the family expense. Especially, the mother's income was diminished during Pim's sickness because she often stopped working to taking care of Pim. Father lost some money with drinking and sometimes betted on football up to 5,000 baht a month. They had a money problem even though the government paid for the child's treatments (healthcare scheme). As a result, mother borrowed some money from her younger sister staying in the same renting house, and also from other coworkers.

Mother took over not only Pim's daily and specialized care, but also all household chores in the family. Father sometimes helped mother take some household chores and occasionally played or went for walks with Pim. However, he never provided daily care or specialized care to Pim. He sometimes accompanied the mother to take Pim to the hospital, but he never went inside to see the doctor. Mother

also received some help from her elder daughter, who often took care of Pim when mother did housework or came back home late. In addition, Pim's maternal aunt living in the same renting house, helped mother taking care of Pim. The aunt also gave mother for financial and emotional support. Regarding working 8-10 hours/day, mother needed to take Pim to a daycare house during daytime. When mother finished her work at the factory, she picked up Pim and went back home, that was usually around 8 p.m.

Pim's family stayed at a rental house located in a small community, 200 meters from the main street. It took about 40 minutes from the house to the hospital by taxi (if there was no traffic jam). This place seemed to support poor people as seen from old wooden houses with various styles and the rent was cheap. The rental house that Pim's family had stayed more than ten years had two floors including eight rooms and two shared wash rooms. Pim and her family had been living in the duplex rooms, at the first floor of the house. Each room had the same size, 4* 5 meters, one door and two windows per room, which was clean and tidy consisting of mattresses, blankets, clothing, a television, a refrigerator, an electric fan and other stuffed food. There were many family pictures on the wall and also contained a sacred place for Buddha images shelf, Buddha and the monks' pictures. In addition, there was a shelf of an old ascetic or "*Por Gae*" (พ่อ, *Por* in Thai or the term used for the one who was a reverent male, แก่, *Gae* was used for aging person), was the father's faithful person.

When mother was first told about Pim's heart disease, she was sad, shock, and puzzle. For mother, heart disease was very harmful and too severe to be cured, especially it occurred in her young baby, and her daughter might die even she was

young. Pim's mother was in a trouble period before knowing that Pim's CHD could be cures by surgery. According to a physician's explanation, Pim's heart disease was caused by unknown. However, mother understood that it might be caused by her own previous karma, and tried to accept it, thinking that it was inevitable. She also thought that the additional vessel of PDA was caused by her eating more food and milk during pregnancy.

Prior to cardiac surgery, mother tried to do everything to help Pim be ready for surgery. She asked for blessing from sacred Buddha images at different places, making a merit, giving her respect to guardian spirit houses or passed temples and sacred places. Mother also practiced many traditional beliefs following recommendation of her own mother and other neighbors. For example, mother symbolically gave Pim to "*Yai*," (ยาย, a female elderly, who was a daycare owner), believing that her child would be healthier when she was given to the one who had taken good care of other children and the children were healthy. Pim also was symbolically given to "*Loung Por Kaesorn*", (หลวงพ่อเกษร, a Buddha image in Wat Tha Pra), to protect Pim from the bad things, to help her be easy to care for, and to make her have a better health.

Following the doctors' recommendation, mother tried to put on Pim's weight and avoid her child catching colds. She fed Pim many kinds of food that the mother believed it was nutritious, especially special powder milk following neighbors' advice. When doctors advised mother to put on Pim's weight to prepare the child for heart surgery, she went back home early, not work part- time, in order to cook and feed her child. She tried to care her daughter more vigilant, observing abnormal signs

and symptoms, keeping her warm, and not to bathe her in cool water. Also, she did not take her to a department store or crowded place such as a market, and did not allow people having URIs to contact her child. However, it was difficult to tell the owner of the day care center to separate her child from other ill children. Even though Pim was provided care attentively, she still had a cold every month. The mother took her to the clinic nearby if she did not get back to health. She also took Pim to get vaccinations at the clinic nearby according the schedule.

In addition, Pim's mother rigorously gave Pim all the medicines given by the doctors hoping that they could help her child's heart malfunction and enhance the ability of the heart. Following doctor's prescription, Pim should be fed one fourth of a Captopril pill mixed with 3 c.c. of water and required 1.8 c.c. But mother gave her a wrong dose of medicines because of her perceptions. Mother thought Pim could be much better from taking more medicine as it could help her heart, so, she used a syringe sucked all powdered medicine and then sucked water to the level of 1.8 c.c. without dissolving or disintegrating the drug before sucking leading an overdose of medicine. Mother and father had a confidence of the doctors' consideration related to Pim's surgical treatment and never had a thought to find other treatments or to change the hospital. Mother said that she was satisfied with Pim's treatments because Pim was better after taking oral medications. However, she mentioned that she did not receive much advice and basic child care from nurses.

Pim's family would like to go to make a merit at the temple. The parents believed in the previous karma and were a good Buddhist. They enjoyed good relationships in the family. Even though the parents did not often talk to each other as the father was quiet, they did not have argument. Pim's mother accepted that she

preferred to keep quiet when she was unhappy rather than expressing with others. However, she talked with her husband and sister. The family felt happier after Pim underwent the surgery when she was 19 months, or 13 months after her first diagnosed with PDA. After surgery, Pim was healthy, gained more weight, and especially talked and walked more than before.

Family 2: Nai's family

This family included three people: Nai, his father and mother. Nai, a three-month-old boy, was an only child and the first nephew in the mother's family. The researcher first met Nai and his parents while he was being admitted due to pneumonia at the pediatric ward of Hospital A. Nai was good-humored and appeared to be healthy like other boys. He was diagnosed with TOF, a cyanotic heart disease, at birth, and was first operated (Blalock-Tausig shunt) when he was two weeks of age. After the first operation, he had taken medicines to control heart symptoms. However, he needed one more operation to correct the last defect when he grew enough, probably at around two years old.

Nai's mother was a teenage mother, an 18-year-old housewife with a secondary school education (grade 9) who lived in Bangkok. Nai's father was 28 years old with a primary school education. He was a taxi driver and earned between 300-500 baht a day. Father did not drink and smoke, always smiled, and did not speak much. For the mother, the father was a good husband. He helped her provide Nai's daily care and gave suggestions for care, and did all household chores. When he was back from working, he usually took Nai for a walk and fed him. He

sometimes accompanied the mother on Nai's hospital visit. Even though he never participated with the doctors, he helped the mother to take care of Nai and let her go to contact officers about documents or others. When Nai was admitted to the hospital and the mother stayed overnight with him, the father would come in the daytime to help the mother care for Nai and let her take a rest. The parents did not have a money problem as they were supported by Nai's maternal grandmother, a 50-year-old ice distributor. She provided majority of financial and mental support to Nai's family. She lived with her family in duplex building next to Nai's parents. Nai's duplex was located in a small community, 200 meters from the main street, and it took only 20 minutes to drive to the hospital.

When parents first knew that their son had a heart disease, they were sad, shock, afraid, frightened, and disappointed. However, the doctors told parents that TOF could be cured by two operations, which made them feel better and gave them hope that their son would be healthier after undergoing surgery. Even though the doctors could not find the actual causes of heart disease, parents felt sure the causes might be related to mother activities during pregnancy, particularly eating certain food such as barbecued or grilled pork as well as drink lots of Pepsi. They also believed it was also their son's fate. Particularly, it was caused by mother's previous karma. Therefore, mother tended to blame herself, and tried to provide best care for the child.

Prior to the second operation, the doctor advised parents to put on the child's weight and to avoid him catching colds too often. To help the child gain weight, mother tried to feed the child as much as possible with her breast milk. Mother also fed him many kinds of nutritious food. The food menu was changed every three or four days. The mother started feeding him solid food such as glutinous rice with fried

pork when he was one year old because she found that Nai preferred to eat them rather than rice porridge. However, she pre-chewed it before feeding him. In addition, mother fed him noodles, cereal, and many different kinds of milk to strengthen him. However, he still ate little food. His mother was worried about his low weight, and slow weight gain.

To avoid getting common cold and other illnesses, mother tried to keep Nai warm, and not to bathe him in cool water. If he had a fever, coughed, or had a runny nose, his mother would give him some medicine to relieve the symptoms. She also took him to the hospital if he did not get back to health. She never gave him any kind of medicine without a doctor's advice. Sometimes, she gave him Chinese or Thai herbs when her baby got cold or diarrhea following a neighbor's suggestion. Mother concerned about the son's cleaning because of his low immunity, so she separated his belongings from the others. She took him to get vaccinations according to the schedule. In addition, mother avoided activities that would make her child tired or "green." She was afraid he might suddenly lose consciousness. She did not stimulate him to crawl, but instead tried to prevent him. She thought he might become so tired that he would stop breathing, or his heart would stop working. She rigorously gave the child all the medicines from the doctor to control his heart working.

Mother accepted that caring for her child with heart disease was quite difficult; especially he was restless, and difficult to sleep. When she found that Nai was difficult to sleep, father's mother brought one traditional practice, *Pithi Jum Jae* (พิธีจั้ำแจ้, Jum Jae ritual, one of traditional rituals of the Northeast region, using warm

glutinous rice to put around the child's body while praying the incantation hope to help the child have a nice sleep and easy to care for).

Nai's family enjoyed good relationships. The parents often talk to each other, and his father was a good counselor. Parents said that they helped ease themselves by *Tham Jai* (ทำใจ, make up one mind to accept whatever happened) about Nai's CHD. Everyone in the family was a good Buddhist and believed in past lives. They sometimes took Nai to give food to monks and made merit at a temple not far from their house. Father liked to pray before going to bed and made a wish for his child's good health and safety. Nai's family enjoyed good relationships. Nai was performed a corrective surgery when he was two years old. Unfortunately, the child passed away within 24 hours after the surgery. That made all in family as well as the researcher sad.

Family 3: Jing's family

Jing was a girl in a big Chinese family of 11 persons. They were Jing, her mother, grandmother, grandfather, three uncles, and grandfather's brother. The researcher first met Jing when she was admitted to Hospital A in case of CHF with pneumonia. She was 17 months but her weight was only 6,100 grams, small, thin and still suckled her mother's milk. Jing had delayed motor and speech development, she could not stand and speak. She was often annoyed, always cried and did not make eye contact when someone tried to talk to her. Mother reveled that Jing was a healthy newborn, 3,140 grams at birth. During the first two months, Jing often caught a cold. When she was four months old, she was often sick and took longer time to recover

from it. Mother and grandmother noticed that Jing's heart beating so hard that could be easily seen. She also began losing weight and did not suck breast milk, so mother took her to Hospital A and knew that Jing had a heart disease Jing was diagnosed having VSD since she was six months, and had taken oral medicines continuously. Nearly every month Jing had respiratory tract infection, particularly pharyngitis, which made her ate little and did not gain weight. Jing had a heart operation when she was one year five months, or 11 months after having been the first diagnosed.

Jing's family, a big Chinese family, lived at the commercial old building next to her grandmother which she had rent more than ten years. Most people living around there were large crowd of Chinese. Jing's renting building was about 200 metres from main road, one hour from the hospital by bus. The old building was two storeys with iron gates, which the front part was three meters wide. There was a little space for the path from the front door to the back of the house. In the house, there were many things lying untidily everywhere such as a rice cooker, household utensils, a TV, a telephone and so many things. In addition, in front of the house was used as cooking area. There was a small wooden bed for Jing to do her daily activity, playing, eating, and sleeping etc. Inside the house there were two Chinese shrines. At the back, there was an old, narrow toilet, which did not look so clean. However, it was a place for Jing's bath tub.

Jing's mother was 31 years old with a professional certificate of accountant education. She was separated from Pim's father since she had a pregnancy and never got any support from her husband. Whenever she took Jing to the hospital, she would go by herself. As she did not work, she faced financial problems. She got money from her mother. Jing's grandmother was another person who helped and gave her

some money. Grandmother was a 63-Chinese woman who could neither write nor read Thai or Chinese language. She could speak Thai but not clearly. She had five sons and one daughter. Grandmother had made and sold paper and red candles for respecting Chinese god. She also sold soft drinks at their house and earned for living 5,000 – 6,000 baht a month. She got money from her sons for 7,000 baht a month. However, it was not enough because she had to pay for the expense of everyone in the house including Jing and her mother's, and other two sons and two nieces, who did not work. Each day she did the housework and prepared food for the family, and also took care of Jing, such as feeding and taking her for a walk. Jing's mother spent most time taking care of Jing, and did not help the grandma do any housework. Mother said she did not help her mother because Jing drank her breast milk nearly every hour. As Jing could not walk by herself, mother had to hold her together every where which tired her and her back ached. She felt depressed she could not care for Jing better because of money and residence's problem. In addition, she felt stressed to be her mother's burden. Mother said the relationship among the family members was not so good because it was a big Chinese family. There were not much consultation and encouragement. However, mother and grandmother usually talked together even if mother thought her mother could not understand her problems. Everyone in the family always spoke with lay terms, impolite words; however, the mother said was used to doing this since she was born although she knew it was not good for her child.

Mother recounted that once the family knew Jing's diagnosis and treatment plan, they were shocked and worried. They perceived heart disease was a dangerous disease as it was incurable; especially it was too severe for young children. When the doctor explained them about the cause of Jing's heart disease that was unknown,

mother thought it was because of her taking medicines for abdominal pains and migraine during pregnancy. She also believed that Jing's father did wrong after asking for the daughter from one Buddha image in a temple, but did not tell him after she was pregnant, so her family was punished having the child with heat disease. She also thought it was her bad doing in the past life and impolitely speaking to her parents in the present life which made her daughter get heart defect.

During the medical cure mother and grandmother tried to help Jing to be healthy and safe by practicing many traditional beliefs as suggested by neighbors and friend. They went to the fortuneteller, symbolically offered Jing to *Kum In Goddess* (เจ้าแม่กวนอิม, one of Chinese female Gods). In addition, her uncle changed Jing's name as well as grandmother took her to pay respect at the shrine in the house and "*Mae Sue* " (แม่ซื้อ, a spirit supposed to take care of babies until they grew up).

Prior to cardiac surgery, the doctor advised Jing to gain more weight that was quite difficult for mother. Mother told Jing ate little food and her weight did not increase since she was six months old, stopping at six kilograms. For mother, it was impossible to increase her weight to eight kilograms before an operation. Furthermore, mother was advised not to feed her salty food, but she could not stop it because Jing could eat food when she ate with the adults in the family who did not avoid salty food. If mother forbade her, Jing would cry so hard that grandmother and the others fed her because they were afraid she would be tired from crying. They therefore still continued feeding her the same kind of food such as snack, seaweed, crisp, rice with salted fish or salted egg receiving that eating some salty food was better than not eating food.

Doctors also advised Jing to avoid catching cold because the operation would be postponed. Mother recognized the doctor's description about the abnormal of blood circulation, which caused too much blood going to lungs, and as a result was susceptible to have pneumonia. She compared the heart's leakage with a hole in the roof, which dropped on the pillow and wetted it all the time, the way to dry the pillow was to close the hole which referred to the operation. So, mother tried to keep warm her child. At night Jing wore long sleeved blouse, in the cool day her mother bathed her with warm water but did not let her soak and choke to avoid having pneumonia. She also prevented Jing from being directly fanned. Although mother tried to take care of her, Jing could be sick easily, she had respiratory tract infection, "*Khor Ukseb*" (คออักเสบ, Pharyngitis) nearly every month. Mother usually took Jing to have a vaccination as appointed.

After being diagnosed as having heart disease, Jing took some medications including E. Lanoxin, Captopril, and Lasix. Her mother gave her all kinds of medicines but not punctually because Jing sometimes got up late, the time for medicine had to be postponed. Some pills had to be divided into four parts, one fourth was mixed with water as limited, but mother broke the pill as small as she could, thinking it was the same amount as the mixed medicine which might be precipitated. Jing had rather slow development, especially gross motor development. She sometimes tried to stand up but could not crawl. Her mother understood that it was her sickness which slowed her development including to speaking; therefore, did not force her. All day long Jing played her toys and watched TV on a small table. While she was watching TV and hearing the song, she patted her mother's arm for her

singing as she could not speak. She could understand and do as told but her spoken words had no meanings.

Jing had the first heart operation when she was one year and eight months of age, or fourteen months after having been the first diagnosed. After the operation, she was healthy, and her mother was going to find a job to earn her own living and helped grandmother. Jing had well motor developed; she could walk and run so quickly that her mother had to follow to prevent the accident. She was more good-humored and could speak more meaning words. The doctor advised mother and the family to adapt how to care for her, not to argue, which was the cause of Jing's scream when she did not get what she wanted. Mother continuously took Jing to the speech stimulation unit and got some nutrition advice which was rather difficult to do.

Family 4: Fah's family

There are four persons in Fah's family: her father, mother, elder sister and Fah. She was a premature baby, weighing only 1,390 kilograms when she born, which made her smaller than real age. She had been diagnosed as having heart disease at birth, at a hospital closed to the house, and kept on taking medicine. Fah was transferred to Hospital A for reinvestigating, and her diagnosis was large PDA and small multiple VSDs. The researcher first met Fah at Hospital A when she was admitted for cardiac catheterization. She was 13 months, and weighed only 4,230 kilograms. After the first cardiac catheterization, the doctors gave her one more cardiac catheterization to balloon occlude the PDA but it did not work. Fah then had the first operation, but it was not effective because of wrong diagnosis. She did not

have large PDA, but an AP window with multiple VSDs, so she had an immediate operation when she was 1 year 8 months, or 14months after she was diagnosed with PDA.

Fah's family had lived in "*Choom Chon Platoo*" (ชุมชนปลาทู, a community in which people were mackerel traders) for more than six years. This community was not big, five kilometers from the main road to the community. It took about one hour from the house to Hospital A by car if there was no traffic jam. In this community each house was built by the owner himself, on the land provided by the Bangkok Metropolitan Administration. The owner paid the rent 50 baht per month. The conditions were generally clean and well ventilated. Most people living here were Fah's father's relatives. Fah's house had two storeys—half wooden, half cement—with 30 square metres. It had a high ceiling, was clean and well ventilated. In the house, everything was put away neatly, including Fah's belongings, medicines, and toys.

Fah's parents were mackerel traders. Father was 35, and finished his education at Pratom six (primary school). He was the person who earned for the family. Every day Fah's father got up at two a.m., prepared mackerels, sold them at different market fairs and came back home at noon. He could make about 1,000 baht a day. The earning from selling mackerels was enough for spending in the family, not for keeping. Father usually helped mother look after Fah and her elder sister. He could do everything excepting bathing the children because he was afraid they would not be cleaned well enough. Fah's mother was a 37-year-old housewife who finished her education at Matayom six (secondary school). On weekends, she helped her

husband sell mackerels at Jatujak market. Every day she looked after the family members and did her housework. Fah's sister was six years old, studying at kindergarten in a private school near her house. She had good health and could study well. His father took her to and from school. When she came back home, she liked playing with Fah and gave her some sweets, then she did her homework. Fah's parents looked after both their children very well. Their father sometimes took them for a walk so that their mother had time to do housework.

Fah's family received much support from maternal grandmother. She traveled to and fro between Bangkok and Udon Thani, a province in the northeastern, because she had to look after her husband who had a heart disease. She always helped mother and gave her many useful advices about children's care. She still had good health, could take care of Fah: bathing, feeding, taking her for a stroll and giving her some medicine. Grandmother also liked sewing. She sewed many things such as clothes and sheets by adapting them from old clothing, which could reduce the expenses in the family. She assisted mother to do housework, cooked food and gave Fah some medicine. In addition, on weekends, mother's elder sister often visited her family and took care of Fah because mother went to sell mackerels with her father.

Parents recounted that Fah had been diagnosed as having congenital heart disease at birth, and kept on taking medicine. Doctor described that she had to get many operations, but they had to wait until she grew enough. The parents were neither afraid nor worried, but rather assured in the doctors' abilities. Besides being a premature baby, based on parents' understanding, the causes of Fah's heart disease were: mother had small amniotic fluid two weeks before giving birth, took medicine and did some traditional treatments during pregnancy. Mother also believed in her

wrongdoing in the past life. Mother recalled that she did not know when she was pregnant since her menstruation was not certain. After two months of pregnancy, she had a bad stomachache, so she took some medicine for gastritis to relieve it. She could not recover from that symptom then she went to the hospital. The doctor told she had a tumor, her father bought her Procaine penicillin to cure the tumor in uterus, her mother also heated a brick and laid it on her abdominal surface to abolish the tumor. After such treatment, she still had a bad stomachache, so she went to have another check and found that she was pregnant. Fah's parents thought these were the causes which affected the fetus to have a heart disease. However, they felt relieve after the doctors explained that their daughter could be entirely cured. They relied on the doctors and followed their advices solemnly. They never tried using herbs or other treatments.

While Fah was waiting for the operation, the doctors suggested her not having a cold or fever. The parents then did not take her out in the sunlight without an umbrella, and put on her hat to protect her from catching cold. On the cool days, mother bathed her daughter in warm water, dressed her with warm clothes and covered her with a blanket. Father told his wife not to give her any ice or ice cream; he thought it could cause her to catch cold or have pneumonia. When he himself or Fah's elder sister caught a cold, they would separate the beds. Parents also told their neighbours that Fah had a heart disease, had low immunity and could easily catch cold. Whenever Fah had a runny nose, her mother rubbed her nose with cold vapouring ointment, dropped some normal saline in her nose, or applied Eliadine got from hospital. When mother noticed she seemed to have a fever, she dried her body and gave her some medicine to reduce the symptoms. Fah sometimes had a sore in

her mouth together with the fever and some pimples on her body, and could not eat. Mother would apply her tongue with herbal medicine, fed and also bathed her with another kind of herbal medicine. If Fah still had high fever, could not eat or drink, or was drowsy, mother took her to the doctor.

About keeping clean, mother separated her utensils, and did not clean them with the others' following doctors' advice. Parents always kept themselves clean, particularly washing hands with soap, before touching their daughter. Apart from preventing Fah's having cold and diarrhea, another thing that the doctors advised her parents was trying to increase her weight. Mother gave her nutritious food such as boiled rice with various kinds of vegetables: carrot, pumpkin, ivy gourd, egg yolk, pork, chicken, and fish. She also gave her plain food, without salt, fish sauce or soy bean sauce as nurses' recommendation. Her mother fed her all kinds of medicines, knew their names and properties well but she did not know how to observe the following symptoms. If she had to go outside, she would prepare Fah's medicine in the syringes with directions and grandmother would give them to her. When Fah had an appointment with the doctor at the hospital, mother would prepare her food and all kinds of medicine in syringes. She also took the rest of medicine to the doctor and asked for some more before the next appointment. Parents perceived Fah had a rather slow walking development because she was a premature baby and had a heart disease. But she had a normal cognitive skill, intelligence and language development. When she had the second cardiac catheterization, her left arm and legs were weak and could not hold things, sit still, and try to stand by herself as before. But her parents did not worry about it, they thought the doctors could help her daughter efficiently because they had treated even the harder cases like a heart disease operation. The day before

Fah's operation, her parents took her and her sister to the temple to make merit and offer food to monks. When Fah was admitted to hospital, parents paid respects to the monument of the King's father and the statue of the King's brother, asking the sacredness to care for her safety.

There was a good relationship in Fah's family. Her parents were polite, always hug and kissed their children with love. Fah's parents said having a child with heart disease was not too burdensome for their daily lives. They gave time to the elder daughter in chatting, teaching her homework, and eating together. Mother was good humoured, easily laughs and always said that she was not serious about anything, even Fah's two operations. She accepted that her husband could help her a lot. When she was uneasy about something, she would consult with her husband as well as her mother. Sometimes they did not talk together, but they communicated with each other only by eye contact. Fah's father accepted that he was sometimes tired, but tried to work harder to earn enough money for his family.

At present, Fah's family felt happier after her operation, everything becomes better. She could gain more weight, ate more, and had no sign of tiredness while playing or laughing a lot. The most important thing was she was good humoured, did not cry very often, and was not much annoyed. The doctors reduced some kinds of her medicine and made her an appointment every three months. Fah gained 1.3 kilogrammes in 2 months. She had physical therapy for her weak arms and legs at Hospital A every Tuesday. Her weak muscles could develop better. She could speak more words. Now Fah could sit and stand by herself including being talkative too.

Family 5: New's family

New's family consists of five people: New, his father, mother, and two older sisters. New is a boy of eleven months old. The researcher first met New and the others in his family at their house while New was waiting for the first heart surgery. New is good-humored and appears to be healthy like other boys. He has been diagnosed with cyanotic heart disease since he was six months and had taken medicine before the operations. New was operated on two times—the first time when he was one year and two months old, the second time when he was one year and eleven months old. However, New needs one more operation to correct the last defect. He will be ready when he grows enough, probably at around five years old.

New's parents used to work on the farm in Lop Buri province, in a central region of Thailand, but they moved to Bangkok for more income. They have been living in this rental house for more than ten years. New's mother is a 33-year-old housewife with a primary school education. Formerly she sewed clothes and earned about 300 baht a day. She stopped working when she knew that her son had heart disease. She needed to take care of New by herself and dared not leave her son with others because she was concerned that New might become unconscious suddenly, or "*nock*," the mother's usual term to describe this condition whenever she told about New's illness. New's mother mostly took care of New and did all the housework. Mother said that she was easily worried and serious. Talking to neighbours made her feel better. New's father was a 37-years- motorcycle taxi driver, who earned between 500-1,000 baht a day. His earnings were enough for the family. He did not help the mother take care of New, or did housework as he went out to work early in the

morning and backed home late in the evening. Nevertheless, he usually played with New and other kids before bedtime and during the day when he came home for lunch and dinner. When New had an appointment with physicians at the hospital, the father never went with the mother because he had to work and thought that the mother was more efficient and could take care of New by herself.

New's aunt living in other Bangkok district sometimes came to visit New and bought him some toys. Also, she provided mental support to the mother when the mother consulted her about New's illness. Another of New's aunts, who lived in the country, brought up his 15-year-old eldest sister until she finished her middle school education and came back to live with the family again. At present, New's eldest sister was studying in a technical school, meaning her parents had more expenses for her educational fees. She helped her mother look after New and did the housework, which made her mother less tired and could sew clothes again. New's other elder sister was 8 years old. She usually played with New.

New's rental wooden house had two storeys. The space at the front was in good and comfortable condition. There were two bedrooms upstairs: one for New and his parents, another one for New's sisters. The rooms were furnished with electric fans, a refrigerator, a television and a video player. New's utensils and medicine were on the plastic shelf, separated from the others.' The house was about 200 metres from main road. It took 30 minutes to go to Hospital A by taxi if there is no traffic jam. New's father could ride New and his mother to the hospital in only 20 minutes, but the mother preferred to take a taxi, as she did not want New to receive air pollution from the traffic.

New was the only son and the first boy in both mother and father's family. At the moment that New was born, his mother said that the parents were happy as they were looking forward to having a son. When he was born, mother was told he breathed rapidly but neither the doctors nor nurses explained this unusual symptom. She herself noticed that New had what in Thai she called a "*Park Keuw*" or "green mouth" (ปากเขียว, the layman's term in English would likely be "blue baby," a baby who has low oxygen in the blood). She never thought this appearance was uncommon until New was six months of age and got two vaccinations at once. On that day he had excessive and long crying so that the green mouth could be easily seen. The nurse advised that he should be checked, so his mother took him to the pediatric clinic nearby. The pediatrician at the clinic transferred him to Hospital A, and New was checked elaborately, including getting an echocardiogram. At hospital A, the parents first knew that their son had a heart disease, which is a cyanotic type. They were frightened, shock, and disappointed. New's parents worried that the child might not survive as one of the father's friends had a child who died with heart disease. The doctor told his parents that this kind of heart disease could be cured by operation, which made them feel better and gave them hope that their son would be healthier after undergoing surgery. As the doctors could not find the actual causes of heart disease, New's parents felt sure it was not hereditary. There was no family history of heart attacks. They thought the causes might be related to New's mother using an electric sewing machine when she was pregnant. They also believed it was also their son's fate. New was "green" and easily tired. He often caught colds and

took long time to recover from them. He ate little, gained weight slowly, and had little motor development.

While New was waiting for the operation, the doctor advised him to avoid catching colds too often. For the mother, this was rather difficult to do because of the changeable weather. Particularly it was inevitable when the mother who breastfed the child had a cold. In addition, mother explained that it was impossible to stay in the house in a whole day. She liked her child playing with other children and thought that helped him have good mood. However, mother avoided activities that would make him tired or had more green. She was afraid he might suddenly lose consciousness. She did not stimulate him to walk, but instead tried to prevent him from having an accident. She thought he might become so frightened that he would stop breathing, or his heart would stop working. She often listened at New's chest to his heart beating. When she heard the loud noise of his heartbeat, she would stop his playing immediately.

To prevent the child from catching cold or other illnesses, mother tried to keep the child warm, and not to bathe him in cool water. If New had a fever, coughed, or had a runny nose, his mother would give him some medicine to relieve the symptoms. She usually took him to the clinic nearby if he did not get back to health as well as took him to get vaccinations according to the schedule. She never gave him any kind of medicine without a doctor's advice. However, mother gave New Chinese herbal soup getting from a Chinese temple, and ginseng believing that it could help the child eat more and be healthy following a neighbor's suggestion. In addition, mother fed him many kinds of nutritious food and vitamins so that New could gain weight and be

healthy enough for the operation. Mother said that her son needed special cleaning because of his low immunity, so she separated his belongings from the others.

After New was first operated on, he was less tired and less green, but he still ate little food. His mother was still worried about his low weight, and slow weight gain, so she gave him many kinds of nutrient food. She rigorously gave New all the medicines from the doctor to control his heart working. Six months after the first operation, New's heart was ballooned to broaden the blood vessel to the right lung, but the procedure did not work and he had another operation. After the second operation he was healthier, scarcely caught colds, ate more food, and had improved motor development.

New's family enjoys good relationships. The parents did not often talk to each other, and his father was quiet, but he liked to play with New and other kids throughout the day at home. His mother often took him to the neighbours' for a chat to relax. When New was in good health and his elder sister could take care of him, his mother increased the family income by selling things such as juice, snack, or dessert, and sewing clothes. Everyone in the family was a good Buddhist and believed in past lives. They sometimes gave food to monks in front of the house. Before New's operations, the family prayed and went to the temple to make merit made a wish for his good health and safety. The parents symbolically gave New to King Taksin, (พระเจ้าตากสิน, a former king of Thonburi Kingdom), hoping that he would help him safe from operations. They also consulted with fortunetellers, which pleased all of them.

Family 6: Mai's family

Mai's family was composed of six persons: her father, mother two elder brothers, one elder sister and Mai himself. He had been diagnosed having complex CHD since he was born. The doctors explained that Mai had to get several operations to improve the symptoms but could not be as normal as the others. Mai was first operated for Atrial Balloon Septostomy when at 26 days and the second operated for Pulmonary artery banding when he was one month. After the operations, he was admitted in the hospital two times because of pneumonia. The researcher first met him when he had cardiac catheterization at the age of seven months, weighing only 6,010 grams. He was third operated on to have Glen's shunt when he was nine months. At present he has been waiting to have another Glen's shunt when he was three to four years, or his weight was about 20 kilograms. Mai's mother said she was pleased to tell the others about her experience of having a son with bad heart disease. She did not know how long her son would stay alive because three children with similar heart disease had already died.

Mai's mother was a 28-year-old housewife who lived in Bangkok. She finished her education at Matayom three (secondary school). She used to sell gift and snack in front of the school but stopped doing that after Mai's birth. After Mai's third operation, she sold some salad and fruit juice in front of the house and could earn about 100-200 baht a day. She also got money from the illegal lottery which she bought very often; she said she was lucky about it. Mai's father was a 31- year old merchant. He sold food in the morning and could earn about 500 baht a day that was not enough for the family expenses, including as house rent (1,700 baht per baht), the

three children's allowances, the water and electricity services fee (2,000 baht per month). Mai's father rarely helped his wife look after their children. After selling food in the morning, he played chess until the evening. When he came home, he would play computer games while his wife did all housework and took care of the children. Even the day Mai had to be taken to the hospital, only his mother took him there. She said that she felt so tired and bored to be responsible for everything without her husband's help, and often had a quarrel with him in case of not doing housework nor taking care of the children. She sometimes wanted to go away from him or even to commit suicide but she was too worried about her children. However, the mother received much mental support from her eight sisters and brothers living in the same area. Mother's sisters and brother also provided other support such as taking Mai's older brothers and sisters to and from school. Mother's younger sister sometimes accompanied her to the hospital and took care of Mai when mother did housework.

Mai's family rented a room on the fourth floor in a four-storey-old building. The hallways were narrow, dim, and damp. There was one toilet and one bathroom on the second floor for everyone who lived in this building. There were many kinds of electric utensils such as a TV, a video and DVD player, a fridge and a computer in front of a bed room. A Buddha image shelf and a shelf for King Rama V's statue were also in this area. In the air conditioning small bedroom, there were bed and beddings which were clean but not ventilated because the windows were always closed. Everyone slept together in this room. Each day mother took all her children to the building where her sisters lived for a bath and meals, then went back to sleep at

the rented room. The building was opposite the market where Mai's father and grandmother (his father's mother) sold food.

Parents recounted that doctors first told them Mai had a heart disease and had to get several operations but could not be completely cured. They were frightened and could not accept in case Mai could not live long. Parents tried to *Tham Jai* (ทำใจ, accept whatever occurred) and thought it was the result of their wrongdoing in the past. Mother revealed she tried her best to look after her son. Mai was operated on after birth; and had to stay in the ICU for more than two months. After leaving the hospital, he had to take many kinds of medicine so he never drank milk from his mother. He drank special formula Olac milk to gain more energy, as the doctors advised. Following physician's recommendation, mother prepared his milk once a day: cleaned and boiled all eight bottles, steamed and kept them in the fridge. His daily food was only 3 ounces of milk, eight feeds a day, and mostly he could not drink it all. However, he was easily looked after; he could sleep well after drinking milk even in the cradle or in bed.

To protect the child against other illnesses and maintain his heart function, mother specially cleaned his belongings and protected him from catching a cold as doctors said Mai could be susceptible as he had little immunity. She always kept him clean and dry, including keeping herself clean. When his brothers or sister came back home from school and wanted to play with him, they had to wash their hands beforehand. Mother told her children and neighbours not to approach him when they caught a cold. Before going to sleep, he wore long-sleeved clothes because he slept in the air-conditioned room so that he would not be too cool or caught cold. Mother said

it was difficult to separate the bed because everyone in the family slept together. She knew she should not take him to the crowded place because her house was opposite the crowded market. Sometimes mother took her children to the department store, especially on the very hot days, even though she accepted that she risked him catching a cold. She found that he liked it and did not catch cold as she expected. Nevertheless, Mai caught a cold about once a month. When he began to have a fever and a runny nose, his mother dried his body and gave him some medicines from the hospital. If he had high fever, coughed a lot and did not drink milk, his mother would take him to the hospital. During waiting for the third surgery, Mai was admitted to the hospital two times because he had pneumonia. After leaving the hospital, nurses visited him at home and noticed that he had much phlegm. They lent his mother the instrument for sucking phlegm and instructed her how to use it. Mother thought sucking phlegm was useful to protect him from pneumonia because the phlegm could not go into the lungs. Each day Mai took more than 17 syringes of medicine by mouth; there were five kinds of heart disease medicine, the names of which his mother could not tell. She could approximately tell their colour and properties, such as white medicine was used to drive urine. Mother insisted she never forgot to give him the medicine but sometimes postponed it. Some medicine sacks and bottles were not perfect, there was some stains of medicine on the sides of the bottles and the labels were torn.

When Mai was admitted in the hospital for the third operation, his mother took him to respect the shrine and the monument of *Krom Luang Choomporn* (กรมหลวงชุมพรเขตอุดมศักดิ์, the son of King Rama V, who was a brave navy, and Thai people

believed that he could help people be safe). She asked him to make her son's operation successful. After the operation, Mai was in severe condition, and doctors told everybody to prepare their minds. His grandfather made a promise at the shrine and Krom Luang Choomporn's monument that he would become a monk if Mai was safe and aunts also prayed for him. Everybody tried to comfort his mother, they did not want him to suffer from the cure. Mai stayed at the hospital only two weeks, his general symptoms were better. He still continued taking medicine to control his heart working and had to be checked at the heart department every month until he had another operation.

The children in Mai's family had close relationships with their mother, more than their father. Their parents rarely had a talk but often had arguments. However, the relationship among Mai's mother and her sisters still pleased her. She did not talk about her relationship with her friends or neighbours. The ways mother relaxed were listening to songs while her son was sleeping and taking all of her children to go shopping in the department store.

Family 7: Bank's family

Bank's family consisted of six people: Bank, father, mother, one elder sister, and two elder brothers. The researcher first met Bank and his mother when Bank was first admitted to Hospital A with pneumonia. Bank was a five-month-old boy who weighed 4,610 grams. He was first diagnosed with VSD and was given oral medicines to control heart function. During his wait for surgery, he got sick often with respiratory tract infections, and was admitted to the hospital three times. Bank

received cardiac surgery when he was nine month of age, or four months after the first diagnosis.

Bank's parents worked as garbage collectors and earned between 200-500 baht a day. They moved from Samut Sakhon province (in a central region of Thailand) to Bangkok for more income and had been staying in their house for five years. Bank's mother was a 30-year-old with a primary school education. She stopped working when she knew that her youngest son had a heart disease. The father agreed with the mother that she needed to take care of Bank by herself, as they dared not leave the son with their oldest daughter, who was only eleven years old. Mother mostly took care of Bank and did all the housework. Even though there was money problem in the family, mother never mentioned the family's constraints. She was a smart mother and had a positive outlook when she talked about her child's illness and her family. Bank's father was 31 years old with an elementary school education. He smoked a medicinal leaf known as a *Krathom* leaf (ใบกระท่อม, or Mitragyna speciosa) and drank sometimes. His earnings were not enough for the family. Having a child with heart disease had made father more serious and concerned about the increasing expenses of the family. He usually followed his wife's thoughts and handed responsibility for taking care of his ill child to his wife, including taking the child to the hospital or talking with doctors.

Bank's sister and elder brothers, ten, eight, and seven years old, were studying in elementary school. The parents paid around 100 baht a day for their three children to go to school. The children sometimes did not go to school, as when Bank was admitted to a registered hospital and they wanted to stay with their mother in the

hospital with air conditioning and cozy place. Bank's sister helped her mother look after Bank and does the housework. While maternal grandmother stayed nearby, she did not give any support to Bank's mother, as she had some argument with Bank's father. Mother had one younger brother living in Bangkok. They rarely visited each other. However, the brother offered money when Bank was admitted to the hospital, 2,000 baht.

Bank's house was located in a small community in Bangkok's Bang-Na district, where most people collected and sold used products. Therefore, this area was full of garbage. Rent was free in the community as it was the land under the control of the Bangkok Metropolitan Administration. When it rained, mud forms, and it took a few days before it dried, which was uncomfortable and unsafe for people, especially children. Bank's house was opposite of a small hill of garbage. The first floor of the house was made of earth. It had a small open passage for storing food and Bank's cradle. The back part of the first floor was a toilet and a kitchen, including a gas stove and some utensils. Two chickens and three cats walked across the floor, avoiding some discarded utensils. Though Bank's house had two storeys, at 3x3 metres it was too small for six people to live in. However, there were some electric appliances in the house, including electric fans and a TV, which father collected from garbage and fixed. Everyone slept together upstairs, which was an open area with four wooden walls. There were no separate rooms, nor any wardrobe for the clothes in the family. Because there was mud and garbage around the house, there were lots of mosquitoes. So, the mother used a mosquito net for Bank and the others in family. Even though the house was not clean and tidy enough, Bank's medicines were kept in a nice cloth basket, which mother collected from garbage and washed. The house was far from

Hospital A. It took more than an hour and a half by taxi, or three hours by bus, to go to the hospital.

The mother revealed that when Bank was four months of age, he got a vaccination and had a high fever, coughed, and breathed much more rapidly. Mother took him to the hospital and the doctor told her that Bank had pneumonia and heart disease. The mother said that when she and her husband were first informed that their son had a heart disease, they were shocked and frightened, especially when they knew that Bank needed heart surgery. It was a big event for the family. Not only did they worry about their child's illness, but also they worried about the expense of the surgery. However, the doctor told the parents that VSD could be cured by operation, which made them hope that their son would be healthier after undergoing surgery. As a doctor could not define what the actual cause of heart disease was, Bank's parents felt sure it was not hereditary, as none of the family members had had heart disease. They thought the cause might be Bank's mother doing something wrong during pregnancy, such as drinking cans of coffee and M-100, or contacting some polluted things from garbage. They also believed it was his son's fate and their own previous karma.

The parents noticed that Bank was easily tired. He often caught colds and took a long time to recover from them. He was small compared with other healthy children at the same age, ate a little, slowly gained weight and had slow motor development. For the mother, it was quite difficult to care for a child with heart disease. Particularly when the child was sick or had pneumonia, it made the mother feel terrible because she worried that the child might die. So, the mother took care of Bank more closely than she did the older children.

While Bank was waiting for the surgery, the doctor advised him to avoid catching colds too often. This was rather difficult for the mother to do for many reasons, especially their housing and living style. Mother, however, tried to keep Bank warm, not to bathe him too long, and not turn a fan to him directly. When there was someone getting ill, the mother would take Bank to sleep separately. However, it was difficult because the house is quite small. When Bank had a fever, coughed, or had a runny nose, his mother would give him some medicine from the hospital to relieve the symptoms. She would take him to the registered hospital nearby if he did not get back to health. Sometimes, she gave him traditional Thai medicine to keep him from catching a cold. When Bank could not sleep at night, or cried for a long time, the parents asked for help from supernatural forces, such as a good ghosts or the spirit guardian of the house.

Prior to cardiac surgery, Bank's mother received advice that her son needed special cleaning because of his low immunity. She wanted to clean and boil his bottle, and also separate his utensils from the others. However, she could not do so completely because she had only two bottles, so she could not clean and boil them every time before she used them. Therefore, she said let it go; she could only do as much as possible. She did not take Bank to get vaccinations according to the schedule because she perceived that he would catch a fever, as he did at four months of age. To put on the child's weight, mother tried to feed Bank many kinds of nutritious food in order to put on some weight and be healthy enough for the operation. Mother also fed him an egg every day, following the doctor's recommendation. However, she accepted that she never fed other kids like this. In addition, mother avoided feeding salty food for her son following doctor's advice. She also avoided activities that

would make him tired by taking care of him attentively. She did not let him cry and did not allow him to crawl or play long, as she was afraid that his heart would work hard and stop working suddenly causing her son to pass way. She usually listened at his chest to his heart's beating. When she heard the loud noise of his heartbeat, she would stop his playing immediately.

After Bank was operated on, he still needed some medicines. He was less tired, and gained more weight. Mother rigorously gave him all the medicines. Six months after the first operation, he was healthier, scarcely caught colds, ate more food and had better motor development. Despite financial constraints, there are good relationships and happiness in the family. The parents did not fight together and often talked to each other. When Bank was in good health and his elder sister could take care of him, his mother increased the income by helping his father collecting garbage.

Everyone in the family is a good Buddhist and believed in previous karma. Although they did not often go to the temple to give food to the monks, or make merit, the parents prayed before going to sleep and taught their kids to do good deeds. Following the traditional belief of the family and the suggestion of a taxi driver, the parents supposedly gave Bank to King Rama V, hoping that he could protect their ill child and help him be healthy. In addition, the parents prayed and made a wish for his good health and safety.

Family 8: Bee's family

Bee's family consisted of three people: Bee, her father and mother. The researcher first met Bee and her mother when she was following up at the cardio

clinic of Hospital A while she was waiting for the first palliative heart surgery. Bee, a-seven-month-old girl, who weighted only 4,700 grams, was the first daughter of this family. She was first diagnosed with cyanotic heart disease at birth. Due to a problem related to referral system, she was medical treated when she was three months of age and had the first surgery when she was twelve months.

Bee's parents worked as silver ornaments: silver earrings, bracelet, necklace etc. and earned about 10,000-15,000 baht a month. Their earnings were enough for the family. Since the family did not have a financial constraint, the parents did not need for a financial support from their family member. In turn, they had given some money to their parents living in the county every month. Bee's mother was a 32-year-old housewife with a secondary education. She helped her husband working such as packing or adorning the silver while taking care of Bee and did all housework. She was a quiet and kind mother. Although she worried about Bee's uncertain symptoms, she expressed in a positive way. As the mother played a major role in caring for Bee and did all housework as well as helped the father work, she had health problems, migraine and weak, due to less sleep. Bee's father was 33 years old with a secondary school education. He did not smoke but drank sometimes. He helped his wife taking care of Bee in general such as taking care of Bee while the mother did housework. When the researcher visited Bee at home, he usually asked questions related to Bee's conditions and expressed their feeling about unsatisfied experiences at the hospital, about limited advice and bad manner of physicians.

Bee's rental house was a three-storey building located in a small community in Bang-Kae district. It was far from a main street around two kilometers. Motorcycle taxi was common transportation in that community. It took about 1.30 hours from the

house to Hospital A by taxi. People in this area worked in many occupations such as traders, cloth makers, mechanics etc. Bee's parents rented this building four years ago. The first floor of the house was a working area. There were some machines and three workers as well as some electric equips including electric fans, a VCD player, and a TV. In addition, there was a big Chinese shrine, which the parents paid respects with fruits and tea every Buddhist holy day. Bee and her parents stayed on the third floor, which was a clean-open area including one wash room with four concrete walls with air condition. Since there was loud noise on the first floor in the daytime, the mother usually took Bee to sleep on the third floor and turned on the air-conditioner in order to ensure Bee to have a nice and long sleep.

Mother recalled that when Bee was born, she noticed that Bee's back was not straight, and also right shoulder was higher than the left. Moreover, mother found that Bee had two nipples on the same right chest vertically. A doctor then provided further investigation and found that Bee had a defect at her heart, and suggested to the parents that Bee needed for more specific treatments in other hospitals having more potential to perform cardiac surgery. According to the doctor's explanation, the expenses for the surgery was quite high and the parents must pay all if they did not have any coverage. So, the parents tried to get a transferred document in order to take Bee to receive treatments at Hospital A. However, it was a difficult process as mother did not have a healthcare coverage of 30 baht scheme of the hospital. Finally, Bee was approved that she was qualified for a disable child with the right for free for treatments of every hospital in Thailand. With the difficult and long process, Bee was transferred to Hospital A when she was 3 months of age.

At Hospital A, Bee was reinvestigated and found that she had Tetralogy of Fallot (TOF). When parents were informed that their first daughter had a heart disease, they were shock and frightened, especially, when they knew that Bee needed for at least one heart surgery. Father expressed how trouble he was when he got a doctor's information about the child's severity. It was a big event for all in the family though the expense of the surgery was not a serious issue of the family. Bee's parents tried to find what the causes of their daughter's CHD. They felt sure it was not hereditary as none of family members had heart disease. They thought the cause might be about Bee's mother inhaling some chemical poison such as dust and chemicals of silver, thinner, aluminum and dust of wooden furniture from neighbors' furniture factory, during pregnancy. They also believed it was their child's fate and their own previous karma.

While Bee was waiting for the surgery, the doctor advised her to avoid catching cold too often. Her mother, therefore, tried to keep Bee warm, not to bathe her long and did not turn a fan to her directly as well as did not take her far from the house. When there was someone getting ill, the mother would take Bee away. When the father had a cold, he avoided kissing his daughter and slept separately. It was not difficult because there were only four people in the house. When Bee had a fever, coughed or had running nose, her mother would give her some medicine got from a pediatric clinic to relieve the symptoms. The mother would take Bee to clinic nearby if he did not get better. She never gave traditional Thai medicine for Bee because she feared the traditional medicines made her child worse. In addition, to on her weight, mother tried to feed Bee many kinds of nutritious food. She still breastfed her baby as often as possible because Bee ate gradually and slowly gained weight. Bee's mother

received some advice that her daughter needed special cleaning because she had low immunity and could be easily contagious. She therefore cleaned and boiled her bottle feeding and also separated her utensils from the others.' Prior to surgery, she did not take Bee to get vaccinations according to the schedule because she perceived that she would have a fever as she did and would make her delayed surgery.

The parents noticed that was small and had slow moving development comparing with other healthy children at the same age. However, they did not force her as Bee was tired easily. When the child was tired, it made the mother was worried because she feared that the child might die without warning signs. So, the mother took care of Bee more closely, did not let her be tired by not leaving her alone, as she worried that Bee might have long crying. She did not let her crawl or play long as she was afraid that her heart would work too hard and stopped functioning suddenly causing her child passed way.

After Bee was first operated, she still needed for some medicines. Bee was less tired, and gain more weight. Six months after the first operation, she was healthier, no cyanosis, ate more food and had better moving development. Everyone in the family was happier. However, she has been waiting for one more surgery to correct the heart defect when she grows enough, probably 2-3 years old and gains more weight.

This family rarely mentioned about their belief. They said that due to their work causing them have limited time, they did not have time to go to a temple or go shopping at department store. However, they were happy to stay at home, particularly to stay with their child. Although the parents did not often go to the temple to give

food to the monks or make a merit, they paid a respect to the Chinese shrine at home on every Buddhist day.

Summary

Six of eight families participating in the study was nuclear family, including father, mother, and children. It appears that husband, grandmother, sisters, or brother of mother were significant persons providing support. Mothers took a major role in caring for the child, while fathers helped to do housework and accompanied mothers to the hospital but did not see doctors with mothers. Most family members who stayed outside Bangkok usually came to visit and helped parents take care of the child in some ways. Friends, coworkers, and neighbor also provided mental support or financial support. Among eight families, it was found that six families faced financial problems. They had to borrow money from friends or informal loan. Two families had their own businesses such as making silver ornaments and selling mackerel fish, so they had enough income and could save some money, by self-report. However, seven families lived in rental houses; four had separate rooms for sleeping or cooking, whereas three had only one room for all people in the family.

When parents were first told about the child was diagnosed, all of them were shock, had stress and negative thoughts. However, they felt better after receiving physician's information that the child's illness could be cured by medicines followed by surgery. All families believed that the child's CHD was caused by previous karma, while seven families thought that heart disease was caused by mother's wrong practices affecting the fetus during pregnancy. All informants had been living in the

Bangkok area, but only two of them talked about environmental pollution causing the child's heart disease.

Hospital was a particular place that families had to go often since the child was diagnosed with CHD. All parents regularly took the child to see doctors at the pediatric cardio clinic of the hospital every month or two months following the child's appointment. It was not surprising to the researcher when parents told her that they came to the hospital because believed that doctors of the hospital could cure their children. Even though they sometimes felt unsatisfied with hospital service due to the large numbers of patients, they usually took the child to the hospitals because some parents told them about efficient doctors and advanced technology. Most parents mentioned that they received encouragement from doctors rather than from nurses. Another kind support from hospital was spiritual support. All parents believed in spirit house in the hospitals, which was the place for people to ask to be cured. It is also the belief that when visiting a stranger's house one has to pay respect to the owner, which is the spirit house. Therefore, parents would give the spirit garland, or wooden elephants. It was also found that most families had a spirit house. Parents sometimes provided Thai traditional medicines or Chinese medicines for their child when the child had a cold, low fever, ate small food, and looked sick. At the same times, they took the child to receive western medicines from hospitals to receive an investigation, oral medicines, and heart surgery in particular.

Home was a place where families spend a lot of time. From the researcher's observation, all informants spent time at home. Since doctors advised parents to avoid taking the child to crowded places, parents were more likely to care their child at home. In addition, most informants' houses contained a sacred place for Buddha

images. When the child got sick, parents or other family members usually increased their prayer and offerings. Their Buddha images' include different gods or symbols of high spirits. Each god or spirit has specific powers. However, one home lived in a slum of Bangkok, with lot of garbage and poor environment. This place was built to support poor people who previously lived in other slum. Even though it was a big challenge for this family to care for the CHD child and other children, parents did their best to care for the children.

Through closely observing the child's symptoms and receiving physicians' information, parents tried to provide their child's care more vigilant. Particularly, promoting the child's weight gain and strong health and preventing URIs was their main concerns. While caring for the affect child, parents had to deal with many constraints, most often financial problem. Most of them did not go out to Malls to have family time together shopping, watching movies, or eating. Rather, they visited temples to make merit together, or stayed at home talking with friends and neighbors. The description of parents' perceptions regarding the child's illness and treatments and the patterns of practices among Thai families in caring for infants and young children with CHD prior to cardiac surgery are described in the next part.

Part 2: Perceptions of Families regarding the Child's illness and Treatments

In the eyes of the parents and family members, heart disease was a disease that seemed distant from them. Some parents heard about heart disease from TV health program. However, they did not pay attention to it. When the parents were first told about the child's diagnosis, they were all frightened, fearful, worried, and sad as they

believed that heart disease was a dangerous disease related to death. Patients were shocked and feared that their child "*Pen Laew Arj Mai Rod*"(*เป็นแล้วอาจไม่รอด*– May not survive)**.** The parents tried to find out the causes of the child's CHD. Even though they were told that CHD had unknown causes, they believed that it was caused by previous karma, or caused by mother's practices during pregnancy. Through closely observing the child's health, understanding the severity of the child's conditions, and being informed by physicians, parents realized that the child with CHD was *Leang Yak Toh Cha (เลี้ยงยาก โตช้า,* Difficult to bring up), and would require medicines followed by surgery.

Pen Laew Arj Mai Rod (เป็นแล้วอาจไม่รอด, May not Survive)

When the informants knew that the child had heart disease at birth, they thought that their child may not survive. They all had negative thought about heart disease and thought that it should not happen to them because none of family had heart disease. They agreed that people who had heart disease usually had severe conditions and could die from it. The one thing that they afraid of the most was the child may not survive as it was a disease with alarming and worrying symptoms, a disease of the heart, being too severe for the child, and an incurable disease.

It is a Disease with Alarming and Worrying Symptoms

Most parents found the child's abnormal symptoms by themselves before taking the child to see a physician and knowing the child's diagnosis with CHD.

However, they did not think it concerned with heart disease as they had never known heart disease could be found in children. With closed monitoring the child's symptoms and signs from the child's general state and signs, they found the child was apparently different from normal healthy children. Being informed by physicians, the parents though that the child's heart and circulatory system were in disorder as shown by causing alarming and worrying symptoms, as shown by cyanosis, strong and rapid heart beat, rapid breathing with tiredness.

Cyanosis or the bluish color on the lips is the first sign that was detected by parents of children with cyanotic heart disease. Parents reveled that cyanosis was more obvious when the child cried or used energy such as forcing out stools, crying and playing too much. They understood those activities could cause the child to turn so blue or dark purple that they could kill the child, as told by the mothers:

> *When he cried, he'd turn blue or purple that is different from other children. I can't accept it. He'll be very dark purple like a rotten dead baby. He turns blue even as he doesn't cry. He's clearly unhealthy and weak. I'm afraid his cyanosis is so acute that even a doctor can't save his life. (P2/1/218-220, 3/134-142)*

> *He's got the blueness on his skin since birth and the symptom is clearer when he cries as his lips would be purple and blue all the time. He looks normal when he sleeps. But after waking up, the skin is back to blue. If I let him cry, his lips would turn very dark purple. It's terrifying. I just knew it's because of heart disease and I fear that he could not survive as his cyanosis is very severe. (P5 Int1/28-37, 550-564)*

Strong and rapid heart beat was another symptom worrying parents that the child could die as the child's heart rate was markedly and apparently more abnormal than that of other children. This abnormality was mostly detected by parents of children with acyanotic type. Pim's mother revealed while she took her 5-month-old daughter to visit her grandparents at upcountry by bus, the hot weather inside the bus

made the little girl cry ceaselessly and the accompanying aunt helped carry the girl and detected the girl's strong and rapid heart beat. However, some could find the symptom even the child was not restless, as told by Jing's mother and grandmother:

> *Her heart beats very strong. I even feel it when I hold my daughter close to my chest. Her strong heartbeat shocked me. Even she was sleeping, I didn't touch her heart, but only opened her shirt and I saw it beat very strongly and obviously. I'm afraid she couldn't live long due to her abnormal heart beat. (P3, Fm,Int2/248-255, 3/298-299)*

Rapid breathing with tiredness was another particular symptom of children with CHD. It was observed by most parents from the child's rapid breathing or mouth breathing with the stomach expanding up and down more quickly and markedly when compared with the respiratory rate of a normal child. That case was particular with the children who had been admitted to the hospital for pneumonia. Two parents were advised by the nurses on how to monitor the symptoms of tiredness or rapid breathing by counting the number of breaths. By this method, parents could know if the child had rapid breathing and tiredness when exerting energy, laughing or playing so much that the child stop breathing, as told by Nai's mother:

> *My child has been breathing heavily since birth. A nurse said his breathing was very rapid and sometimes very deep. I could notice his tiredness from his breathing as he'd open his mouth and inhale deeply when he had long crying. It's his heart malfunctions that make him tired and have rapid breathing. I worry if it occurs suddenly, my son may not survive. (P2 Int1/240-249, Int4/ 367, 579)*

Some mothers had seen that their child had a rapid breathing since birth, but they did not know it was an irregularity. Bank's mother told that when her neighbors came to visit her after Bank's birth, they said her baby breathed rapidly like an asthma patient. They thought the child might have the large lungs. The mother observed that

her baby sucked milk for only short time, but she did not know that it was a sign of tiredness, that the child had to pause from sucking. She afraid the child might not survive because of such symptoms after obtaining an explanation of a doctor, as Bank's mother expressed her concerns:

> *He has had a rapid breathing since he was born. I see that his belly moves quickly. If it moves quickly, it marks tiredness, unlike other children. He doesn't drink frothy milk either. He can't suck for ten times, and then stop. Firstly, I think it's because there is too much breast milk that makes him unable to suck. The doctor told me later that he can't suck because he has a shortness of breath or tiredness that was related his heart disease. I fear he could get so tired that he can't reach the hospital in time. (P7 Int1/121-126, 266-274)*

It was appeared that families viewed heart disease as a suffering fatal illness consisting of frightening symptoms that were related to people's live. This perception was depended on what experience they had with it and how they perceived it.

It is a Disease of the Heart

The parents in this study realized that heart disease was dangerous, as the heart is the most important organ of the body, necessary for life. When the heart had a disease, it could not work properly or might stop functioning, and then people could not survive. Some parents viewed that people have only one heart and it cannot be replaced when the heart cannot function. Therefore, they admitted that when they were told the child had heart disease they were terrified by the disease and afraid that their child may not survive. Two mothers provided their statement regarding the child's illness as follows:

Heart disease is dangerous. It's hazardous to my child's heart, the most important organ. It sends the blood around my kid's body. She can't live without the heart. I was fearful when hearing that she had heart disease. I'm afraid of its danger. I worry if my child will survive. Will she die? (P1Int3/696-699)

It is a dangerous disease as the heart is a vital organ. If the heart has a problem, it is dangerous. We have two lungs, but only one heart. We can't live without the heart. So, I feared that my kid would die as she had a big hole at her heart (P3 Int3/139-141).

Bank's mother was also concerned about her son's illness. She compared the heart with a machine of a factory, as she said,

Heart is the most important for my son's life. It could be at risk if there's something wrong with the heart. Heart is like a machine. If the machine breaks down, the factory can't operate. Like the heart, if it doesn't work or when it stops beating, we can't live. So, it's a very dangerous disease (P7, Phone communication, May7, 08)

All informants had taken for grant that the heart was vital. It seemed that heart disease was more dangerous when it occurred with the child's heart. Everyone in the family was already affected by the diagnosis of the child's heart disease.

It is Being too Severe for a Child

As parents had known or watched in the TV that adult patients who had heart disease mostly died, they were afraid that the child might not survive. The parents admitted that an adult patient with heart disease would be in severe and critical conditions, particularly when the disease afflicted a child. Most of them understood that it was an illness among adults and never knew it could be also common among children and was a congenital disease. Some noted that adults, despite their larger bodies, stronger health, and more developed immunity, could still be in critical

condition and die from heart disease. In other words, if a baby suffers this disease, parents thought that their child could be in so intolerably critical and severe condition that he could die. Some mothers described about the child's severity as follows:

> *Heart disease is an adult's illness. It's dangerous and even more dangerous when it affects an infant. Even an adult, he couldn't survive from this disease. When my child has this disease, I'm afraid it's too severe for him. (P2 Int 1/175-179, 2/173-178)*

> *It's a severe disease. It's dangerous. I heard only that adults could die from heart disease, but never knew that a little child could suffer this disease. And I never thought that my child has this illness. I fear if he'll survive. It's too severe for a little child. (P8 Int1/9-13, Fm, Int2/439-453, 679)*

Meanwhile, some parents had known that heart disease could be found among children and it was a critical and serious illness that could kill a child. The mothers of Mai and New revealed that they had seen their neighbor's child and some child patients at the hospital suffered heart disease and died after the surgery. Mai's mother described her thought when she knew her youngest son had heart disease:

> *I think my son's heart disease is serious. All three children with heart disease whom I knew can't survive. Their condition was as serious as my child's, and they all died after the surgery. When it happens to my child, I question if he could survive. I worry he could get worse as it's the problem at his heart and he's too little. I don't know what it is, but I think heart disease is a severe illness. (P6 Int1/48-49, 114-116)*

It seemed that heart disease was more severe when it occurred in infants or young children. It was appeared parents were sometimes caught between physicians and information from TV as well as their direct experiences.

It is an Incurable Disease

Parents mostly believed that heart disease was intractable and incurable, and that it could kill its victim eventually. Obtaining the information on heart disease

from TV health programs and their experience knowing adults who died with heart disease, all families thought that a child who was born with heart disease would live with it throughout his life, as it was an incurable disease. Jing's mother expressed her concerns:

> *Heart disease is a big problem because it's incurable. It's a lifelong illness. I've watched TV and found that many people with heart disease can't be cured. I never knew that heart disease will go away from its sufferer.*
> *(P3 Int3/128-133)*

Pim's mother was afraid of incurable disease so she was worried about her daughter. She explained that:

> *I think heart disease is incurable. It's a rare disease and it's intractable. When I first heard that my child has this disease, I got worried if she'll die. It's incurable. Ouch! It happens to my child. Can my child be cured?*
> *(P1 Int 3/663-670, 4/369)*

Parents and family members had negative thought regarding the child's heart disease. The parents and family members interpreted heart disease using their personal beliefs and experiences, which was based on western hospital-based biomedical knowledge.

Caused by previous Karma

The parents tried to discover the causes of the child's heart disease. Even though it was explained to them that scientists do not know the reasons for CHD, parents perceived that it was a result of karma in the past life, or caused by *previous karma*. As the certain cause of heart disease is still unknown, karma was cited by parents as an acceptable reason for the child's illness. *Karma* is related to the Buddhist teaching that plays an important role in the parents' perceptions. They believed that karma— the deeds in the past life—rules one's life in the present and

future. Bad karma or deeds in the past would return to the owner of that deed. Being sick with heart disease in the present life of the child, is described as "the karma of retribution" or "his karma catches up with him." That belief was reflected in the parents' explanation that their child's heart disease was a result of three causes: karma of the child, karma of parents, or karma of both parents and the child.

It is Karma of the Child

Among eight families in this study, three of them believed that the child's heart disease was a result of the child's own karma in his previous incarnation continuing to have an influence on his present life. Nai's father told that when his wife was pregnant, a monk at a temple near his rural house prophesied that this baby did bad karma in his past life. To lessen it, he took his wife to make merits, covered gold leafs on a *Luk Nimit* (*ลูกนิมิต*, a consecrated stone ball buried under a temple) and gave the offerings to the monks in order to relieve the anxiety and ask the Buddha to help make their child healthy with their good deed. When the child was born with heart disease, the father admitted it was the karma as said in the monk's prophesies. Nai's father said:

> *I thought it's karma of my child. It's his old karma. I don't know what he did in his past life and caused him unhealthiness unlike other children. (P2 Int2/399-405)*

It is Karma of Parents

Some parents believed that the child's heart disease was a result of their bad karma in their past life. They believed that they did bad deeds but their child was the one who received the result. Pim's mother told when she was in her own family in the country, the grandmother usually persuaded her and her siblings to make merits, in hopes of prolonging the life or correcting the karma. When some family members felt sick, the grandmother also made merits in order to devote the merits to the enemies in the past lives. The mother believed that her youngest daughter had heart disease because of her bad karma, as she said:

> *I think it's my own karma that caused her illness. I don't know what I did in my past life, but it affects my child in this present life. It's not her karma, it's mine. (P1Int2/ 1031-1035)*

While another group of parents believed that they had to pay for their own bad karma by taking care of their child with heart disease. Jing's mother told that she is sharp-tongued, emotional, and rude, and behaves badly to her parents, causing her to suffer for saddening her own parents. The mother stated that:

> *I think karma affects my child's suffering of heart disease. But it's not her karma, it's mine. If it's her karma, it should be her own pain without making me any troubles. Rather it's my karma as I've got difficulties. It's my retribution for hurting my parents because of my rudeness. It's the karma I deserve in this present life, not in the future life. (P3 Int4/219-229)*

It is Karma of both Parents and Child

Parents from two families believed the child's heart disease was the karma of both parents and child in their past lives, and that the karma extended through their

present life. All had to be responsible for the karma that led to their child suffering from the disease. Mai's mother told that a paternal grandmother asked a monk to prophesy from the birth date of her son who had a heart disease, the monk said that the child was born to pay for karma through his illness and sufferings from many surgeries. This mother believed it was karma of the child and her own in their past lives that made the child suffer this disease. Mai's mother explained that:

> *It's my karma and my son's karma as well. That's why he suffers heart disease like this. I don't know what either I or he did in our past lives. That karma has come into this life, causing him to be ill and prompting me to be tired in taking care of him. (P6 Int2/29-32)*

Parents also believed that their karma and the child's karma in the past life did not only result in the sickness of the child, but also caused parents the burden of higher expenses. Bank's father told that his daily income from garbage collecting was already not enough for the daily expenses. The fact that the youngest child had heart disease worried him as his family had to be burdened with more financial problems while the little child suffered the disease. Bank's father expressed that:

> *I sank into despair when I was told by my wife that my child had heart disease. (he said with teary eyes) We don't have enough money. I don't know what karma I and my child have done and that karma came to punish him through the illness. (P6 Int2/29-32)*

Families tried to search for the causes of their child's heart disease, and they still were not clear. Traditional Buddhist belief was brought to inform about the causes of the child's heart disease.

Caused by Mother's Practices during Pregnancy

When considering the causes of the illness, some parents blamed themselves, believing their child's heart disease could be caused by mother's practices during pregnancy. They presumed that consuming certain food and drink could cause the child's illness. Other parents believed that taking certain medicines, doing certain activities, or being exposed to pollutants during pregnancy, could cause heart disease in the child. These beliefs persisted despite professional explanations.

Consuming Certain Food and Drink

Parents from three families presumed that consuming certain food and drink, i.e. grilled pork, canned coffee, Pepsi or M-100 energy drink, could have caused their children's illnesses. They thought that consuming those food and drink was not right in terms of type and amount during pregnancy, having too much of food and drink, or taking some foods unsuitable for a pregnant mother, could be hazardous to the child, causing the child heart disease. Nai's father, a 28 year old taxi driver with primary school education, said,

> *My wife ate lots of barbecued pork and grilled pork. I think that played a part as she ate a lot. The doctor said it was not related to my child's disease. It has unknown causes. But I still believe that's the cause as the child was in her belly. Eating that could be dangerous to the child. That's why my child has heart disease. (F, P2/2/338-350)*

Nai's mother disclosed that she had drunk almost ten bottles of Pepsi soft drink per day since she was young until the pregnancy. When she knew that the child had heart

disease at birth, she presumed that drinking Pepsi too much caused their son's heart disease. She was blamed by her husband, as she said,

> *My husband blames me everyday for drinking Pepsi that has acid in it and that caused our child's heart disease. I myself thought I should have not drunk it. It's my fault (she looked sad in a trembling voice). (P2 Int1/ 189-206)*

Moreover, parents of one family presumed that the mother's drinking of instant canned coffee and energy drink during her pregnancy caused their child heart disease. Bank's mother told that due to her family's low-income status, she had to work hard and drank several cans of canned coffee and M-100 energy drink. She stopped drinking it when she got pregnant of her elder children, but she failed to do it when she got pregnant of her youngest child, as she did not know that she got pregnant. When the youngest child had heart disease, she thought that it might be caused by her drinking of energy drink, as she read from the side of the can that it contained something unsuitable for a pregnant woman. She said,

> *I think it's because I drank too much of coffee and M (M-100 energy drink) during pregnancy. I had drunk 3-4 cans of coffee and M since I was a teenager otherwise I don't have energy and can't work. The label says pregnant women should not drink coffee as it contains caffeine, but I drank a lot. I think that was the cause of my child heart disease. (P7/1/640-652)*

Taking Certain Medicines

Three parents believed that taking some types of medicines during pregnancy could be the cause of the child's heart disease. Those medicines included pain killing drugs, migraine treatment drugs and gastritis treatment drugs. After learning from the physicians and discussing with neighbors, they knew that the medicines could affect the fetus. Nai's mother said when she was around 2-3 month pregnant, she had a

toothache and headache everyday, and so she took some pain killing drugs usually. After her child was born with heart disease, and, she presumed that it was caused by those drugs she took. As she said,

> *It was probably my eating of pain killing drugs. I took Para Cap [a capsule of Paracetamol] drugs to cure my headache. When my child was born with heart disease, I thought it must be related to the drugs I took. (P2 Int3/27,47)*

Likewise, Jing's mother had taken migraine treatment medicines, pain killing and gastritis drugs since was 2-3 month pregnant. She took medications during the early months of pregnancy because she did not know, at that time, she was, in fact, pregnant. She stated,

> *I heard that taking pain killing and migraine drugs during pregnancy would harm the baby. The strong effect of those medicines could cause heart disease in my child, and I took both migraine and pain killing, and also gastritis drugs. I think it was the medicines that were absorbed into my blood and flew directly to my baby. (P3 Int4/206-213)*

Another family believed that the child's heart disease was caused by the mother's taking of antibiotics during pregnancy. Fah's family told that the mother took over-the-counter medicines to cure her serious stomachache and she did not know that she was already pregnant for about 3 to 4 months. After that, she was diagnosed with a uterus tumor. Her father then administered her oral procaine penicillin, whereas it was an injected form, to remove that tumor. She was not yet cured even after taking two bottles of it; however, she decided to see a doctor again and found that she was pregnant. When her baby was born with heart disease, the parents presumed that it was caused by the medicines she took.

> *It's my fault that I didn't take right medicines to my illness. Like the drug my dad [a child's grandfather] gave me, it was a strong type of antibiotics to remove my uterus tumor. I think it was another cause as the drug was very strong. That's why my child has heart disease. (F and P4 Int 3/20-26)*

Doing Certain Activities

Two families in this study believed that CHD in their child was caused by activities the mothers engaged in during pregnancy. Using an electronic sewing machine, New's mother earned extra income making clothes until she delivered. She found that her neighbor worked as a seamstress using an electric sewing machine, but her baby was dead after birth. When she learned her baby was born with heart disease, she thought it was related to her job because electricity from the sewing machine was absorbed through her baby. She provided her description that:

> *I think it was because I used that electric sewing machine and got the electricity shock. I had used it until I delivered my baby. The electricity current would gradually flow into my body and harm my baby. When he was born with heart disease, I think it was that cause. The electricity might affect any parts of my fetus. It could affect so strongly that caused heart disease in my baby. (P5 Int2/455-473)*

In addition, some practices as part of the traditional treatment were cited as one of causes of the child's heart disease. Fah's mother told that besides the antibiotic given by her father, her mother used a hot-steamed rock to compress on her stomach to destroy her uterus tumor according to the successful traditional beliefs of older people in the Northeast. She said that her mother used a hot rock covered with a cloth to compress on the spot of her stomach that moved up and down and was moveable. She believed that the movement was the movement of the tumor. She placed the rock on the swelling part of her stomach to make the tumor smaller. After Fah was born with heart disease, her parents believed that it was caused by that action which placed the baby at risks. Fah's father recounted as follow,

> *My mother in-law put a brick on my wife's belly in belief that it could destroy the tumor. I think it was one of the causes because the baby was in her belly and doing something like that could have some impacts on her. That's why she has heart disease. (Fm, P4 Int4/422-436)*

Being Exposed to Pollutants

Three families believed that the mother's exposure to pollutants, i.e. cigarette smoke and/or chemical fumes, during pregnancy, could have cause their children to have heart disease. These families learned from the media that exposure to toxic fumes, especially cigarette smoke, was hazardous to the health and could lead to heart disease in a fetus.

> *My husband smokes, but he would walk away and try not to be near me when he smokes. But the doctor said the toxic from smokes could be on his body or his shirt and I indirectly got that toxin. I think it's partly related to my child's heart disease. (P6 Int1/50-51)*

Bee's father, a 30 year old father with a secondary school education, earned his living producing silver accessories, while two neighbors molded aluminum and made wooden furniture. He thought his wife, during her pregnancy, could have received toxins from these industries, which could have had an impact on the child's heart. He indicated,

> *I think my daughter's disease is related to my work. I make silver ornaments and there would be some dust and chemicals involved. We also live behind the house where there is also a small aluminum mold factory that uses chemicals. The house over there is a wooden furniture factory that has some chemicals like thinner, that my wife might breathe in. It might harm fetal development, causing heart disease in my baby. (F, P8/2/686-701)*

Bank's mother also agreed, saying that her contact with some chemicals during pregnancy was possibly the cause of heart disease in her child, as she told,

At that time, I was hired to type documents. I probably inhaled that printer ink. It was the black chemical in the computer and typewriter. It's possibly the cause of my child's illness. (P7 Int3/630-639)

In summary, parents articulated a mix of etiological belief systems for their child's heart disease, from karma, mother's actions during pregnancy to environmental toxin. They sometimes struggled between competing belief systems. When medical knowledge could not explain or answer the families' questions about the causes of the child's CHD, they turned to their personal or family beliefs to interpret life and their practices that might cause heart disease.

Leung Yak Toh Chaa (เลี้ยงยาก โตช้า, Difficult to bring up)

All parents in this study said that their CHD child was *Leung Yak Toh Chaa (เลี้ยงยาก โตช้า***,** difficult to bring up) comparing with other typical children. They explained that their child could not eat much food and drink, and that this resulted in growth delay, slow weight gain, delayed motor development, frequent colds, and a slow recovery. Through closely observing the child's health, parents found that the child was irritable and nervous and could not get to sleep easily.

Growth Retardation and Slow Weight Gain

All parents said that their CHD child could not eat much, leading to slow weight gain and growth retardation. That was a result of the child's underlying heart disease, leaving their child weak and tired. Parents explained that when the children had heart disease, their inner unhealthiness, and could not eat. The perception of parents stemmed from their child's care experience that the child usually ate less,

often tired, and they did not force the child to eat because that might make the child cry and tire. Other parents said their children could eat, but their weight did not go up or their weight gain was slower than other children. However, physicians explained that this condition was common among children with heart disease, that seemed not help parents feel happy as the. Nai's mother revealed that:

> *My child is smaller when compared to other children. His legs are thin like chopsticks. Other people always said my child is small and looks unhealthy, having small legs and arms like a child with polio, claiming that a healthy child would have a large body size. Why does a cardiac child have a small body like this? I think it's because of his internal illness. Doctors said I have to accept that he has heart disease. (P2 Int3/71-89, 4/ 362-376)*

According to parents' descriptions, children with CHD ate small food and milk; therefore, their weight did not gain or slowly increased when compared with their elder children or other children of the same age. In other words, they said *"Kin Thao Rai Koh Mai Tho" (กินเท่าไหร่ก็ไม่โต, how much food he eats, he doesn't grow).* The parents thought that the child's underlying heart disease caused their child tiredness, or fatigue, and lack of appetite.

Through receiving information from physician, it was common for children with CHD to be unable to eat much and have slow weight gain. These problems could not be solved until the child undertakes the heart surgery, as told by Jing's mother:

> *I told a doctor that my child's weight did not go up, and he explained to me that it was common.. The child would feel so tired that he doesn't want to eat. He said the weight of cardiac children doesn't increase easily. It can be solved with the surgery only. (P3 Int1/421-423)*

Difficulty to Sleep

Through closed observation, parents mostly admitted that raising the child with CHD was difficult, or *"Aoo Yak"* **(***เอายาก*, difficult to care for), as the child was irritable, nervous, and whimpering. Particularly, before bedtime, the child would weep and could not get to sleep easily or wriggle around as if the child was sick. When they cried and could not stop crying easily, they could turn blue and get tired. Consequently, the parents could not leave their child alone for fear of the tiredness and sudden cyanosis, prompting them to keep a watchful eye on their child. They thought that those conditions were due to the child's heart disorder or *"Kang Nai Mai Dee"* (*ข้างในไม่ดี*, inner unhealthiness), causing the irritableness. Pim's mother explained that:

> *It's difficult to raise my CHD daughter as she's self-willed, always fretful and stupid before bedtime, wriggling around as if she was sick...Aoo Yak …She can't take a long sleep...Never…She'd sleep and get up and sleep and get up* *said with serious face* *. She can't get to sleep easily as she gets annoyed. She easily gets sweaty and has a bad temper easily. I think all of these symptoms are related to her heart disease. Her inner was unhealthy. Her Kang Nai Mai Dee (P1Int2/519-530, 578-579)*

Catching Colds frequently and Slow Recovery

Through receiving information from physicians, parents perceived that their child would be vulnerable to other illnesses, particularly the common cold, fevers, and similar frequent sickness, and that it would have a slow recovery. The parents realized that the children would be not immune, leaving the child susceptible to cold infection. Most of them admitted the disease was partly related to the difficulty of

solving the child's growth retardation; therefore, they needed to be more careful in protecting the child against other illnesses and tried to get him recover as soon as possible. Catching colds frequently also caused the child loss of appetite and slow weight gain. They realized that one symptom of cardiac children that was clearly different from typical children was their frequent cold or sickness and longer recover time. As New's mother stated,

> *This child [the child with heart disease] often catches cold, that is different from his elder sisters. He always falls sick, has colds and fever throughout the month. Last month, he took all antibiotics and I had to buy some more and it took a half month for him to be cured. It's difficult to raise him because of his frequent sickness. (P5 Int 1/820-836, 1696-1698)*

Parents found when the child was having a cold, the child would eat less as well as the weight would not gain, making the child's health condition worse than other healthy children due to underlying heart disease. Jing's mother revealed that:

> *My daughter falls sick quite often. She'll be ill for 3-4 times within two months. Sometime when she got a sore throat, she wouldn't eat, but vomited. She's frequently sick, so she couldn't eat. When she could eat much for a few days, she would fall sick again. It's like she can eat well for 3 days a month and she eats less for the remaining days of that month. When her weight goes up to 7 kilograms for a while, it'll drop back to 6 kilograms. (P3 Int1/124,418, 2/259,434*)

Delayed Motor Development

Parents mostly realized that their child experienced delayed development, particularly the balance or motor skills development. It was evident from the child's development table in the health care pink book, or when compared to other normal or elder children. They thought the slow development was related to the child's heart

disease, which would cause the child easy tiredness and unhealthiness, impeding the child's normal development like other children. The physicians suggested to some of them that their child development was not too slow, and that development would be improved after the heart surgery. This perception helped ease parents' anxiety. They also knew that the child's development in other aspects—the fine-motor, speech and cognitive skills—was still normal. Parents did not worry about the child development, as a result.

Parents realized and understood that their child would have a slow development of gross motor skills such as sitting, crawling, and walking due to the heart malfunctions. Sometimes, the child would not have energy, or would feel so tired that he does not want to move or do any activities, as told by some mothers:

> *My kid's development is slower than other children. He's not able to creep, but rolls over and goes backwards. He's also unable to crawl. I think he isn't strong enough to move forward because of his heart disease. He must use much energy to go crawl. I saw him very tired when trying to sitting up by himself. (P5 Int1/517, 2/777, 3/428)*

> *Her development has been since delayed. She is unable to crawl but can move in a sitting position. She sometimes pulls herself up and stands. For a child who could roll over, he's able to crawl, but my child can't crawl but can creep. Her disease makes her unhealthy and tired. My cousin who is in the same age can run now, but my child can't even stand up. (P3 Int2/335-360, Informal Int, 9 Aril.07)*

However, the interviews of parents showed that most of them were not concerned over the child's delayed development after being informed by the pediatricians that children with heart disease would have slower development than other normal children, and that their development would be improved after he is recovered from the heart surgery. That relieved parents' worries. Fah's parents explained that:

Ajarn (a head of pediatric cardiologists) told that he was not concerned about my child's development, but her weight was worrying. I think her heart disease contributes to her slow development and growth as she can't eat and play much. I felt relieved after the doctor said that it is common among children with heart disease. (P4 Int1/589-654)

I think her development is delayed when compared with other children. It seems slow but not too much. I think it's her heart disease that causes her unhealthiness. I'm OK if her development is a bit slow. I wish only she'll be cured (he laughed softly) . Let her get the surgery first. (Fm, P4 Int 4 / 915- 918,)

Moreover, parents optimistically talked about the child development in other aspects such as fine motor, brain and cognitive skills that are normal. They said the child could quickly understand what he heard, or was smarter than other elder children. As New's mother said,

His walk and creep is slow, but he could grasp an object with his two hands normally. He is able to look in the direction of an object. According to the development table in his health pink book, his development is normal. He can recognize my sound or many other things. He could remember what I taught even as I just taught him once. So I don't worry that he is unable to creep. (P5 Int1/533, 3/481-483)

Perceptions of families regarding the child's illness were a mix between the biomedical world view and their personal belief as well as myths of heart disease. All of the perceptions were negative because of severity of the disease, which can cause either family's uncertainty or the children's death. However, there was one positive thought among families dealing with CHD, they hoped that their children could be cure by medicines followed by surgery, which will be explained in the next category.

Requiring Medicines Followed by Surgery

Through closed observation of the child's health and improved understanding of the severity of the child's conditions, as well as through receiving information from physicians, parents realized that the child required pharmacological management followed by cardiac surgery. They believed that following modern medical treatment would be the best way to help the child. In particular, the parents were confident and faithful in the physician's ability, leaving the child's life into his hands. Exchanging experiences with the mothers of other children with heart disease and the support of family members contributed to their decision of taking the child to receive the modern medical treatment.

Requiring Medications

Most parents were informed by that heart disease of their child was curable by the surgery. However, the child could be performed only when the child was physically ready, of a suitable weight with no infections. While waiting for surgery, the child required medications to help the heart function and relieve the heart disease symptoms or heart failure. Through direct experience in caring for the child, parents realized that the medicines prescribed for the child before the heart surgery were greatly important to prop up their child, preventing from tiredness, slowing the heart beat, or preventing the overwork of the heart. Medicines also improved the general condition, as the child would not catch cold often. Nai's father whose son born with TOF was operated when he was two weeks explained that "*A doctor said my kid must*

undertake another surgery to be cured. Before that, he has to take medicines and be stronger and older." Likewise, Bank's mother described that:

> *I follow doctor's advice. He told my child must take medicines followed by the surgery to get cured. I hope that my kid would be cured with a single surgery… (P7 Int3/696)*

Regarding heart disease medications, Lanoxin or *Ya Huow Jai (ยาหัวใจ*, heart disease drug), was cited and recognized by the majority of parents as helping slow the heart rate or preventing the heart from overworking, and they knew it must be taken continuously. As Bank's mother, a garbage collector with a primary school education, said:

> *I know Lanoxin is Ya Huow Jai. My kid's heart had beaten very rapidly until he took this drug. His heart beats more irregularly than others and the drug could help it slow down. (P7Int1/531-548, Int 3/ 497-499)*

In addition to Lanoxin, parents perceived that other types of medications were vital for the child to help improve the heart function. Some parents could remember the English names, instruction and properties of the medicines, as they realized all of medicines were important for the child's heart. Fah's mother, a housewife with secondary school education, explained that:

> *Phoo-rew-tic (Furetic) is to increase the urination rate while Cap-to-pew (Captopril) is used to treat high blood pressure. I don't know why the doctor prescribed the high blood pressure drug. For the urination medicine, I think it's for removing excessive fluids in his body to prevent the pulmonary edema. I know my child must take all medicines, as they are all important. (P4 Int1/231-251, Int4/552-555)*

Some mothers noted that after taking medications, their child would not catch cold frequently and not feel as tired as before. Pim's mother recognized that medications were vital to the child's life, as she said:

> *My daughter with heart disease must take all medicines as they'll help her. Without drugs, she must be bad. Simply speaking, if Pim didn't take medicines, she could have been worse. Taking medicines helps her heart work better without fatigue and difficulty breathing. (P1 Int4/644-649)*

Requiring Surgery

All parents in this study were explained that surgery was the treatment of choice to cure some types of heart disease. Seven families were informed that their child could be cured by the surgery only. The child of one family had complex cyanotic CHD, which could not be treated by the surgery. However, all families made the decisions about the treatment according to the pediatricians' recommendations, including the decision about heart surgery, without any questions. They were confident in the pediatric cardiologist and surgeon's ability to cure their child safely, as told by Fah's mother that:

> *The doctor told me that my child would have a surgery. It depends on him when he will perform the surgery. If he'll do, let him do. I never think that he should wait until my child grows up. I think my daughter will be cured by the surgery. (P4 Int 2 L25-30)*

Parents were informed that CHD could be divided into two types according to the change of skin color: cyanotic and acyanotic. Parents viewed some defects different, depending on which area of the heart they affected. If the defect was found to the extra blood vessel, parents viewed it as differently and less severe than other defects,

like the ventricle or heart valve. They realized that it is easier to treat or perform the surgery for a child with blood vessel defect than the one with heart disorder.

As mentioned in the demographic data, four parents of children with acyanotic heart diseas, PDA and VSD, were told that the child's heart disease could be completely cure. Pim's mother, whose daughter had PDA, said:

> *A doctor said my child has PDA and needs a surgery to be completely cured. After the surgery, the disease won't attack her again. He reiterated that the surgery is needed. My kid would be in pain, though, I'm confident she'll be completely cured. It's lucky that her disease can be cured with the surgery. (P1 Int2/375-392, 596-597, 4/1043)*

A mother of a child with a VSD realized that the surgery was the only way to cure her child completely, as the ventricular septal defect would be closed with stitches. Jing's mother with a high school education, stated:

> *The doctor said it's not worrying. My child will be cured definitely. He said a VSD is a hole in the wall of the heart which he compared with a hole in the roof. If it rains, the rains could drop onto a pillow. We have to repair it, so that pillow wouldn't be wet. We have to tackle the cause. I guess there's over 90 % chance that he'll be completely cured and not suffer it again. (P3 Int3/146-147, 200-205, 4/252-260)*

Meanwhile, three children with cyanotic type, Tetralogy of Fallot and Pulmonary stenosis, could be cure after two separate surgeries. Based on information provided by physicians, the mothers understood that the second surgery would be performed when their children grew enough, as told by Nai's mother:

> *The doctor said my kid has narrow blood vessel and a hole in the wall in his heart and he requires two surgeries. In the first surgery, the doctor would repair the narrow blood vessel in his heart, and he would close the hole in the wall of the heart in the second surgery. It's a major surgery, so he must become older. (P2 Int1/66,78-80, 3/ 49-58)*

However, there was one child with complex cyanotic type, Common Atrium and Single Ventricle, that needed more than two surgeries, but could not completely cured. The physicians informed the parents of the steps and reasons of each surgery to help improve the child's condition. As Mind's mother said,

> *Ajarn (a cardiologist) said my child needs several surgeries, but he's not completely cured. There's no chance for him to have a complete heart like other children [said with sad face]. My child needs more surgeries according to the treatment steps. He must be treated step by step. I know the disease of my child is incurable and he must receive the treatment continuously. (P6 Int1/80-85, 3/16-18)*

In the meantime, parents in this study also learned the surgery could not only cure the child of heart disease, but also reduce the development of complications like pneumonia during pre-surgery periods; therefore, they needed their child to undertake the surgery as quickly as possible. Bank's mother told that her child was admitted to the hospital for pneumonia for two times with severe conditions, and had long recovery times both times. She hoped that the child would not often have pneumonia after undergoing surgery. As she said,

> *I want him to get the surgery quickly. He'll be cured with the surgery only. I don't know how the doctor would perform the surgery, but I know for sure there's less chance for him to develop pneumonia. I felt very pity for him when he suffered pneumonia [(she said with sad look)] .So I want him to get the surgery quickly. I don't want him to sleep weakly. (P7/1/188-190,3/399-400, 543-546)*

In summary, families understood that heart disease was a dangerous and life-threatening disease. The CHD children may not survive, and that their child would be difficult to care for. The children all required pharmacological management followed by surgery. They believed that the child's CHD was caused by previous karma or mother's practices during pregnancy. Most families interpreted the child's illness and

treatments using their personal and cultural belief, their experience as well as physician's information, which was the combination of western hospital-based biomedicine and Thai traditional belief. The nature of belief and perceptions of the child's heart disease and treatments would contribute the practices of families providing care for their child, which will be presented in the next part.

Discussion of Families' Perceptions

The perceptions of families regarding the child's illness started with the negative thought: "*Pen Laew Arj Mai Rod,"* or "our child may not survive." Over time, however, parents found out the causes of the child's heart disease, and learned about symptoms and treatments. After receiving more information from physicians and learning from other families with CHD children at the hospital, parents understood that their children required pharmacological management, followed by surgery. It was found in this study that families' understanding of their children's illness, as well their perception of that illness, was formed by a combination of biomedical and traditional Thai perspectives.

The biomedical aspect initially led families in this study to believe that CHD would necessarily be fatal, as it was a disease of the heart. It was clear that the families had taken for granted that the heart was the body's most vital organ. As the one most necessary for life, the heart was also considered central to every aspect of life. Its importance surpassed, or at least could not be considered separately from, the mind. The Thai language does not even distinguish the two concepts—*jai* is used to describe concepts that in English would be considered the realm of the intellect.

Therefore for Thai people a disease of the heart is of extreme importance. Such an ailment is seen as involving more than simply a particular organ that pumps blood through the body. "Heart trouble," in addition to leading to weakness or poor health, is generally considered to be incurable, given the centrality of the heart in the Thai way of thinking. Furthermore, Thais speak of loving and sharing as the "heart of a family." Thus when the heart has an illness, it is a terrible event not just for that person, but also for the entire family.

Most parents believed that heart disease typically occurs in the elderly or in adults, and when it happens to very young children, it must be more serious. Particularly, as parents recognized the rapid and strong heart beats that were among the child's signs and symptoms, they thought that the child's heart might stop functioning suddenly without warning.

Likewise, parents viewed the idea of surgery for an infant or young child as very serious. They felt their highest stress after first learning that their child might undergo an operation. Parents feared that death might appear to their child at any second during that time. They were constantly faced with uncertainty and unpredictability about the child's future. Similar to the findings from previous study concerning the impact of CHD on parents and family (Emery, 1989; Garson, 1978; Goldberg, Morris, Simsons, Fowler, & Levison, 1990; Goldberg, Simmons, Newman, Campbell, & Fowler, 1990; Nukulkij, 1993), all parents in this study found their lives full of stress. This uncertainty and unpredictability about the child's condition and survival of the child contributed to the practices of families in caring for the child that will be presented in the next section.

The parents' ability to recognize the child's condition, and thus the degree to which they became alarmed about unstable conditions, depended on the child's signs and symptoms. Typically, children with cyanotic heart disease were recognized by their parents earlier than those with acyanotic heart disease, which mostly included strong and rapid heart beats or rapid breathing and tiredness. Based on the pathology of heart disease, the clinical presentations of children with CHD are caused by hemodynamic changes (Bowden, Dickey& Greenberg, 1998). In children with cyanotic defects, cyanosis is caused by hypoxia, or arterial desaturation, which produces hypoxemia and tissue hypoxia, a lower amount of oxygen in the blood. The parents could easily see a purple color in the child's lips, nail beds, gums, and around the eyes. With the central cyanosis, infants and young children become tired easily and out of breath with activity. Symptoms such as shortness of breath and fainting often worsen when the child exerts himself (Ashwill & Droske, 1997; Suddaby, 2001).

It was clear from interviews with the parents that they believed in the effectiveness of treatments, especially the efficiency of doctors performing heart surgery in the study settings. After receiving information from physicians and improving their understanding of the severity of the child's conditions, parents realized that the disease could be cured by continuing medical management, including medicines followed by surgery. During the period of waiting time for surgery, parents were able compare their child's conditions with other CHD children who had more severe conditions, but had been cured and were healthier. The parents thus had hope that their child would be cured or would be as healthy as other typical children again. Consequently, parents believed that surgery was the significant method by

which the child might fully recover. They then strictly followed the doctors' treatment without questions.

It was found that the parents deeply believed in their doctors' efficiency, as well as in the competence of advancing medical technology to investigate and relieve the child's symptoms. This might be because parents had a chance to share experiences with other parents whose child had CHD were cured after receiving treatments from the doctors in the hospitals, which are very well-known. With the capacity of more than 3,000 beds and more than one million outpatients visit per year, Hospital A is one of the largest public hospital in Thailand (Siriraj Hospital, 2009). Also, Hospital B is one of the most famous hospitals in Thailand (Ramathibodi Hospital, 2009). It was clear that those perceptions were formed by biomedical perspectives, which were based upon an increased understanding of the pathology and physiology of the illness, and upon a confidence in medical and surgical treatments, and in advanced technology and scientific methods.

Regarding the causes of the child's illness, families articulated a mix of etiological belief systems regarding their child's CHD. These beliefs ranged from karma to the mother's practices during pregnancy—including the consumption of certain food or medicines, and the exposure to environmental toxins.

Nearly all of the informants mentioned the child's illness and karma. Most of parents believed that the heart disease suffering of their child was a result of karma in the past life. As the certain cause of heart disease was still unknown, karma was cited by parents as an acceptable reason for the child's illness. Parents tried to explain the cause of illness by all sorts of means. When medical knowledge could not explain or answer all parents' questions about the causes of the child's heart disease, they said

they felt regretful and helpless, and so they turned to their personal or family beliefs to interpret life and their practices that might cause the disease.

Karma appears to be a popular issue that Thai people use to explain the causes of illness (Junda, 2002; Klunklin, 2003). All of the parents in this study were Buddhist, and deeply believed in karma, which is a main theme of Buddhism and forms the Thai ways of thinking (Chunuan, Wanaleesin, Moukreungsai, & Thitimapong, 2007). Buddhist belief holds that karma is connected to the evolution of all life's events and that after one's death, that karma is reborn in the new existence. In this way, everyone has it in their own hands to determine their next life, for better or worse (Chunuan, Vanaleesin, Morkruengsai, & Thitimapong, 2007).

Buddhist teaching influenced the perceptions of parents in the study that karma from the past life and present actions caused their child's illness (Phra Saneh Dhamavaro, 2003). Briefly, Buddhism teaches that one's life does not begin with birth and end with death, but rather is a link in a chain of lives, and that each condition is caused by previous actions committed in previous existences. The cause of heart disease in this life was perceived to be linked with *previous karma*, especially with bad actions such as killing or causing suffering to animals or people in a past life. *Present karma* is also thought to contribute to illness, such as when current bad behaviors cause sadness to one's parents. Illness might be retribution, for example, for having hurt one's parents because of rudeness, as in the case of one families. As Buddhists, the parents believed that the karma of both parent and child, from both past and present actions, could have caused the child's sickness. Karma provided an explanation that the parents could accept. This belief reaffirmed that people had no control over this disease, and therefore should accept it and live with it. The findings

of this study were consistent with other studies conducted in Thailand (Jintrawet, 2005; Klunklin, 2003; Nukulkij, 1993; Pongjaturawit, 2005).

In addition to from karma in the past life, parents tried to find other possible causes of the child's heart disease, using a biomedical perspective. They strongly ruled out heredity because of none of family members had heart disease. Seven mothers blamed themselves, believing that their incorrect conduct during pregnancy—such as eating certain foods, taking certain medicines, participating in certain affecting activities, or receiving pollutants—could be a cause of the child's heart disease. The blame was based on hindsight, because at the time of their pregnancy the mothers did not feel concerned about their conduct.

When told that their child had heart disease at birth, mothers thought that their poor antenatal practices could have caused the disease, and consequently felt guilt and blamed themselves. This belief may have been strengthened by the fact that all mothers in this study had received antenatal care from the hospitals and gotten advice from health professionals about helpful and harmful actions that may affect the fetus. The mothers' beliefs about their own role in the cause of their child's illness may also have been reinforced by messages in the mass media, such as a TV health programs, advertising labels shown on the side of food or drink containers, and information on message boards at the hospital. Although such information did not specifically mention heart disease, mothers of CHD children became very aware after the diagnosis that some substances in food, drink, and medicines were unsuitable for a pregnant mother and could be hazardous to the child. Environmental toxins and polluted air, they believed, could also be harmful to a fetus and cause the child's heart defect. Mothers felt even more guilt if they were blamed by family members,

especially by their husbands. The belief that a mother's antenatal practices contributed to a child's illness contained several elements, among them modern biomedicine, western culture (food advertising), and traditional beliefs. Sometimes the mothers struggled between these competing belief systems, suggesting the need for information and emotional support to be provided by nurses or other health care providers.

Regarding the perceptions of families about the child's symptoms and treatments, parents recognized that CHD children were difficult to bring up and required medicines followed by surgery. The parents found that their child ate little, and could not drink enough milk, resulting in slow weight gain, growth delays, and frequent long lasting colds. This finding was supported by many studies regarding feeding children with CHD that reported such infants often take less volume per feeding and become dyspnoeic during feeding, so parents had to spend considerable time to feed their child (Behrman, Kliegman, & Arvin, 1996; Saenz, Beebe, & Triplett, 1999).

Six of the eight children in this study were infants and their ages ranged from 3 to 15 months. They all presented lower weight, some severely, when compared with healthy children. The mean weight for age of the children was 5,430 grams, which is lower than the third percentile. This finding is consistent with a western study that up to 37% of children with CHD will be below the third percentile on the growth chart (Mitchell, Davies, Day, Pollock, & Jamieson, 1994). The children's low weight also fits studies in western countries suggesting that after accounting for energy needs, infants with CHD might have only one half as much energy available for growth as healthy infants (Saenz, Beebe, & Triplett, 1999). Infants with heart

failure and/or cyanosis are also more likely to present with malnutrition and growth failure (Cameron, Rosenthal, & Olson, 1995; Odette, 2000; Varan, Tokel, & Yilmaz, 1999). Children with heart defects who were symptomatic mostly presented the signs and symptoms of congestive heart failure (CHF) including tachypnea, difficulty breathing, tachycardia, being pale and cool, and tiring easily (Laohaprasittiporn, 2003). In addition, infants who have chronic hypoxia are more likely to have dyspnea and tachypnea during feeding. Therefore, they are often tired easily, and as a result, reduce the quantity of food consumption (Wheat, 2002), which parents could also recognize easily. Some infants were very lethargic, awaken poorly for feeding, take extended periods of time to finish feeding, have a poor suck, and experienced episodes of vomiting, resulting in overall delayed growth and development due to these poor feeding patterns (Gudermuth, 1975; Lobo, 1992).

Information from the children's outpatient books showed that every child in this study caught a cold once or twice a month. Parents mentioned that the child was difficult to care for because the child got URIs frequently and took a long time to recover. Six of eight children were admitted to the hospitals 1-3 times due to pneumonia. The results illustrated in this study could support the general pathology of CHD regarding susceptibility to respiratory infections, including upper respiratory tract infections or pneumonia because of the pulmonary edema and lowered efficiency of the lungs (Cook & Higgins, 2000). Recurrent respiratory infections are common in infants who have large intracardiac left-to-right shunts because the lesions cause an increase in pulmonary blood flow caused by a left-to-right shunt that allows excessive pulmonary blood flowing from the right ventricle to the lungs (Smith, 2001).

After diagnosis, surgical correction was suggested for all children. The families perceived that surgery was a helpful treatment to correct the child's heart defect. Although parents and other family members worried and feared that their child might not survive, they allowed the child to receive surgery. This could explain that parents realized that the child had some defects in the heart or the blood vessels. Most of them could see the possible defects via the TV while the child was having an echocardiogram. Thus, they thought that those defects could be repaired directly by surgery. The parents also got positive information and experiences regarding the surgery. They had met other parents of cardiac children and knew that their children who underwent surgery could be cured and had stronger health.

They also got positive information from doctors and other parents at the hospital regarding the chances that their CHD child could be cured by surgery. Through observing various children's health and understanding the severity of their child's condition, parents realized that surgery was the most significant method by which the child might fully recover. In particular, they had confidence in the physician's surgery expertise at Hospitals A and B, which were big and famous hospitals in Thailand. Thus, they followed the child's treatment plan and took the child to follow up as scheduled, choosing not to wait until the child was older. This finding was in contrast to the findings of Nukulkij (1993), who reported that some parents with CHD were hesitant to allow their child to undergo surgery and preferred to wait until the child was more than five years old.

In summary, families' perceptions regarding the child's heart disease and its treatments were influenced by biomedical and traditional beliefs. Most families interpreted the child's heart disease using their personal beliefs and experiences, and

integrated biomedical knowledge into their beliefs about CHD. The families perceived that heart disease was a fatal illness caused by karma as well as by the mother's practices during pregnancy. The children might not survive and were difficult to bring up. However, they realized that the CHD child would require pharmacological management followed by surgery. The families' perceptions would contribute to their practices in caring for their CHD children. These practices will be presented in the next part.

Part 3: Practices of Families in Caring for Children with CHD Prior to Cardiac Surgery and the Socio-Cultural Context Influencing the Practices

This section presents the findings of the study following the second and the third research questions; 1) what were the daily practices of Thai families in caring for children with CHD aged 0-3 years prior to cardiac surgery? and 2) how did Thai socio-cultural context influence their practices? The practices among families caring for children with CHD aged 0-3 years prior to cardiac surgery was categorized by the phrase "Doing Our Best to Get Our Child Ready for Surgery." Families tried to deal with the child's heart disease as best as they could. They incorporated the child's heart disease into their family. Perception and understanding of the diagnosis and treatments contributed the practices of families. Despite there was difference in each family context, financial problem in particular, it was clear that families tried their best to care for their child in order to prepare the child to be ready for surgery.

Doing Our Best to Get Our Child Ready for Surgery

The pattern of practices of families in caring for children was characterized by the phrase "Doing Our Best to Get Our Child Ready for Surgery." Based on information provided by physicians, families explained that "Doing our best to get our child ready for surgery" was the main goal of their practices. The families understood heart disease was a dangerous disease that could claim the child's life, and the child had severe and worrying symptoms. They thought that children with CHD were always ailing and had growth retardation. Particularly, having informed by the physicians of the chance that their children could be cured by the heart surgery when they grew up and gained proper weight without infections, the families tried to care for the child as best as they could to get the child gain weight and strength to withstand and recovery from heart surgery. Pattern of the practices included: 1) promoting the child's weight gain and strong health, 2) preventing the child from getting worse, and 3) managing the child under the constraints

Promoting the Child's Weight gain and Strong Health

With appropriate weight gain and strong health, the child could be ready for the heat surgery, prevent from complications and a quick recovery after the surgery. The parents realized that milk and rice are major foods that are of great importance in the child's growth from newborn to toddler. This perception developed from applying their knowledge and previous experience as well as the information from relatives, neighbors and health care professions. The parents focused on two main points: feeding sufficient food and feeding nutritious food.

Feeding Sufficient Food

Parents found that their child with CHD ate less and gained weight slowly due to the illness. To have the child eat more, they put all their effort to feed a small quantity frequently, feeding various foods, and feed solid food. Thai traditional medicine, Chinese herbs and supplementary food were also used as recommended by their neighbors and elder relatives in the family. However, parents still considered the child's preference and safety by feeding the child favorite food in an amount that the child could take. They also avoided salty food due to concern over the potential hazards to the heart as advised by health care professionals.

Feeding a small quantity frequently. Mothers tried to feed the child with more food by feeding more often as possible or continuing feeding, feeding 3 to 4 meals a day, on the understanding that the child would not feel bored and could eat more. When mothers found that their CHD child could eat a small amount of milk and food for each meal, they were mainly breastfed as frequently as needed.

While interviewing mothers who still breastfed their children, the researcher found that the mothers breastfed their children continuously everywhere and every time the child was hungry. When the child cried, they would suddenly breastfeed him/her. The child would suckle for 5 to 10 minutes, stopped to play with toys, and then came back to suckle again. Jing's mother revealed her reason why she still breastfed her 1-year-5-month daughter, despite her relatively small weights of only 6100 grams: Jing was breastfed until she was two years old. Jing's mother provided her description as follows:

My daughter eats gradually. This morning she ate only two table spoons of rice. So, I mainly fed her with breast milk all the day. She doesn't eat much, just enough to fill up. So I let her suckle frequently, as I'm afraid she won't be full. She has a very gradual gain weight, so I want her to have more weight in order to receive the surgery. (P3 Int1,733-736)

Bank's mother told that her son was five months old and weighed 4,600 grams. She started to feed him with banana and boiled rice since the child was three months old like her elder children. However, this infant could not eat much so she fed him more often.

I feed my kid three meals and he eats gradually each meal. He eats often but not much, so I divide his meal for feeding several times. It's better than eating nothing. He can drink little milk. I'm afraid that isn't enough for the body requirement. I fear there could be something bad with him or he could have complications. I want him to gain weight before the surgery. (P7 Int1/ 86-87, Int 2/ 294-295, Int 3/437-454)

Not only breastfeeding more often, mothers also offered 3 to 4 meals, though the children were less than one years old. Bee's mother said that her child was seven months old but weighed only 5,600 grams. When she took her daughter to see doctors, they often mentioned said that Bee was quite small and her body weight was low. The mother therefore continued to breastfeed her child several times, or as frequently as possible. She fed the well mixed food (Cerelac cereal mixed with boiled egg and vegetable and minced soup) alternatively with plain water and the girl could eat it all which, equaled to three table spoons. The mother explained her feeding method as follow:

I tried to feed to my kid milk and food as much as she can. I specially care her as she couldn't eat much. She eats gradually. This morning she ate only two tablespoon of rice. She ate little but frequently. I'm going to feed her again this afternoon. I feed her 3 to 4 meals, but she eats less. She's also breastfed often but gradually. I want her to gain weight before the surgery. Being strong and healthy could help her tolerate the surgery. (P8 Int1/218-226, Int 2/100-107, 123-124)

Feeding various and preference foods. To encourage the child to eat more, mothers fed various foods as well as changed the flavor of milk and food the child wanted. Various foods with different types and flavors were served apart from boiled rice to encourage the child to have good appetite and eat more. Mothers avoided the same food for several consecutive days thinking that their children would feel bored with the same food every day. The taste of formula milk was changed as did the type of vegetable boiled with rice.

Four mothers mentioned that they tried to feed many kinds of food the child wanted, as seen in cases of Pim. While visiting Pim at her house –a 1 year- old girl with PDA, weighing only 6,400 grams, the researcher saw the girl lying down and sucking a four-ounce bottle of infant formula. She sucked around one ounce, then paused and cried for the snack that her elder sister was eating. The mother shared some snack with Pim with the little girl eating only one piece of it and holding it as a toy. In the meantime, another girl was walking with a sausage in her hands, Pim cried for it again, so the mother fed her with some sausages that she ate a few bites and later threw them up. For Pim's mother, feeding sufficient food was the first approach to help her daughter gain more weight. Therefore, she woke up earlier to feed her child before going to work as well as did not work part time in the evening to come back home early to make food and feed her child. Pim's mother told how she fed her child each day after the doctor advised her to increase the weight of her child as follow:

> *I've tried to push my kid to eat a lot, so I keep feeding her. In the morning, she'll have boiled rice and the grandma at daycare center will feed rice with fried egg, snack and banana for lunch. At around 4 o'clock in the afternoon, she'll be served boiled rice again and before bedtime I'll feed her some banana. I want her to gain weight before the surgery. At least, her health is*

strong enough for the operation. (P1 Int2/433-443, 456, 2.1/340-341, Int 4/206-215)

Likewise, when the researcher visited New—a 10–month-old boy weighed 6,300 grams, several kinds of fruits like apples, Chinese pears and oranges were prepared for the boy. All of these fruits were given by her neighbors. During the conversation with the researcher, the mother often fed him with fruits and sometimes let him eat by himself. The mother told her feeding method to help her child gain more weight and be healthy before the surgery that:

My kid can't eat much but I try to feed him as much as possible all the day. I think it could help him be healthy and gain weight. Like this morning, I fed him with rice and fried chicken and later he had a box of Bear Brand milk and some fruits. At lunch, I fed him with Pad See Aew (fried noodle) or noodle or whatever he likes. (P5 Int 2/965-967, 1063-1076)

Feeding solid food. Feeding solid food refers to parents feeding their child cooked rice instead of boiled rice or soft rice porridge, on the belief that the grain could fill up the child faster and keep the child's stomach full for a longer time of period. Since mothers believed that rice grain was more filling that other than milk, all mothers fed their children solid food. In addition, they believed a bowl of cooked rice was more nutritious than a bowl of soft boiled rice because of rice grain could satisfy their children's hunger faster and keep their stomachs full for a longer period of time. This understanding was also based on physicians' recommendation that parents should feed more solid food when the child's weight was steady or gained gradually without enough information. Some mothers therefore fed the children with cooked rice and boiled more to make it softer, glutinous rice or rice porridge.

The child would be also encouraged to eat more rice than milk, while the mother would delay her breastfeeding time in order that the child would eat more rice.

Mothers tried several methods to feed solid food such as changing from rice porridge to cooked rice that was boiled again to make it softer or feeding him with the same food that adults ate. Jing's mother said that her child could not eat much and had the weight unchanged since she was 6 months old or after he was diagnosed as having a heart disease. The child now became 1 years and 5 months old, but still weighed only 6,100 grams; therefore, the mother tried to feed more solid food, as she said:

> *The nutritional doctor told me to avoid soft boiled rice, but feed solid food as it could help her gain weight. So I feed my kid with rice by boiling cooked rice again to make it softer. She can eat more solid food because she usually shares food with us and we usually eat cooked rice. (P3 Int3/1186)*

Fah's mothers tried to feed her child with boiled rice and infant formula to keep the child's stomach full for a longer period of time and gain weight, as recommended by physicians. As a pre-mature infant, Fah was small and had lower weight than other children with heart disease. Therefore, she was fed with solid food added with special formula as told by the mother as follow:

> *My daughter was now 1 year old, but weighed only 4,100 grams. So, doctor gave my kid special formula to gain weight, but I think it couldn't fill her up as milk is light meal. I think eating solid food could make her stomach full and she likes it. So I feed her boiled rice 3 to 4 meals. (P4, Int3/152-159)*

Nai's mother said that her child was ten months old but weighed only 6,200 grams. The child had been breastfed and offered rice porridge when he was four months old. She began feeding cooked rice or glutinous rice for her child when he was eight months as the doctor informed that the child could undergo the heart

surgery when he weighed 8,000 grams. However, due to fear over the chokable foods, the mother would pre-chew foods before feeding the child. Nai's mother said that her child was 10 months old but weighed only 6,200 grams. The child had been breastfed and offered rice porridge when he was 4 months old. The researcher observed that the mother pre-chewed food for her baby. The mother said:

> *I want my kid to gain weight so I feed him solid food as he can have more intake of rice than soft rice porridge. A ladle of cooked rice can be made as much as a pot of rice porridge. I try to feed him with what I eat and he can eat it. Like fried rice, I would pre-chew it* before feeding him. His favorite *dish is now glutinous rice and grilled chicken. So I'll pre-chew them for him smiling. (P2, Informal Int 15 Mar, 25 April,07, Int4/93-97)*

Delaying breastfeeding and feeding less breast milk could be another method to encourage the infants to eat more solid food even though they were less than eight months. Bringing up the child closely let the mother know well what time he would feel hungry, when she should breastfeed and how long she should delay breastfeeding to help the child eat more solid food. Mothers in this study largely delayed breastfeeding around 2-3 hours, as told by Nai's mother about delayed breastfeed and feeding of less milk.

> *The doctor told me my son can have surgery when his weight is up to 10 kg, but now he is only 6 kg. So I gradually weaned my baby. I stopped breastfeeding him at 4-5 o'clock in the morning so that he could eat more rice for breakfast around 7 o'clock. I try to feed rice because only milk is not enough to make him full while rice could. (P2 Int 2.1/ 266, Int 3/227-232, Int 4/482-486)*

Three mothers believed that their children suffering other ailments preventing them from food, then tried to use Thai traditional medicine and Chinese medicine to help the child grow an appetite. The practice stemmed from their own experience of

raising other elder children or advice from older relatives and neighbors. They believed that their children could not eat much because of *Saang disease* (โรคซาง, a disease of children following Thai traditional medicine, which could be remedied by Thai traditional medicine). When a child was afflicted by *Saang disease*, the child would have a fever, sometimes having thrush in mouth or a sore throat, causing the child to refuse milk and food. Mothers also believed that the disease could be cured by applying Thai traditional medicines like *Yaa Kieow* (ยาเขียว, an anti-pyretic medicine made from powdered medicinal plants) and *Yaa Saeng Meuk or Yaa Saeng Meuk Bai Poh* (ยาแสงหมึกหรือยาแสงหมึกใบโพธิ์, an anti-pyretic medicine made from powdered medicinal plants) to remedy the infection of the baby's mouth and help the child eat more. Bank's mother mixed a black powder medicine—which the label writing *Khaolaor Phaesaj* (ขาวลออเภสัช, a tongue infection medicine)—with water and applied it on her child's sides of cheeks, lips, gum and neck. The mother believed that disease was the main cause making her child eat less or unable to eat. It is similar to Nai's mother who told that,

> *My cardiac child can't eat much. Mom (the child's grandma) told me that it's because of Saang disease causing sore in his throat. I just put Sang-Muek drug on his tongue for once. If he still can't eat, I'll put it again because I want him to eat more rice to gain weight, and it works. Now his weight is increasing (P2 Informal int, Feb9.07)*

New's mother, whose neighbors were many Thai Chinese, said that her neighbors recommended that she made Chinese herbs for her child to have an

appetite. The mother also provided the child with ginseng and Brand's essence of chicken for children as advised by her neighbors. New's mother stated that,

> *I took my kid to pay respects to Chinese monks at Wat Mungkorn Kamalawas (วัดมังกรกมลาวาส) and I shook fortune sticks. There I got Chinese herbs and boiled them with a bowl of water for such a long time, until the water was reduced to a half of a bowl. That was for 3-4 days of intake. It was good for him as he looks healthier, having pink mouth and can eat more. ..My neighbors also gave ginseng and Brand's essence of chicken to me and said these could make my child eat and be healthy. So I tried them and it works. My kid looks healthier. (P5 Informal int, Feb23,07)*

Amid the effort to encourage the child to eat fully, the mothers were also concerned for the child's safety. Some mothers told that the main obstacle to feeding was the child refused eating, even though they tried all methods. They admitted that they dared not force or displease the child, for fear over the possible hazards to the heart. When seeing their child cry and vomit a lot, the mothers decided to stop feeding as they were afraid the child would not be safe. Mind's mother explained about her difficulty regarding feeding the child's foods that:

> *I fed my ill kid with rice porridge with egg and pork and Cerelac cereal, but he refused them all. I tried all, but it failed. It's difficult to feed him as he'll split it out. How many times I feed him, he'll vomit it. So I dare not to push him as I'm afraid his body can't tolerate it. I also dare not forcing him as he could vomit and the phlegm could block the bronchus and esophagus. I don't want to see him admitted to the hospital again. Every time he's admitted, that could make him skin and bone. (P6 Int2/193-201, 213-215, Int3/47-48)*

Bee's mother stated the same problem about feeding her daughter's food that:

> *Eating much could make her vomit and tired. It's difficult to force her because if she cries, she could turn green and I'm afraid she'll get worse. I also dare not to let her eat too much as it could make her full and she can't breathe. (P8 Int1/222-225, 2/210-211)*

In addition, mothers perceived that salty food was a food to be avoided, as they were advised by the nurses that it could threaten the child's heart. Parents were given information that salty food could lead to heart attack; therefore, flavorless food was served, instead. When buying food, they would tell the cook not to add such additives as fish sauce, soy sauce, salt and monosodium glutamate (MSG). Especially for parents whose children had had heart attacks before, they were more concerned and cautious on food selection as seen in two participating families.

> *I stopped adding salt in her food since the nurse told me that salty food is not good for children with heart disease. I avoid salt, fish sauce, soy sauce and sauce in his food even in the rice. I feed him with flavorless food and he can eat it. (P4 Int1/208-220, Int 4/730)*

> *My kid had heart failure before. So I avoid salt and MSG. When I buy noodles, I'd tell the seller not to add MSG and fish sauce. However, I feed him only noodles, and don't feed its soup as it's salty. For rice porridge, I won't add fish sauce, soy sauce and MSG. Even soup, I'll prepare another bowl for him. Bread is also avoided as it contains butter that is salty. I used to add little salt in cooking rice, but now I didn't as advised by the doctor. (P7 Int1/308, Int2/169-189, Int3/307, 311-322, 567-568)*

However, Jing's mothers revealed that she could not limit salty food as well as crispy snacks and fried seaweed as her child liked it and liked eating what others in the house ate or fed her. Although the mother knew that it was not good for the child's heart, she thought that it might be better than their child did not have any food, as Jing's mother told:

> *I know salt is not good for my kid's heart, but I don't know how to stop her. Limiting salty food is good for her health, if you can do it. But she likes to eat what I and other adults in the house eat, that's difficult. The food we eat is a bit salty. Anyway, I let her eat it, as it's better than she doesn't eat anything. Today, I prepared salted fish. I let her eat a bit with rice and she can eat a few bites. This is better than nothing as I want her to eat rice. (P3 Int3 1025, 1167-1168)*

Feeding Nutritious Food

Parents tried to feed nutritious food, which they believed contained nutrient and vitamins their child. The food selection was based on their own experience and advice from older relatives in the family and neighbors as well as the information board at the hospital, the child health handbook as well as TV health program and advertising. It appeared that parents brought their traditional belief integrated with biomedical perspective receiving from physicians and other advertising culture. Bananas were favored fruit as the parents believed that it could help the child gain weight, contained no disadvantages, and keep their children's stomach full a long time. In particular, parents tried to feed all five main groups of food even though some did not have knowledge about the values and vitamins of each type of food. In addition, mothers fed infant formula milk and instant baby food additionally or replacing breast milk.

Feeding all five main groups of food. Parents fed five main groups of food on the perception that the child would receive nutritious food according to nutritional principles. However, eight of them said that they did not know details about which nutrition or vitamin was contained in food. Nai's and and Bank's mothers provided their statements as follows:

> *I feed my child nutritional food, like protein from pork, egg yolk, fish and vegetables. Sometimes I fed my son rice and omelet, as well as ateaspoon of vegetable oil, in order to add more fat in his food. I try to feed him the 5 main groups of food to help him gain weight. If he gains weight, he will be strong and be able to safely undergo the surgery. (P2 Informal Int April25.07, Sep 16.07)*

> *I feed my kid with rice mixed with egg, liver, pumpkin and carrot. I try to feed him with eggs everyday as advised by the doctor because they contain vitamins to help him gain weight quickly. I pay more attention to this kid than*

my other children for fears over the potential complications during his surgery. And I want him to gain weight before the operation. If his weight is too low, I'm afraid he won't be able to tolerate the surgery. I want him to have a larger body. (P7 Int1/292-294, Int3/193-196, 604-607)

Fah's mother revealed that her child would stay longer at the hospital than other cardiac children every time she needed a hospitalization as she was very small with low weight. When the child was going to undergo the surgery, the mother tried to feed the child with five mains groups of food, as she said:

I want her to get many calories like carbohydrate in rice, protein in meat, fat in oil and minerals and vitamins in vegetables. That's 5 main groups of food according to the nutritional principles. I pay special attention to her diet. If she's strong with proper weight, that could prevent her from any risks during the surgery, reducing the risks of complications. In contrast, if she's small and thin, she could be highly vulnerable to any illness like if she has a fever, it will be very high. (P4 Int3/152-159, 168-177)

To nourish the children, traditional Thai families play a part, indicating that parents would obtain counsel and information of food from their relatives as seen in the case of Fah's family. Fah's grandmother would come from her rural home to visit her grandchildren and help caring them. Fah's mother said that the grandmother has helped her a lot such as cooking and giving advice on food. The mother said,

Grandma would cook the ivy gourd that was collected from the house fence. She said ivy gourd sold at the market is dangerous from insecticide. She mostly advised me about food, recommending what food is good for my child. She said vegetable is good as it could enhance the excretion. So she cooked vegetable soup mixed with pork and said the kid probably likes it. (P4 Int1/250-251, 698,750-751, Informal int, 20 Dec.06, Int3465-474)

Feeding infant formula and instant baby food in addition to or a replacement for breast milk. Due to their concern that breast milk had fewer advantages than formula, eight mothers gave their children infant formula and instant baby food, in addition to or as a replacement for, breast milk. The mothers breastfed their infants for at least

three months as they realized that breast milk was the most valuable for babies, that it helped them be healthy and strong, and it was convenient and cost saving as well. After knowing that the child had CHD and would undergo a surgery, the mother fed infant formula milk as a supplement. This perception was informed by physicians, neighbors, TV programs, and food advertisement labeled on the food.

Five mothers in the study mentioned that they fed infant formula replacing or adding to breast milk following physicians' advice. After the physicians found tat their child had slow weight gain, they recommended the mother to add the child bottle feeding. As Bank's and Nai' mothers said:

> *I supplement my son's diet with infant formula. I'll feed less than two ounces plus my breast milk per day. But some days, I didn't breastfeed him. I just give him infant formula. I think infant formula is more nutritious because my breast milk is tasteless and the doctor recommended infant formula, as it contains more nutrients. So, I'd like feed him with infant formula as advised by the doctor. Even though it's expensive, I fed him as I want to help him strength to withstand for heart surgery (P7 Int2/93-119)*

> *Doctor advised one kind of special formula, saying that Pedia Sure milk should be suitable for a small-sized kid like my child. So I bought a small bottle first as this brand of formula is quite expensive. That's fine if it could help my kid gains weight and be healthier. (P2 Communication via the phone, 19 Sep. 07)*

To encourage the child to have nutritious food, three mothers tried to wean their children or stopped breastfeeding them so as to feed them with infant formula and utilized milk. When the child was 8-9 months old, the mothers tried to wean their babies according to the traditional way told by older relatives such as applying some Thai herbs like *Boraphet* (บอระเพ็ด, Tinospora crispa) or *Fah ta lai jone* (ฟ้าทะลายโจร, andrographis paniculata) to stop babies from suckle. Nai's mother said:

> *Mom (the child's grandma) told me to apply Boraphet on my nipples, but my child could still suckle. But when I applied Fah ta lai jone, he's weaned now and doesn't suckle again. The doctor said infant formula is now more nutritious. Now I feed him with Carnation brand milk in daytime and my breast milk in nighttime. Some days he'll have 2-3 boxes of UHT milk as he refuses infant formula. (P2, Communication via the phone Mar15, June15, Aug8,Oct20 07)*

In addition, three mothers fed instant baby foods after receiving information from the TV commercials and the food labels showing the nutritional contents. The mothers also chose this kind of food after seeing their neighbors' children gain weight due to the food. They believed that instant baby foods that were generally available were more nutritious than the meals they cooked by themselves. It was found that instant baby food is popular among mothers living in urban area where parents need to earn their living and have no time to cook. Mothers accepted that it is easy to prepare, convenient and time saving for cooking. As New's mother told:

> *I started Cerelac cereal when my child was 6 months old as it's high in vitamins. I read its label showing the nutritional breakdown of vitamin, iron and vitamin B that helps the kid stronger with gained weight. I also feed Nestle biscuits mixed with honey flavored milk of Bear brand and he likes it as he could eat all in every meal. I think this kind of food is richer in nutrition than rice. Especially, it's easy and not take time to cook (P5 Int1/ 1205-1213, 2965-967, informal int July1, 07)*

It was clear that mothers did not receive accurate and adequate information about what kinds of nutritious food from health care professionals while the physicians often advised them to put on the children weight before surgery. Without accurate advice about infant formula, mothers followed the physician's recommendation thinking that infant formula could make the child gain more weight and healthier, and then tried to stop breastfeeding. However, mothers tried their best to feed various nutritious food following their own experience and recommendation

from older relatives in the family and neighbors as well as information from T.V. programs and advertising.

Preventing the Child from Getting Worse

Apart from promoting the child to gain weight and strong health, parents prevented the child from getting worse. The practices included preventing the heart from working too hard, meaning to help control their child's heart disease and enhancing the heart's ability to work efficiently. Families also tried to prevent the child from contracting other illnesses, especially contagious disease such as common cold and diarrhea, believing that being afflicted by other illnesses would only worsen their child's already precarious condition. In addition, families practiced traditional cultural beliefs In addition, parents practiced traditional beliefs such as making offering or asking for help from Buddha images, hoping the child recover from the illness, stay health, and remain safe through their heart operation.

Preventing the Heart from Working Too Hard

Families tried to support the child's heart function by preventing any activities on the part of their child (or parents and relatives) that could make the child's heart work too hard. These practices developed from parents' perception of what it means to be afflicted by heart disease, and their fear that their child cannot live when the heart cannot function. Their direct experience of child care let them witness the child's terrifying and frightening symptoms related to the heart pathology. Improving the heart function could prolong the child's life. Conversely, if there were any factors

making the heart—which had already had defect—worked so hard that it could stop functioning, then the child might not survive. The practices fell into four categories, including 1) providing correct dosages of medications and not skipping medication doses, 2) ensuring sufficient sleep; 3) preventing tiredness.

Providing correct dosages of medications and not skipping medication doses. All parents acknowledged the great important of medications. They believed in the doctors, put the child's life in the doctor's hands, and getting the treatments from hospital was their choice. They thought that following the physicians' treatment plans would prevent progression of the children's illness and pre-operative complications. Therefore, the parents tried not to miss dosing their children, and were concerned their children's conditions would worsen and they could die before undergoing surgery, if they did not take their medications. Thus they tried to follow physicians' directives regarding administration of pre-operative medications. The practice was based on hospital-based biomedicine perspective. It was found in this study that parents as well as family members dealt with their ways of living differently and appropriately within each family's way of life, dosing the child with the right amount and on time, as well as never letting their child miss the medicines.

After knowing their child had a heart disease, like other parents in this study, Bank's parents let the physicians decide on the child's treatment, believing and trust in them. The parents also strictly followed the physician's advice without any doubts on the treatment, including medicines and surgery. Bank's mother revealed that they were instructed by the physicians to administer all types of medicines continuously during the pre-surgery period, they tried to feed them all, as the mother said:

> *My child never misses a drug. I dose him on time. He'll be given every pill. If not, his heart will beat rapidly. He can't live without it. He has to be dosed at midnight, so I set an alarm clock to feed him. He never misses it. (P7 Int1/535-545, Int3/504, 185)*

Parents tried not to miss dosing the child after they observed that the child was better and healthier when compared with before taking medicine. Pim's mother noted that if her daughter did not take medicines, her disorder would be obviously seen. To illustrate it, when the daycare provider, who cared for the child in the daytime, forgot dosing her at 8.00 p.m., the girl could not sleep at that night, felt clearly nervous, and her heart beat very strongly. When medicine was going to be short, the child was taken to see a doctor for a prescription, as told by her mother that:

> *She never misses drugs and I never dump any of them. All medicines prescribed will be taken, every single pill. She'll be dosed on time as prescribed. Before this, I monitored how her condition was. I saw her get better after taking medicine. I paid lots of attention to this point. She'll be dosed every morning before I go to work. Giving medication is the first priority. (P1 Int3/ 81-84, Int4 141-159)*

Two families whose members worked away from their home prepare medications for the child care center personnel or their relatives who babysat to administer to their children as prescribed. The families provided detailed written information about dosing and attached it to each of the syringes to be used. For example, "*This syringe is given before lunch.*" and "*Don't forget to give the dru, in this syringe, with red sweet drink.*" (FN, P4, March25.07). After working, the parents were concerned about medicines by asking the babysitter or relatives every day to make sure if their child took all drugs given.

When taking the child on outings such as to the hospital, medicines and water would be prepared for their child, as parents were concerned about continuing the

child's medicines. Also, the parents would bring the remaining drugs in order that the doctor could check if the drugs prescribed would be enough for the next appointment. According to the observation of Fah's family during the examination at the hospital, the researcher found that besides cooked food in well-sealed containers, drugs that were already crushed and kept in a paper package were brought with them as well as plain water. The remaining drugs would be shown to the doctor, as told by Fah's mother that:

> *I'll bring the remaining drugs when going to see a doctor so that he could check that they're enough for the next appointment* [smiling]*. On the appointment date, I'll prepare the drug too so that my child won't miss it. Yesterday when I took her to the hospital, I prepared drugs for feeding after meals there. (P4 Int1/347-356)*

Two mothers faced some obstacles to feeding the child's medicines, such as when the child vomited the drug. Mind's mother told that it was difficult to dose her child. Feeding the child's medicines took a long time, as there were more than five types of drugs, and the child usually vomited after taking them. The researcher's observation of this participant at her house found that the mother would carry the child, walk around and find her toys while trying to feed drug in a syringe gradually. But after taking drugs, the boy vomited up, and the mother repeated the medications. Mind's mother expressed feelings that:

> *It's difficult to dose him all medicines but he must take all, I know serious face. He usually vomits. The doctor said if he vomits after taking drugs for less than 10 minutes, dose him again. If it's longer than 10 minutes, don't dose him. If he vomits suddenly, dose her again. So he never misses it. (P6 Int2/275-276)*

However, some mothers admitted they could not give medications on time every time due to several factors, but they never forgot it. Some mothers adjusted the

time of giving medicines to help the child take complete drugs. Bank's mother admitted she did not give medicines on time, especially at midnight or in the morning, as she sometimes fell asleep and did not set an alarm clock to wake her up for doing such at midnight. She solved the problem by giving medicine earlier or later than scheduled time by spacing the dosing time. In other words, they gave all medications as prescribed but not punctually. Bank's mother explained that:

> *Sometimes I was late by half an hour, but I never forgot it, just later than the time given. Sometimes I was deprived of sleep, so I woke up late in the next morning, and was a bit late. But I still dosed him. For midnight drug, I give him around 10.00-11.00 p.m., as he's still awake. I sometimes give him medicines around 2 a.m. However, I always see that each dose is spaced more than 6 hours (P7 Int1/539-545, Int 3/697-701)*

Three mothers postponed the dosing time because their child was still sleeping. The dosing time of the child depended on the time he/she woke up. Jing's mother said that she could not give drug before breakfast and at 8.00 a.m. punctually as her child would wake up at 9.00 or 10.00 a.m. The child would be dosed after waking up, and the medicine at 8.00 a.m. would be given instead at 11.00 a.m. The drugs at midday and other meals would be postponed respectively.

The burden of caring for all other siblings and doing chores were also the obstacle preventing mothers from giving medicines on time. As told by Mind's mother, who had to take care of four children and did all housework without any help from her husband:

> *I do all house chores and take care of my kids. So…I used to forget, but not frequently. But I never omit it. I might give medicines later than the scheduled time. But I dose him up every meal. Sometimes it was late by an hour, but I still gave him. I don't know that pre- and post-meal drugs must be given at 5.00 a.m., 9.00 a.m., and 9.00 p.m. punctually. (P6 Int1/219-233, int 2/270-271)*

Feeding all kinds of medicines and not miss dosing the child was the most concerns for all families. Families had limited understanding and accurate information about the actions of medicines. Some families had challenge to adjust ways of living as well as faced some obstacles related to feeding the child's medicines. However, they tried their best to do this care practice.

Ensuring sufficient sleep. Based on their perception their children had difficulty sleeping and that sleeping was the best rest for the heart, parents sought to assure their children's sleep was comfortable and lengthy. The evidences was visible—the child did not turn blue often but looked healthier, breathed more slowly, and their heart did not beat as fast as when they woke up. When their child had sufficient sleep, the parents believed that the heart could take a rest and not work as hard, slowing the heart rate. Parents tried to help their child get enough sleep by focusing on getting ready to go to bed and sleeping in a cozy, quiet, and safe place as well as accompanying and soothing the child.

1. Getting ready to go to bed. Parents kept the child clean, dry, and full so that their child could have a nice and long sleep. They would bathe the child, put the child on in clean clothing and a diaper, and feed the child enough milk and food, as well as change the diaper every time after a bowel movement. Apart from bathing the child one to two times a day, the child would be bathed or rubbed down and dressed in clean clothing before bedtime. Parents put their child on a diaper to prevent the child from waking the child because of wetting himself. To help the child get a cozy sleep, parents also cleaned the child shortly after bowel movements. The observation of Nai's mother when cleaning her child, who passed stools during sleep, showed that she cleaned the child's bottom with a wet cloth and rubbed him down before putting

him new pants. She told that she would normally wash his bottom after excretion, but if the child passed stools during sleep, she would only use a wet cloth to clean his bottom. She said that "*I look after him best. I changed his nappy to make him clean so that he can sleep longer cozily*." (P2, Informal Int 14 Dec.06)

2. Sleeping in a cozy, quiet, and safe place. The parents realized that perspiration was a common effect of CHD, even in cool temperature. They especially wanted their children to sleep in a comfortable, quiet and safe place. Thus, they often placed them on a thin mattress and used an electric fan. It also helped if the room was quiet, not too cold or hot, and there were no bugs to bite or harm the child during sleeping. The child would be put in a net or mosquito net with an electric fan on to help dispel the bugs. Parents prepared a room suitable for their child's sleep; and controlled the temperature in the room by turning on an air-conditioner or an electric fan to keep the air fresh and well-ventilated. Pim's mother described what their practices helping the child sleep in a cozy, quiet, and safe place as follow:

> *I changed to a mat and covered it with 2 blankets, as the mattress is hot for her and makes her wriggle around. I'd turn on an electric fan as she could sleep cozily in a cool air. The room is quite musty so an electric fan is turned on for good ventilation. I want her to get a cozy sleep and not roll off of the mat. Sleeping on cement floor might be too cold, so I try to find what could make her get a nice sleep so that her heart would not work much harder (P1 Int3/484, Int4/460-477)*

Fah's father also told how to prepare a cozy and safe place for his daughter.

> *I have to turn on a fan to dispel mosquitoes, and hang up a net in the nighttime and a mosquito net during the day with a fan turned on, as it's quite hot. He couldn't sleep when it's hot. I want her to have a long sleep as it's good for her heart. I try to keep her heart work well (P4,F Int1 /330-336, Int2/174-189)*

3. Accompanying and soothing the child. This would be another method parents used to help their child sleep. Parents understood that their child was at the age that needed the parents' love, voice, carry and touch, especially for those suffering heart disease. The experiences let them know that the child needed parents or other loved ones to stay with the child before bedtime. If their child woke up and found nobody around, the child would begin to cry, and if soothing or touch was not yet given to the child, he/she would cry causing tiredness and the heart may stop functioning. To prevent the heart from working too hard, they learned what the child liked or disliked, and how to help the child sleep. The parents responded that by not leaving their child alone. They would talk or sing the child a lullaby while carrying the child or rocking the cradle, or giving warm and soft touches before bedtime and/or during sleep. When the child began to cry or was restless, parents would take turns carrying the child, dangling him, and walk around until the child slept, and then put him on a mattress or cradle.

From observations both at the informants' homes and the hospitals, the researcher found that parents would give special attention and care both during the child's drifting off to sleep and during awakening. When the child began to fall asleep and started to cry, parents had various ways to stop the child's crying and get the child to sleep. Parents learnt what and how to do to soothe the child and get him sleep, as told by Fah's father,

> *We learn to understand her needs. She likes me and grandma to carry and walk around so that she can sleep. She likes being put on my shoulder or grandma's. For her mom, she likes to touch the mom's hair [smiling]. Doing so for a while could make her sleep. When she gets to sleep, we see that her breathing is slower, and her heart beats slower and lighter, and that's good for her heart. (P4,F Int2 L133-135)*

When their children continued to have difficulty sleeping, four families prayed to a Buddha image, followed a fortune teller's advice or performed local belief rites, in hopes their children would sleep peacefully. These parents believed the supernatural played a part in their life and health, as well as in their children's sleep patterns. They believed the supernatural could help with sleep by protecting their children from annoyances and/or unseen dangers. A 35 year old mother, who worked in a snack factory and had a primary school education, revealed her mother told her if her child was unhealthy, fretful and could not sleep, she should offer her to a Buddha image. The mother stated:

> *When my child gets sick and fretful, I'll burn incense to worship Loang Por Kasorn (the Buddha image). Sometimes she can't sleep, no matter how hard I try to soothe her. She keeps crying, so I think it's because Kumarnthong (a fetus ghost) from the house over there came to play with her. So I pray before bedtime and ask Kumarnthong not to annoy my child. Please let my child sleep, as she's suffering from a heart disease and if she's frightened, her life could be at risk. I also pray to Loang Por Kasorn and asked for his help. After that, she's better and can sleep (P1/2,375-385)*

Preventing tiredness. Through closely observing the child's symptoms, parents found that when the child was tired, the children would have cyanosis, rapid breathing, and strong or faster heart beating. Because they believed exertion made the heart work harder, which could cause it to stop and lead to the death of their children, parents tried to prevent constipation, crying, or having excessive physical activity and excitement.

1. Preventing constipation. Parents would look after their child to help the child pass feces easily without any forces. They thought that forcing to pass feces could make the child get more tired, leading the child's heart to work harder. They

therefore sought methods to help the child pass feces easily, such as changing the type of formula, and feeding vegetables and fruits as well as easy- to- digest food.

To help the child's defecation, mothers changed the type of formula that caused the child difficulty in passing feces. A mother of a 9 month old child with PDA commented:

> *I used to feed my daughter S26 formula, but it seemed not right for her as her feces were hard, causing her difficulty in passing stools. So I changed to Dumex Dupro formula, since my neighbor told me that their child passes stool easily after drinking this type of formula. I don't want my child to strain passing feces, as I don't want her to get tired. (P1 Int2/328)*

Feeding vegetables and fruits was another method to help the child's bowel movement. Parents had information regarding feeding those from a TV health program and their direct experiences, as told by New's mother:

> *I feed my kid with fruits every day like orange, banana, ivy gourd and pumpkin. These are very helpful for him to pass stool every day. After eating these foods, he never has constipation. He used to have difficulty in bowel movement as the stool was hard and it was painful to pass. I don't want him to force passing feces. I'm afraid that could make him tired. I once saw his lips very bluish after he tried to pass stools with force. (P5 Int1/981-995, 3/ 229-231, 1143-1148)*

Two mothers, avoided pumpkins as she thought they caused the child constipation. Pim's mother said, "*Pumpkin is high in vitamins, but eating too much is not good as it could make the stool hardened. Eating it occasionally is ok, but not everyday*." (P1 Int 3/237-241). In addition, Jing's mother observed that her child had difficulty in bowel movement after eating too much UHT milk and pumpkins, so she reduced them, as she said:

Eating pumpkins causes him flatulence as does UHT milk. He drank as much as 3 boxes of UHT milk. Now I don't feed pumpkin and feed less UHT milk. That prevents constipation. I don't want my kid having tiredness (P3 Int3 L1461-1469)

In the meantime, one mother thought feeding crushed and easy to digest food could prevent constipation. Bee's mother filtered the food of crushed rice, vegetables, liver and pork through a sieve and then mixed it with soup to make soft food for her child. She explained that:

My kid hasn't teethed yet, so I have to feed food that is soft, tender and not too thick to help her bowel movement…I prevent her constipation by taking precautions myself. I don't want her to turn blue. If she does, she could stop breathing and it'll be very dangerous. So I'm afraid. (P8 Int 1/292-301,4-15)

2. Preventing crying. After recognizing their children became tired, cyanotic and experienced a forceful heart beat when crying for a long time, parents and family members soothed their children with a gentle touch, did not leave them alone and picked them up as soon as they began to cry, on the assumption that crying could make them tired.

To prevent crying, parents never let their child cry. When seeing the child start to cry, the parents would hold their child right away as told by Bee's father that his child, suffering cyanotic congenital heart disease, would turn blue when she cried. The father told his method to prevent the child from crying as follows:

I try not to let her cry. If she starts to cry, I'll soothe her. Or when she starts to cry, I'll hold her immediately. The doctor told my sister not to let her cry much as it could shock her and her heart could stop beating or she could stop breathing. So I'm scared, as it's dangerous (P8 Int1/43-48, Int2/14-15)

New's mother said she heard the doctors saying that her child had an abnormal heart sound. Then, she kept listening to the child's heart and heard louder heart sound

when he was tired, which was different from the other two elder children. Thus, she did not let her child cry, as she said,

> *I hardly let my kid cry. If he cries, he'll turn blue. When I notice that he is starting to cry, I'd suddenly stop him by carrying him and walking around. If he cries a lot, his heart will sound a murmur, showing his tiredness. I don't let him cry as I'm afraid that he could be knocked out. And crying a lot could cause him a shortness of breath, impeding the brain blood flow. How could I do if he is suddenly knocked out? (P5 Int 1/550-564, 1314-1322, 1376)*

In the meantime, parents would not let their child alone or place the child under others' care and they also asked the cooperation from other family members not to make the child cry as told by Bank's mother. After knowing her child suffer a heart disease, she would suddenly stop everything she was doing then when her child got up, saying that she did not want to leave him alone. Before that, this mother used to work with her husband and let her 10-year-old daughter look after her little child; but she did not do that again after knowing her child's disease. She also warned her other three children against making the little child cry.

Soothing the child with gentle and tender touch was another way to console the child. The observation revealed that while breastfeeding the child, most mothers would fondle the baby's arms and legs and pat on the child's bottom. When the child was full and fell asleep, the mothers would softly pull their nipples from the infant's mouth, carry and place their child in a rocking chair that was rocked gently. When the child cried, the mothers and fathers would take turns to carry him and walk around while soothing the child tenderly. As Nai's mother said, "*I try to be gentle to avoid making him cry. And I try to prevent him from tiredness for fear that his heart would work hard*" (P2 Int1/ 425-427, Informal Int, 25 April,07)."

3. Preventing too much play and fright. Four parents would not allow their children to engage in age appropriate games (tickling, flips and laughing excessively) because they believed such activities would consume too much of their children's energy. The assumed that those activities could make their child tired and make the heart work harder.

Three parents did not allow their child to play, but let the child get a long sleep in order that the heart would not work too hard. That understanding was a result of their perception that their child has a disorder of the heart and they used to see the disorder symptoms while the child was playing. However, when the child was in the toy age, parents watched for the disorder while the child was playing, did not allow the child to do tiring activities such as rolling over and laughing, and stopped the child's playing when seeing the heart beat stronger or rapid breathing. Bee's and New's mothers provided their statements regarding preventing too much play as follow:

> *If my kid plays a lot, her heart will beat strongly and rapidly. I put my hand here [put his hand on the child's chest]. I could feel her strong and rapid heart beat. She also breathed so strongly that I could feel from touching her chest. Laughing a lot could also make her tired like this [acted having a rapid and strong breath]. If I see her lying down during play, I would hold her to stop hers playing. I don't let her play long (P8 Int 1/209-215)*

> *I must be careful when he plays as he easily gets tired. If I let him play too much, he could be knocked out and he'll be at risk. Sometimes he still wants to play, but I have to stop him or he'll be too much tired. I'll keep watching him while playing. If I could hear an unusual sound from his heart, I'll stop him right away. When he gets tired, his heart will murmur that is clearly heard. I keep listening to it. If there is an extra sound, I'll stop him from playing. (P5 Int 2/905-909, Int 3 L126-131, 436-437)*

Parents acknowledged that their child had slower motor development than typical children and wanted their child to reach his age development appropriately. To enhance the child's development, parents would assess if their child got tired while trying not to push the child. They said that they did not allow their child to do some activities for too long, even those activities that promoted normal development. Despite the slow development, parents did not want to motivate the child, or even sometimes stopped normal development activities to prevent the child's tiredness. Bee's and New's mothers provided the following statements:

> *I won't let my baby flip over for too long as I'm afraid he'll get tired. Even it's his development, I want it natural. Forcing is not good, but sometimes I let him do it for around 5 or 3 minutes and I'll carry him and never let him roll over for too long. Like sitting on this baby walker, if he starts to puff, I'll stop him. I keep watching over him. If he shows fatigue, I'll stop him. (P7 Int2/ 317-321, Int3/462-465)*

> *I didn't push him. He still can't crawl because of his heart disease, so I didn't force him to do it as I know he'll get tired. I dare not to let him do activities like other healthy children. For other healthy children, I'll teach them if they can't do something. But for him, I won't because teaching or forcing could make him tired and turn blue. Getting too tired could knock him out (P5 Int2 L819-835, Int3/428-440)*

To prevent fright, parents averted any activities or actions that might scare their child, on the perception that the child's heart will work harder if the child was shocked. Parents stopped all activities that could cause loud noises or fright for their child like taking cold bath, some games or toys, opening/closing a metal door, and preventing accidents.

Parents also would not play peek-a-boo due to believing their children's heart would have to work harder or stop, if they became frightened. A 30 year old father of a five month old child with acyanotic CHD said:

> *I'll tell my elder children and my neighbor not to play peek-a-boo with the little one, as I'm afraid he could be shocked. I don't know if it'll happen or not, as I've never seen it, but I'm cautious. I fear he could be scared or there could be something worse than that. It's like his heart is working and if I play peek-a-boo, he could be shocked (P1 Int4/ 68-74)*

When doing some activities like laughing, the child could be watched over gets tired. As Nai's parents said,

> *We rarely play tinkle toys with our kid. We used to see that those toys make him shocked and startled. We didn't allow him to play and the doctor also banned this type of toy as it makes loud noise (P2, Father Int2/723-733).*

In addition, parents tried to do activities that could make loud noises as softly as possible such as opening and closing a metal front door. Parents were also watchful to prevent their child from accidents. Some parents described worrying when their child started to stand, totter and climb, putting their child at risk of accidents such as falling down or falling on his back. They had to be more careful than when the child was still an infant and could not walk, as New's mother and Fah's father said:

My kid can walk around the room by holding onto the wall. I let him walk on his own. I'll be more careful when he starts to climb or step on to climb. I'm afraid he could fall on his back, get shocked and knocked. His heart will beat so strongly that he could be unconscious and couldn't reach the hospital on time. So I take cautions by not leaving him alone. (P5 Int2/380, 3/ 459)

My kid can stand with me propping her up from her back. She'll hold onto me and I'll support her and won't let her fall down. Now when she starts to crawl, I'll be more careful as she can walk on her own. I fear she'll be scared as his heart could beat very strongly and terribly. (P4, Father Int4/ 703-706, Int1/ 600-619)

Preventing the Child from Contracting Other Illness

Twelve informants believed that their children, due to having CHD, were unhealthy and vulnerable to other diseases. Thus, they used protective methods, gleaned from experience in caring for their children, as well as from what relatives, neighbors and physicians suggested. The parents tried to prevent their child from contracting other illnesses, especially such contagious diseases as the common cold and diarrhea, perceiving that being afflicted by other illnesses would only worsen their children. Their practice activities, in this sub-category, centered on four areas of concern: a) protecting against common colds and pneumonia; b) protecting against diarrhea; c) ensuring hygiene care; and, d) obtaining immunizations.

Protection against common colds and pneumonia. Having been warned by physicians to protect their children from common colds and pneumonia, while they await surgery, parents avoided exposing them to cold weather and kept them warm. This seemed especially important during bathing because of concern they would become chilled and, subsequently, catch a cold. Thus, children were bathed in lukewarm water and overdressed to stay warm. Because of fear they would become ill if chilled, eight parents only bathed their children during the middle of the day and

washed their hair only when it was dirty. Four main practices to keep the child away from other illnesses included: 1) avoiding cold weather and keeping warm; 2) keeping the child away from contacting person with upper respiratory tract infections (URIs); 3) avoiding crowded places and air-polluted areas, and 4) monitoring fever.

1. Avoiding cold weather and keeping warm. Parents tried to keep the children's body warm all time, in the belief that a constant body temperature could help the children acclimate to the weather changes. They were very cautions when giving their children a bath, out of concern that bathing could make the child so cold or chilled that the children could catch a common cold. Other parents avoided bathing in the morning or nighttime, or did not wash the child's hair everyday, only after the hair was starting to get dirty. Some avoided places where it became hot or cold suddenly, like department stores, concerned that if the child could not adjust to the weather or air conditioning, the children could develop a cold.

Few parents gave their child a normal temperature bath or "cold water." They also avoided bathing in the morning or nighttime when the weather is colder than the daytime. The child would be normally bathed one to times a day, in the late morning or afternoon. If the weather was a bit cold or the child was ill, parents would clean their child with a warm towel. Parents also bathed their child in a short time, patted the child dry with a towel quickly, and did not allow the child to stay in the water for too long. Nai's mother said that:

> *Common cold and pneumonia is related to a long and slow bath, so I avoid giving my kid a long shower that could make him chilled, leading to pneumonia. I'd quickly pat him dry for fear over the cold. He's not as healthy as others, so I must be more careful. (P2 Int 4/177-195, Informal Int, 25 April,07)*

Jing's mother said she had a chat with one mother whose child had been admitted to the hospital due to pneumonia because of choking on water. So she avoided her child having pneumonia using the following method,

> *I don' let my daughter sit in the water tub as it could cause her lungs problem and if the water flows into her nose, that could lead to pulmonary edema. I also prevent her from choking—that could make her catching a cold. Choking on water could also result in pulmonary edema. (P3 Int3 864-871, 957-961)*

Parents were more careful when washing the child's hair to protect their child against cold or pneumonia. Most of them washed the child hair with lukewarm water once a day in the late morning or afternoon and did not do so on a cold day. One mother would wash the child's hair when it got bad smell, as Bank's mother said,

> *I didn't wash my son's hair everyday, as he could catch a cold. I wash it only after it gets dirty or has a bad smell. Other children could have their hair washed everyday, but not the ill child. He must be paid more caution than others. I'll wash his hair once every 3-4 days. If it's too cold, he could get a cold or pneumonia. (P7/ I3/222-224, 712-717)*

Parents also tried to prevent or keep their child from the cold, misty and dewy weather as believed that it could cause the child to catch a cold or pneumonia. They then protected the child further by having the child wear a hat, or by keeping their child under an umbrella when taking the child out in the nighttime or morning. Fah's mothers said,

> *When we have to go out when it gets dark, I'll put an umbrella up to keep my daughter from the mist. Also, early in the morning, she'll wear a hat as it's misty and dewy which could cause her a cold or pneumonia. She's highly vulnerable to cold. She's an unhealthy kid who needs more care than normal ones. (P4/2/252-258)*

Avoiding places where it becomes hot or cold suddenly, like department stores was another preventive way of some parents. Pim's mother explained that :

> *I'm afraid of weather changes, so I avoid taking her to a department store. She can't acclimate to the weather changes when the weather outside is hot and inside is cold due to the air conditioner. If she can't adjust to the weather, she could get a cold. (P1 Int 3/449-453)*

Keeping the body warm by overdressing the child and keeping the child away from fans during sleeping were some of the practices parents used to protect their child against cold and pneumonia. Parents mentioned that wearing clothes to keep warm would prevent the child from contacting the cold when the weather changes. Even on a hot day, the child still wore a long-sleeved shirt and pants or two layers of shirt. In the nighttime, the child would be blanketed and put in a diaper to prevent catching a cold after wetting the child's pant. All parents realized that a cardiac child was sensitive to hot, noting that their child would cry, get fretful, and not be able to get to sleep when it was hot. They had to turn on the fan, but did not let their child sleep near the fan. As Pim's mother described,

> *I'll blanket my daughter and put her in a thick shirt. Wearing a thin shirt could make her catch a cold suddenly. I look after her clothing specially. During bedtime, I won't let her sleep near the fan. Getting too much air from the fan could make her so chilled that she can catch a cold. I try to keep my kid away from any illness and protect her against pneumonia. (P1Int3/431-442,)*

2. Keeping the child away from contacting people with upper respiratory tract infection (URIs). To prevent the child from contacting the cold virus from breath, coughs or sneezes, parents kept their child away from people with URIs, and prevented people from contacting or getting close to their child. Most parents asked family, neighbors, relatives, and others with URIs not to close to the child, explaining

that the child had had heart disease and was really unhealthy, so the child could catch cold and have pneumonia easily.

To prevent exposure to possible contagious illnesses, family members kept their children out of contact with individuals with an URI. Ten parents asked family members, neighbors, relatives and others to not have contact with their children if they had a URI. They explained their children had heart diseases, and, thus, were unhealthy and susceptible to colds and pneumonia. Two mothers stated:

> *When his dad is sick, I'd warn him against kissing the child, as he could catch a cold from his breath. When he coughs, the germs could flow out with the saliva and breath.(P8 Int1/120-124)*

> *I asked my neighbors, relatives, and everybody with a URI not to get close to my child, as she could catch cold and get pneumonia. Most of them followed my request. Sometimes I held my child away from them. I didn't want her sick. (P4/1/380-386)*

However, two mothers accepted the difficulty to protect or prevent their child against cold, especially when they caught cold themselves, as they were the ones who were close to the child all the time. New's mother who still breastfed and usually caught a cold explained that:

> *When a mom catches cold, a child does too. It's not preventable as I still breastfeed and dose my son. He catches cold anyway. And when I get sick, I can't stay away from my child anyway, but I could ask others with colds not to hold my child. He gets sick from me as I have to care him. It's unpreventable. My son doesn't undergo the surgery yet, so he's vulnerable to the virus when I catch cold. And it's not easy for him to be cured in a short time. (P5/3/68-83)*

Several parents revealed that even though they feared infection, they hesitated to tell their neighbors not to get close to or carry their children because, in line with Thai culture, they were considering their neighbors' feelings first or "*kreng jai*"

(เกรงใจ, feel considerate to ask others to do or not to do something, could not say directly what was on their minds). They were afraid of a broken relationship between them. Parents therefore tried to keep their children away from others who might be sick or have a cold due to children's vulnerability to diseases. Fah's father told that everyone in this area (*Platoo* community) was his relatives and he had a way to keep his daughter from others for fear over infection. As Fah's father explained:

> *When I catch a cold, I would stay away from my kid, but if others do, I dare not to tell them not to get close to my kid. So I take my precaution by keeping her away. I didn't want her sick, but I'm afraid that if I tell them not to get close, they might be angry. (Fm, P4 Int4/563-566)*

Likewise, while parents earned a living and placed their children under the care of daycare centers or neighbors, it was difficult to prevent children from contacting others who might be sick or have a cold. As seen by Pim's family, whose parents worked at a snack factory all day long, they had to place Pim under the care of a daycare center where five children aged 0 to 5 years old were being taken care of, slept and played together. Pim's mother told that even she worried that the CHD child would get infection, but she acknowledged the inevitable. Pim's mother expressed her feelings that:

> *It's difficult to be cautious as the daycare center cares for many children. I cannot tell "Yai" (an elderly, who is the daycare center's owner) to separate my kid from other children. Yai won't do it for me, as she has to let children play together, making it difficult to separate our kid. And I can't tell her to pay attention to our kid as she might feel disdain. So when I bring my daughter back home, I have to check if she is sick. I'm afraid that if I tell her or blame her, she won't take care of my kid. And I'll be in trouble. (P1 Int3/518-522, 767-792)*

3. Avoiding crowded place and air-polluted areas. Parents tended to avoid crowded and air-polluted spaces**.** Seven parents believed markets and department stores were sources of diseases, and their children could pick up germs in the air, causing them to develop a cold or pneumonia. Due to concern that polluted air could cause lung problems, six parents avoided smoky areas where fumes from cooking or cars were prevalent. Mind's and Bee's mother explained that,

> *I try to keep my son at home and avoid crowded places like the department stores. It's not good for him as there're many people. It could make my child sick. When many people with diseases are in there, the diseases flow in the air, and my child could pick them up. (P6 Int1/196-202, 3/93-105)*

> *I rarely take my daughter out. Playing around here is OK, but I don't let her out for long. I sometimes take her to the market, but the department store is forbidden for her. Her immunity is quite low and she's vulnerable to cold. She might develop the complications like pneumonia when she undergoes the heart surgery. The doctor told me to be particularly cautious one month before her surgery. Before that time, I must keep her healthy. (P8/1/113-117, 3/575-759)*

Parents also kept their child from smoky areas, where there were fumes from cooking as well as protected the child from car fumes, over concern that the exposure to polluted air could cause lung problems. Nai's father stated of his practices as follows:

> *I wont' take my son to smoky areas, like open air food stall to avoid the smoke from the cooking pot. I think inhaling this smoke is not good for him. Even an adult, breathing in this smoke could make him feel bad. What if my child inhales it? I don't want him to, as it's bad for his lungs. (P2, F/4/282-293)*

However, some mothers accepted that it was difficult to prevent their children from catching a cold by avoiding to go to such crowded places as department stores, as they had to buy necessities. Also, while they wanted their children to be in an air-conditioned place, as it was hot at home and most children didn't like hot weather.

One admitted that they could not avoid taking their children to the market, which was opposite to their house, as Mind's mother said:

> *It's difficult and impossible not to take my baby to anywhere. I don't know how to protect him as my house is near the market. I try as much as I can. I take him out there sometimes as it's quite hot at home. Actually, I want to take him out. I feel sympathy for him and I want him to see new things. He likes going out but I don't do so often. (P6/2/ 133-139, 3/93-95, 104-108, 426-433)*

Likewise, one mother thought it was difficult to avoid polluted areas, as their houses were located near the street, and not to avoid contact with their neighbors. The mother adjusted themselves by avoiding toxic fumes as much as they could, and paying special attention to her child when he caught a cold, as told by New's mother who preferred to have a conversation with neighbors:

> *I can't help taking my kid out. He likes going out to see many people. I think that could make him have good temper. I have to take special care of him as he's vulnerable to common cold. I don't want him get worse. However, it's difficult to prevent. But I try not to take him to such polluted areas as main roads where there are lots of toxic fumes and try not to take open-air vehicles like tricycles. (P5 Int3/575-759)*

4. Monitoring fever. Their child care experience enabled the parents to observe the changing symptoms easily, with some saying that touching the child's body was the best indicator of fever without a thermometer. They thought the symptoms would be more serious and take longer to cure the child than healthy children. Typically, they believed that having fever could cause the child's heart worked harder. Therefore, parents tried to monitor changes of the child's temperatures closely. When the child was starting to get sick, the child would be cared for at home by keeping the child warm and feeding the child with modern

medicines or sometimes with herbal medicines, according to their belief, until they felt they needed to see a physician.

All parents in this study had experience with caring for the child with heart disease who was having a cold. If the child's symptoms seemed worse as evidenced by a bad cough, difficulty breathing and eating, tiredness, or inactiveness, the child would be quickly taken to the hospital suddenly for fear over the potential risks realizing that the child had underlying heart disease. When the child was starting to show a low fever, the parents would care for the child at home attentively, as one mother said that:

> *When my son started to get sick, he would have a mild fever, be moody, cry, and cough. I needed to care for him more closely. I would use a wet towel to rub him, and overdress him. I also fed him with paracetamol syrup I got from the hospital. If he had a high fever, coughed more, had a runny nose, had difficulty breathing or didn't get better in a few days, I'd take him to see a doctor because of fear about a worsening condition or problems with his heart.(P2, Informal Int, April 25.07)*

For parents whose children had had pneumonia or cyanosis, they would take them to see a doctor soon after any disorder was clearly noticed, concerned over the potential hazards, such as heart failure or unconsciousness of their child, as told by Mind's mothers whose son had complex CHD and used to be admitted to hospital with Pneumonia twice said,

> *Every time my son who has cardiac problem has a fever, I'd take him to see a doctor quickly. Especially, when he starts to turn blue, has difficulty breathing and shortness of breath, I'd take him in immediately as his heart might have some disorder. I'm afraid his heart will work so hard that he could have a heart failure. (P6 Int1/ 161-169, Int 2/310-315)*

When the children had a fever and difficulty breathing, parents used many methods including modern and traditional treatments to relieve the child, following

their own beliefs or experiences. Fah's mother said that apart from applying Vicks VapoRub on the daughter's chest, she dripped a couple of Eliadine drops into her child's nostrils for 3-5 days. She stocked this medicine for future use. Meanwhile, Pim's mother used a rubber bulb syringe to remove the mucus. She also hung shallots near her bed and applied Vicks VapoRub on her child's chest. Pim's mother told that when she was young, her own mother also put shallots close to her pillow to relieve her difficulty breathing. For her experiences, shallot was better than Vicks VapoRub. However, she applied both herbal and modern treatments following physician's advices. Pim's mother described her practices regarding caring for her kid when she got a cold as follow:

> *When my daughter has difficulty breathing and Vicks VapoRub can't help, I'd put shallots near her mattress, as they could relieve her and help her breathe well. I also used a rubber bulb syringe to clear her runny nose. I fear she'd have difficulty breathing and feel congested. If she isn't cured well, I'm afraid the mucus will flow back to her throat, causing fungi that could go to her lungs due to the swelling of mucus in her lungs. If she isn't recovered by my treatment, I'd take her to see a doctor because I fear that her heart would be worse. (P1 Int4/361-377)*

Three mothers applied Thai traditional medicine together with the incantation according to their personal belief. New's mother lived in a large community not far from the hospital and her neighbors were both Thai and Chinese. She revealed that there was one time when her child coughed a lot and was not cured. Even after seeing a doctor who prescribed cough medicine, she decided to rely on Thai traditional medicine Bai Pho (ใบโพธิ์, an anti-pyretic and throat infection medicine made from powdered medicinal plants) by applying some traditional medicines as advised by one of her neighbors. New's mother explained that "*I applied Bai Pho branded Mandl's*

paint by myself, so I took my kid to an older person to apply the drug with her incantations. My child was remedied once." (P5 Int1/945-967).

Likewise, Fah's mother, who came from the Northeast, told that her child had a fever and infection on her tongue that older people called Ron Nai (**ร้อนใน** , apthous ulcer), causing the child have a fever and loss of appetite for milk and food. This mother then applied Thai traditional medicine and Chinese medicines as advised by the child's grandmother, as she said,

> *My daughter had an infection on her tongue with a fever. The doctor gave some medicines but she wasn't recovered yet and couldn't eat. So I applied Sangmuk drug (แสงหมึก,Thai herbal medicine). Grandma said it is the traditional drug for applying on the tongue. She was recovered then and could eat now.…I also used Bai Pho drug(ยาใบโพธิ์, Thai herbal medicine) and Gui medicine (ยาเขากุย, a Chinese herbal medicine) to be dissolved as a bath and a drink. I think these drugs are OK as they are herbs that can reduce the body temperature and cure rash too. It's not dangerous. (P4 Int1 406-421)*

Protecting against diarrhea. Parents learned that when having diarrhea, the child would lose his weight and have their surgeries delayed. Therefore, they kept all food dishes and utensils clean, used separate eating dishes and utensils for their children, and fed them clean and freshly cooked food. This practice stemmed from their perception that due to the child's low immunity, the child was susceptible to infection and vulnerable to diarrhea.

1. Cleaning and separating utensils. Parents would clean the utensils related to the food and medicines such as milk bottles, water bottles, dishes and cutlery to prevent the diseases contaminated in the utensils to protect the child against diarrhea.

They cleaned the child's utensils with the dishwashing liquid like other utensils of other family members and then boiled them to kill germs. Mind's mother said that the doctor suggested to her that everything for the child must be as clean as possible to protect the child against diarrhea. She explained her methods to keep her child's bottles clean as follows:

> *I'll put all the bottles and pacifiers into the boiling water after washing them and boiling them for a half an hour. I try to clean as much as possible to prevent him from diarrhea so he won't lose weight. (P6 Int1/204-209, Int 2/93-97,121-122, Int 3/443)*

Apart from cleaning the child's utensils, parents protected their child against diarrhea by separating the child's utensils from those of others. The observation at the participant's houses showed that most of them separated the child's utensils, especially medicine glasses and syringes. These would be put in a clean and separate container. Feeding equipments was also separated, as seen in Fah's family, who arranged the child's utensils and accessories in a well-organized manner and separated the child's belongings as advised by the physician.

> *I separate my cardiac child's utensils and keep them clean to prevent any infections. The cups, bowls, bathing accessories are separated to defend her against the infections from adults. Any separable items are also set apart, such as kitchenware to prepare food for her. These would be washed separately. I'd wash her utensils first and adult's utensils later as I have only one dishwasher. She's susceptible, unhealthy and not immune. I try to keep her clean as much as possible to prevent diarrhea which could make her lose weight. (P4 Int 2/236-250, Int 3/334-339)*

This was a particular challenge in some of the homes where there was no refrigerator, not enough clean water, or no gas oven.

2. Feeding clean and freshly cooked food. Parents fed their child with fresh-cooked and day-by-day food, not the leftover food, so as to prevent the child from

diarrhea, on the perception that the child should eat cooked, clean, and fresh food. Bee's mother said that "My kid's foods must be clean. I cook her every meal. I never cook and store it in the fridge. I think it's not good for her as it can cause her diarrhea" (P8 Int1/127-129). However, this was a particular challenge in some of the homes where there was no refrigerator, not enough clean water, or no gas oven, as told by Bank's mothers who was a garbage collector,

> *I cook my youngest son's food daily and don't feed him with the leftovers. I don't have a fridge to store food, so I cook each meal and feed him to ward off diarrhea. I don't want anything wrong with him, so I have to be more careful, as the doctor said he's susceptible. (P7 Int1/ 296-297)*

Some parents had to feed the food that was left out overnights, as their child needed to drink the formula milk given by the hospital. The formula would be prepared once a day to be fed for every meal. It was then necessary for their child to take the formula stored in the fridge. Nevertheless, mothers managed to prevent the deterioration of the formula and maintain the cleanness of milk bottles, as told by Mind's mother.

> *I'd blend the mixed formula milk and steam it to sterilize. It can last longer. I'd steam it for 30 minutes to prevent the deterioration as much as possible. A bottle of milk should be taken within 3 hours. If he can't take it all, the remaining must be left. If he takes the leftover, he could have diarrhea that could make him lose weight. His milk bottles will be boiled for a half an hour before use. I take cautions to prevent diarrhea. (P6/1/204-209, 2/93-97)*

3. Ensuring hygiene care. Parents realized that the risk of infection was lower when their children were kept clean. Thus, they bathed their children with soap and clean water, and provided them clean, dry clothes. In addition, parents were conscious of their own hygiene and washed their hands regularly to prevent transmission of disease. However, they recognized they could not wash their hands

each time before providing care and felt uncomfortable asking others to wash their hands before having contact with their children.

None of the families had a washbasin in the house, or child care area, in their home. Seven families lived in a rented house where the bathroom was outside. Hygiene was a challenge for low-income families, particularly for the family in the house surrounded with garbage and flood water.

To clean the child's genitals, the child would be put in a new pair of pants after urination. For diapers, the child would be put in a new diaper when it's very wet. Every time the child passed stools, the child would be cleaned with water and sometimes with soapy water and put in a new pair of pants or a new diaper.

In addition to the child's hygiene care, parents paid attention in preventing themselves from transmitting the disease to their child by caring for their personal hygiene and washing hands. Most parents told they would take care of their own cleanliness and wear dry and clean clothing before carrying or getting close to the child. Parents tried to wash their hands before preparing and feeding food and medicines and after cleaning the child after his bowel movement. Nai's mother stated that:

> *I'd keep myself clean, take a bath and won't wear sweaty clothes before carrying my child. But my husband, he's very clean (she drawled). He spends a lot of time taking a bath. He told he must clean before holding the kid… I'll wash hands with soap when they get dirty before carrying my child. But if I'm lazy, my husband would bring me soap. I also wash hands after cleaning his bottom after bowel movements, to prevent him from getting any disease. I think it could help prevent infections well. It's important as my hands would get dirty after touching many things (P2 Int 4/500-518)*

However, parents accepted they could not wash their hands every time before providing care, and as well could not ask people to wash hands before carrying or

contacting the child. The observation found that most mothers or grandmothers provided the child's hygiene care. After the child passed stools, mothers would wash the child's bottom at the bathroom and put on a new pair of pants, but the mothers did not go to wash their hands before preparing and feeding medicines. Parents said that they would wash hands depending on the convenience and possibility:

> *I'd wash my hands if time allows, but I can't wash hands every time. It's great if I can do it every time. My daughter with heart disease is susceptible. If I can do it, I can prevent her from infection. But in fact, I can't. I do a lot of work and when I can remember, I'll go to wash hands. However, I can't tell everyone to wash his hands before contacting my child. (P4/3/343-351)*

In spite of trying all methods to prevent diarrhea, all parents admitted that their child had suffered mild diarrhea and they did not take the child to see a doctor. In this study, there was a child who was admitted to the hospital for diarrhea or passage of smelly loose stools. Four parents believed that the watery stool that did not smell was normal because of *Dek Yeod Tuo* (เด็กยืดตัว, the child's body growth, which was often found during the child's changing of position), so they needed no treatment. In the meantime, a family treated the child's diarrhea by applying herbs as advised by the child's grandmother. Nai's mother said that,

> *When my child passed watery stools, mom [the child's grandma] said it's due to Yeod Tuo. He passed loosed stools, but not often. It'll be cured when he can adjust to it. The grandma picked up the guava and pomegranate leaves, boiled them and fed that drink. He was cured amazingly within one day after drinking it. (P2/4/404-407, 5/205)*

4. Obtaining immunization. Parents were aware if their children developed other illnesses, their lives could be at risk. Ten parents made an appointment to have their children vaccinated, with documentation of the vaccinations recorded in their

health book (pink book), even though they did not know the rationale for the vaccinations. Most parents took their child for vaccination by appointment or as scheduled in the pink book given by the hospital (immunization record) given by the hospital even if they did not know of the rationale for giving vaccines. Fah's and Bee's mother told about their practices as follows:

> *I'll take my child for vaccinations as scheduled in the pink book, but I can't remember what they were. I realize all vaccines are to protect her against diseases, but I have no idea what diseases she is protected against (P4 Int3/250-266)*

> *At six months old, my baby was given two vaccines, but I can't remember what they were. I took her for vaccination as scheduled in the book. She'll get another one when she becomes nine months old. I know vaccines are to protect against diseases, but I have no idea what disease can be protected against. (P8 Int2/181)*

However, two children did not get vaccinations as scheduled because they received repeated treatment at the hospital for a long time and repeatedly. After discharge, parents dared not to take him for vaccinations, out of concern that their child could have a fever and need to be admitted to the hospital again. However, the physician gave combined vaccines, as told by Mind's mother.

> *My child never got any vaccines as he received treatment at the hospital. I didn't take him, as it could cause him a fever, and he'd need to be admitted again. The instructor (doctor) then wrote on the book that he was never vaccinated and recommended him get six combined vaccines in one shot. Even though it was expensive, I paid for it so that he could be immune from to disease. (P6/2/383-392)*

Bank's parents failed to take him for immunizations by appointment while the child was waiting for the surgery, as they were worried that the child would have a fever that could postpone the surgery. They were afraid their boy would have a fever like his previous vaccination, as told that:

> *I want my kid to undertake the surgery before getting vaccines. He used to have a fever after being vaccinated. It took longer for him to be cured from the fever than other children. So I want him to undertake the surgery first. I'm afraid he'd have a fever. Vaccines can protect against diseases, but for him suffering other disease is tougher than suffering a fever, as it is more difficult to cure. (F, P7/1/ 508-518, 3/ 686-692)*

Practicing Traditional Cultural Belief

As one examines health care practices carried out by these families**,** the socio-cultural context of their practices must be taken into consideration. Apart from modern medical cures, the result of this study showed that parents practiced traditional beliefs, and did everything based on their own beliefs in an effort to help their children recover from illness and surgery, prevent from getting worse, and to be healthy. Such traditional beliefs were often based on sacred or supernatural powers, and usually helped the parents feel relieved and having the feelings of "*Sabai Jai*" (**สบายใจ,** relaxation/comfort).

As previous mentioned, karma related to causing the child's illness in a previous live. Buddhist parents used different approached to lower their karmic effects by making offering, giving food to monks, and apologizing for wrong doing in the past. The traditional practices began when the parents first learned that their children had had a heart disease since birth, and continued during the course of cure, until the child would have an operation. Some parents symbolically gave the child to the former Kings, while others prayed or asked blessings from sacred Buddha images at the temple. One family symbolically gave the child to the king or others who had good experience in taking care of children, or to *Goddess Kum-in* **(**เจ้าแม่กวนอิม, Goddess of Mercy) as well as performing traditional beliefs descended from their

ancestors. Others paid respects to the shrines, spirit guardian houses, and a monument of the King in the hospital, as a way to ask for help with their children's sickness. Hoping the children recover from illness, stay healthy, and remain safe throughout their heart operations, most families would pray or asked blessings from sacred Buddha images at the temple. New's mother would take her child to the temple before having the operation, as she explained that:

> *Before my kid has an operation, I will take him to Wat Sothorn (*วัดโสธร*, a famous temple located in the eastern region of Thailand). I'll ask blessing from Leoung Pho Sothorn (*หลวงพ่อโสธร*, a famous Buddha images in Wat Sothorn) to take care of him and save his life. After doing that I feel pleased, I think I have done the best thing for him. (P5 Int1/763-769)*

Some parents would pay respects to Buddha images and asked blessings from sacred things at different places. Pim's mother said that in the past, whenever she had respected Buddha images, she would ask to win the lottery. After she knew that her daughter had a heart disease, the only blessing she wanted was her daughter's recovery from illness. Pim's mother said, "*When I go anywhere and find the sacred things, I will beg them to help my CHD daughter. At my office, there is a room of Buddha images. I pray and make a wish for my daughter every day*" (P1 I1/763-769)

Some parents said they respected the shrine or spirit guardian houses every day or on Buddhist holy days. Parents begged the gods to take care of the family and help the sick child recover sooner. Also, Fah's parents said, "*We will respect the shrine in front of our house to ask blessings before taking our daughter to the hospital*" (P4 Int 2/ 443-444). Jing's grandmother, a Chinese trader, told about her respecting the shrine at home:

I always take my grand-daughter to respect gods and ask for her good health. We believe in Chinese gods who will look after the people in the house. I believed that the god will protect my niece from any bad thing and help her safe from her surgery as well (F, P3, Int5/ 307-310).

Parents normally paid respects to other important monuments in the hospital, such as a monument of the king, in order to ask for help with their children's sickness. Mind's mother said that her four children were born at the hospital. Her youngest son had heart disease, so she paid respects to the shrine there and asked for blessings.

Whenever I go to the hospital, I will respect Krom Luang Choomporn's **(**กรมหลวงชุมพรเขตอุดมศักดิ์) *shrine and give him a garland. I told him that my son was his son and asked him to bless and protect my son and let the operation be fulfilled (P6 Int 2 L58-63).*

Parents also paid respects to the monument to King Bhumibhol's father (พระราชบิดาของพระเจ้าอยู่หัวภูมิพลอดุลยเดช หรือ กรมหลวงสงขลานครินทร์), located centrally at Hospital A. In this area, many patients and their relatives brought flowers, candles, and joss sticks to ask for help. Some people promised a future sacrifice of some food and fruit. When the patients recovered from illness as they had asked for, they kept their promise. Nai's mother stated that:

Mom (the child's grandmother) told me to ask for help from the monument of the King's father. I promised to offer him 100 boiled eggs if my child felt better and had good health. I really relied on sacredness (P2 Int1/120-122,155-156).

Six families made merit to apologize for their wrong doing in the past, which they connected to the child's getting sick. They thought their children had heart disease because of that sin. They believed making merit and apologizing for wrongdoing in the past would reduce the sin or get rid of it. Mind's mother said,

> *I took my son to give offer to monks, making merit while apologizing for wrongdoing in the past. I asked him not to harm my son and to take good care of him. Doing like that makes me feel relax as well. (P6 Int 2,33-34)*

Parents in many families take their children to make merit, give food to monks, gild Buddha images, sprinkle holy water, and offer dedicated to monks. Fah's father took the child to offer dedications to monks before having the operation, asking for a safe case. Also, Pim's aunt took the child to the temple, as the aunt said:

> *Before my niece would have the operation, I took her to pay respect to Buddha images, and I released fish and birds into the wild. Her father made merit at nine different temples, asking for her recovery (P1, F Int4/671-673)*

One mother consulted with fortune tellers, then followed their advice to help their recover from illness and be safe. Pim's mother said that when she knew her daughter had a heart disease, her sister suggested that she consulted with a fortune teller. The fortune teller advised her and she did as suggested and found that everything seemed better, as Pim's mother told:.

> *I consulted with the fortune teller, he told me to remove my daughter's bed and to remove furniture such as the shelf where the Buddha image sits. My daughter was not allowed to sleep close to the wall. I noticed that her general condition was better. I had done everything to help my daughter. I really had* [smiling] *(P1 Int1/729-735, 759-760).*

Another belief about weak and sick children was that the children were better and had a higher position than their parents in the past life. So, the parents should symbolically give their children to the one who is known as the most respect person, such as former kings of Thailand, who are still widely worshiped. Two examples were New's and Bank's cases. The parents symbolically gave their children to *King Taksin and King Rama V* respectively. Bank's father, a garbage collector with primary school education, said that when he took a taxi to visit his child at the hospital, the taxi driver whose child had CHD and underwent surgery advised him to

symbolically give their child to the former king. He said that his child was safe and healthier, and thus Bank's parents followed the driver's advice, as they said:

> *A taxi driver told me to symbolically give our son to King Rama V. We lighted joss sticks in the open air, then told him our names and our son's. We asked him to bring about a successful operation. After the operation we offered a bunch of bananas, red drinks, and some whisky. We had to look after our son very well, he could be punished but not scolded.* *ending with serious faces and sounds* *. (F,P7 Int1/614-630)*

In case some children were often sick, or the parents had difficulty taking care of them, it was believed that they should symbolically give the child to someone who had good experience in taking care of children. The parents would get some small money from that one and spent it on merit. Pim's mother said that she had two children: the elder one was healthy but the younger one had heart disease. The younger daughter hardly grew, and got sick often, so she symbolically gave her to the owner of daycare center. The mother had learned of this practice from villagers in the country. Pim's mother said,

> *I symbolically gave my kid to Yai* **(**ยาย**,** *an elderly, who was the owner of a daycare center in this study), as she looked after the children in this community very well, including my oldest daughter. Then, she gave me 20 baht and I took the money to buy some food and offered it to a monk. I wanted my kid to grow and to strengthen in short time (P1 Int1/655-666).*

In addition, Jing's mother, who is Chinese, said that she knew her daughter had heart disease when she was only six months old. The operation was the only way to cure her. She tried to find other methods to help her daughter without having an operation. Jing's grandmother took her to a spirit medium and he advised to give her to Goddess *Kum-in*, as Jing's grandmother said,

> *The medium told me to give my niece to Goddess Kum-in. Her mom didn't have enough charisma to look after her. I did as he told me and kept the amulet of Goddess Kum-in with Jing all the time. Soon my niecer got better and healthier (P3, F Int1/ 758-789).*

Some families got traditional beliefs descended from their ancestors in order to help the children be safe and have good health. Fah's mother said that her daughter stayed in the hospital for two months after she was born. Before going back home, her grandmother put something under her bed to make her safe. Fah's mother explained that:

> *My mom (grandmother) put a kind of leaf under her bed the first day after moving from the ICU. She told me that it would keep my daughter safe and strengthen her soon (P4 Int 2/ 408-412).*

In summary, families tried their best to get the child ready for surgery by "promoting and preventing," promoting the child's weight gain and strong health, and preventing the child from getting worse. The day-to-day practices were deeply influenced by the socio cultural context including hospital-based biomedicine, folk medicine, traditional Buddhist belief, and global TV culture as well as hospital services. Sometimes they were caught between physicians and family recommendations for the child's care. However, it was not problematic. Rather, parents could integrate those cultural perspectives into their practices.

Managing Child's Care under Constraints

Parents mentioned several constraints that influenced their ability to care for the children and everyday household life. While the families tried to do their best to get their child ready for surgery, they had to do their best to deal with the constraints. Most of the constraints arose from either financial limitations or child care and housework responsibilities as well as from hospital services. Additionally, problems usually came from parents' emotional stress and strain related to their children's illness and difficulties in taking care of the children. The families tried to deal with those constraints in varying degrees within their family context to help everyone in the family to live their lives, in particular to provide optimal care for their child. Families managed their child's care under constraints in many ways including confronting the problems by themselves, asking for help from family members and/or significant others, and *Tham Jai* (ทำใจ, making up one's mind). However, some constraints could not be managed so they just accepted them and let them be.

Managing Child's Care under Financial Constraints

Having children suffering from such a chronic illness as heart disease affected parents' incomes. In turn, financial constraints had effects on every member of the family, particularly on the children with heart disease. As the majority of the eight families participated in this study were low-income families, financial constraint was a major problem. Many parents lost income because the worked less overtime or because they had to take leaves from paid employment to care for their children or to

take their child to the hospital. Their main expenses were not costs paid to the hospital, but rather were transportation costs to get to the hospital and living expenses during hospital stays. However, families tried to deal with those constraints by adjusting their ways of caring for their children, changing parents' and family's ways of living in order to save costs and increase earnings as well as seeking help from both family members and outsiders in order to provide optimal care for their child..

Eight of fourteen informants, or six of eight families, noted that they did not have enough income for their living expenses. The average incomes of all informants ranged from 200-500 baht or 6-15 US dollars a day. It was found that financial problems were mostly found among families whose mothers were unemployed and could not earn their own livings, as opposed to self-employed families. Five parents mentioned that they lost their earnings due to working less overtime or deductions in daily wages, as they had to take leave to care for their children, or take their children with heart disease to the hospital. Two mothers revealed that they were unable to earn money, as they wanted to care the children by themselves.

To reduce expanse of transportation, parents changed the mode of transportation by taking the low-fare public bus instead of higher-fare taxi. Even though families had financial constraints, they took the child to the hospital as scheduled appointment. Due to financial limitations, the parents had to choose the best way to take the child to the hospital as well as to reduce the family expense. Bank's mother, whose houses was very far from the hospital, explained about her changing way of transportation that:

> *I spend almost 500 hundred baht when going to the hospital by taxi. If I go there by bus, I have to use 2-3 buses to get there. Anyway, I fear my child would be too tired. So my husband tells me not to get on public bus as it's quite hot and he's afraid that our son will suffer and cry. So I choose a middle way by going to the hospital by taxi and getting home by an air-conditioned bus. (P7/3/519-520)*

Parents and other healthy children in the family had to adjust their ways of living in order that the CHD child would receive nutritious and sufficient food as the physician recommended. Even when faced with financial problems, most parents tried to give their children nutritious or favorite foods in order to give the child enough nutriments. Bank's mother described that:

> *Doctor recommended me to feed my kid with eggs every day. My elder kids never have eaten eggs every day, only him. I can't afford to feed my four children with eggs every day. I have lots of expenses. My three elder children eat the same as I, but my sufferer child can't. (P7/2/179-180, 3.604)*

Even when the parents themselves did not have three meals a day, they spent more money to buy high-quality but expensive instant powder milk for their children before the operation, in order to help their children get nutritious food. Pim's mother, who works at a snack factory and gets a daily wage of 180 baht, said:

> *I buy one brand of powdered milk as it contains honey and alternate it with Pediasure milk, which is more expensive. But I don't mind how expensive it is. I can pay for it. It's not too hard to help my kid healthier. I can starve for my child. I don't feel hungry. Or if I do, I'll eat some. When I feed my child, I'll eat some of her food too. I can starve, but my kid can't. I want her to be ready for the operation. (P1/2/914-920, 4/278-279)*

One way to mange the financial was paying for things that were necessary for their child, and especially, it was the child's preference. Parents would ask for some infant formula or special formula milk from neighbors, as they wanted their children to try it before buying that milk. Pim's mother found, after seeing that one neighbor's

kid gained more weight after taking Pediasure milk that was expensive. Therefore, the mother asked for some milk to let her child try first. Then the mother bought a small can of the milk. Similarly, Bank's mother asked some milk from her neighbor for her child, as she said,

> *I observed that the neighbor's child gained weight after taking that kind of powder milk. So, I asked for some to have my kid test it. If he liked it, I would buy it, even it's expensive, as I want my kid to gain weight too (P7/2/159-162).*

Since mothers believed that formula contained higher nutrients than breast milk, they asked for nutritious food from health service centers in order to feed nutritious food the children to reduce the expense as well as to help the child gain weight and strong health. They tried to do what was best to get the child ready for surgery, as Bank's mother explained that:

> *I went to ask for powder milk from Wat Ta Klum Center (ศูนย์สาธารณสุข วัดตากล่ำ) and I got one can per month. An officer said my kid would get one can of milk per month for one year. That's fine. However, it's not enough. So, I went to get more from Pak Kred Center (ศูนย์สาธารณสุขปากเกร็ด), but I did not tell the officer of the later center that I got one from the former one. laughing (P7/1/5,26)*

Despite having financial constraint, parents had ways to store and mix medicine well. It was found that some families did not have any electrical appliances, not even a refrigerator. When they were told by a nurse to keep medicine in the refrigerator to prevent the medicines from changing to a worse condition, they dared not to tell the nurse that they did not have a refrigerator to store the drug. To solve the problem, without receiving advice from healthcare professionals, the parents kept it in a cooler, even though they forgot buying ice sometimes. Additionally, some families did not have an electric pot but had to use a gas cooker to boil water and keep it in a

pot. When the hot water was used up, they would use bottled water to mix the drug for their child, as they thought water was clean enough and the medicine mixed by this way did not cause the children diarrhea, preventing the child from getting worse. Though the house did not look clean, the mothers did organize the medicine of their ill children very well; for instance, by keeping them in an old but nice-looking cloth basket which one mother collected from the junk.

Due to limited space in their homes because of financial constraints, the parents accepted that it was difficult to prevent the children from other diseases such as common cold. For example, one family rented a 3 x 5 meter room, which served as all purposes: bedroom, dining room and living room for every member. Father, mother, and kids had to sleep together. When any of them got a cold, they did not have a place to sleep separately and the child with heart disease inevitably caught the cold. The family lived in the slums—the populated area where squalid houses were built unstably and always flooded with the dirty environment's garbage. The parents realized that it was easy for their ill children to contact infections, or to have diarrhea. However, they expressed that they could not move to other better places due to limited budgets. In addition, they did not have to pay the rental fees for their current places, even though they were located in an improper environment for their children. That helped them save a lot of money. Due to the limitations of places, the parents accepted that they could not cope with it, as told by Bank's mother that:

> *The doctor suggested to me to keep my kid clean. I know that it's good for my kid. So, I did as much as possible. But you see! Our house was close to garbage. Around the house isn't clean, neither is my house. Anyway, we have to stay here. It's difficult to avoid. Let it go, I can do as I can. (P7/1/671-685)*

Meanwhile, financial constraints would prevent parents from handling the cleanliness of children's belongings well. They did not have enough milk bottles for a whole day as well as no have a gas oven. Bank's mother told she had only two bottles: one for milk and the other for water. She washed bottles with dish washing liquid and sterilized them once in the morning. Before using them in the midday, she only poured hot water into the bottle to clean it again. Despite accepting the fact that milk bottles must be cleaned in boiling water every time before use, the mother said she could not do as she had to work while taking care of the CHD child. As she said "*I try to clean my kid's bottles as much as I can, but I can't do it every time before I use it. I have to work—otherwise we don't have enough money. It's difficult to do.*" serious face (P7 Int1/682-685)

Parents tried to solve the financial problems by trying to lower their household spending as much as possible. They told every member not to spend carelessly, as mentioned by Pim's mother who asked her husband to stop drinking and football gambling—habits that cost him almost 3,000 baht a month—to save money for the treatment of their child. Meanwhile, some families tried to work harder and spend prudently.

To manage their financial constraints, some parents asked for help from immediate families. It is noteworthy that the assistance mainly stemmed from the mother's relatives, such as grandmother, elder or younger uncles, or aunts as follow:

> *It's great that my sister gives her helping hand. She always asks me if I have enough money for milk. If I'm a little short, she would buy milk for me. She helps me a lot. When I didn't have money for my eldest daughter, she would ask it from my sister who always gives her some. I could say that she's like another parent laughing. (P1 1nt /831-835, 3/608-610)*

Two families were granted interest-free money from the mothers' friends, neighbors or co-workers. Pim's mother revealed that she always received help from her long-time co-worker, especially when they were aware that her child had a heart disease. Pim's mother expressed:

> *I was then a little short when I didn't get my wage yet. So I borrowed from my co-worker. They realized that I need money to treat my kid. They were pleased to lend me without interests. They usually asked me if I have enough money. I have a lot of good friends at work. (P1 Int1/976-981)*

Two families tried to contact charity groups to seek assistance for operation costs as seen by Jing's family. After getting information from a TV program, Jing's family asked the Association of Children with Heart Disease to fund the operation costs. Likewise, after knowing that the additional sum of operation cost was 10,000 baht, Fah's mother asked the community head to help contact the Rotary Club under the Royal Patronage in order to seek help.

After having done their utmost to solve the problems, some families needed to rely on informal loans, even as they were given assistance from relatives, as seen in two families. For Bank's family, making a living from collecting garbage did not provide them with enough money for six people in this family. The situation was worse when the youngest child suffered heart disease, preventing the mother from going out to collect garbage with the father as usual. The father had to work for neighbors in exchange for a chance to borrow their money when necessary. He admitted that his family's income fell short of expenses every month, forcing him to seek informal loans with 20 % of interest rates.

In summary, parents and all in the family tried to adjust or manage their daily life to deal with financial constraints in various ways in order to provide best care for their CHD children. Some important aspects of Thai culture were considered favorable contexts, such as receiving assistance from family members and outsiders to manage those limitations.

Managing Daily Life, Child Care, and Household Chore

All mothers in this study admitted that taking care of the CHD children added to their daily tasks and prevented them from getting the housework done. When managing child care and household chore, mothers asked for help from fathers and others in the family who live in the same household or nearby.

Some families rearranged their daily life and work to juggle the demands of child care and household chores, such as waking up earlier, managing time and prioritizing tasks etc. Bee's father told about his changing way of working and time management. Doing so allowed him to have time to make ornaments in time according to the customer's order, have more resting time and free time, and to be close to his child with heart disease. Bee's father explained that:

> *Before my kid was born, I didn't have any burdens, only my job. But now I have to reorganize myself by managing time more efficiently. I used to get up late around 8-9 o'clock, but now I must wake up at 4-5 o'clock. I also manage time when going out to work. I must prioritize my tasks and get things done before going out. After work, I can work fully at home. I used to have much confused and can't sleep, but today I can sleep tight and have a full rest. After finishing work, I can have more time to play with my kid. I don't feel worried about the future. That improves my life. (F/P8 Int 2/637-664)*

Fathers played a main part in helping mothers manage their child care and household chores. To relieve the child care burden and allow mothers to have time

for doing housework, fathers would help taking care of children. Nai's mother, 18 years of age, accepted that she could not finish housework daily. However, her husband, who was around 10 years older, lent his hand to take care of Nai and did housework for her, making her feel great and less tired. Nai's mother said:

> *I was very tired [stressing voice] some days. Luckily, my husband helps me a lot. If I don't have him, I could be in trouble. He'd take care of our kid after getting home during which I have time to wash clothes and clean the house. We help each other, but he mostly does for me. But I'll feed medicine to my kid by myself because my husband doesn't know how to do. He keeps telling me not to forget feeding drug. (P2 Int1/278-282, 2/274-277)*

As also seen in Fah's family, where the mother worked as a housekeeper. Fah's father would get up at three o'clock in the morning to prepare mackerel for selling and then got home to take care of their two children after finishing work. Fah's mother said:

> *His help is by far greater, as he has to work. After work, he would help me take care of our child. We help each other. He goes out to sell fish in the morning and then get back to help me so that I can do housework. (P4/ 4/510515)*

Mothers also ask for help from other family members who live in the same household to help lessen burdens. Pim's mother told her elder daughter, aged 10 years, to take care of herself in order that the mother could provide care for her younger daughter and could manage other housework. In addition, Pim's mother sought help from her own younger sister who lived in the same house to take care of her children. As the mother said:

> *I told my elder daughter 'Mom begs you. Mom feels tired and has to take care of your sick sister and you don't obey me.' I told her to take a bath and eat without my repeated prod.(P1 Int3/592-593)…I also asked my sister to help because I was unable to do it. I feel tired and want to have some rest so I let my sister take care of my kid and I take a nap. I rely on her. She always helps me everything [laughing]. (P1 Int1/532-539,612-613, 616-621)*

Relatives who lived in other places also played a part in dealing with child care and household chores, as seen in the case of Fah's grandmother, who came to visit occasionally. She generally stayed with her husband upcountry, but sometimes came round to take care of Fah. The grandmother helped the mother feed medicine and do housework so that Fah's mother could take a rest. Besides being assisted with household chore and child care, her grandmother always made clothes for her grandchild, made a blanket and bed sheet from remnants, and used unused sarongs to sew diapers to replace disposable nappies. That helped Fah's mother save a lot of money and time in cleaning diapers. Fah's mother explained that:

> *Grandma helps with everything from cooking, feeding, and giving my kid a bath while I do housework. When she goes back home, I'll be very busy. I must do housework while my kid is sleeping …Grandma also made disposable nappies by sewing her unused sarongs. She said it was more convenient. Previously, we had to wash (drawling voice) nappies very often, but the Grandma-style nappies help me save money and time for doing housework smiling. (P4 Int1/250-251, 698,750-751, Int2/ 284-295)*

Managing Social Activities

Parents adjusted or changed their habits of joining or refusing their usual social activities appropriately and consistently within limitations and each family's context. Social activities include participating with friends, neighbors, or co-workers in social setting such as department stores, temples, etc. Changing social activities also involves parents' usual behaviors or habits in taking care of themselves in order that parents have more time for taking care of their children and household chores.

Realizing that parents were deprived of their self-care and resting time due to the duty of caring for children with heart disease, some decided to acclimate or

change their habits of joining social activities so as to have more time to rest, care for children, and deal with household chores, as told by Pim's mother:

> *All of my time is devoted to my ill kid and housework, so I hardly go anywhere. I have free time on Sunday only, but I don't feel like going out because of tiredness. Sometimes my friends persuaded me to go out somewhere else, but I refused them, saying I need a rest. Though I didn't actually have a lie down, sitting around was enough for me. I could see them at the factory. (P1 Int3/ 355-358)*

One mother changed their habits because of concern over their child, as seen in case of Nai's mother, a teenage mother. She revealed that after her child suffered the heart disease she stopped drinking and hanging out with friends, as she needed to look after the child by herself. The mother realized those habits were not good, but never gave them up successfully until this child was born. As well, she stopped making up her face and body. Nai's mother expressed as follows:

> *It's because of my CHD child. I dare not to leave him. I'm afraid. I dare not to place him under others' care. So I don't go out. I change over. I used to hang out very often. My friends told me I've changed to be a brand-new one. Though I've been fat, I was never like this before. I had to look good all the time. I had to wear make-up. I've changed everything for my child to be cured. My mom said that this child changes me from a drinker to be a better person. (P2 Int4/297-307)*

Managing Constraints related to Hospital Services

Many parents described the struggle of dealing with the constraints of hospital services-especially the limited advice from nurses and physician. When taking children to the hospital and/or when the children were admitted to the hospital, parents had to adjust to the service system of each hospital and cope with the problems and obstacle. The children had to wait due to a long queue for surgery, and

also the parents needed to have a long wait for hospital services as well as dealt with problems with of the referral of patients from the parent hospital.

Managing constraints under limited advice and care from health professionals. Many parents described the struggle of dealing with the constraints of hospital services-especially the limited advice from nurses. Nurses played a minor role in giving advice and caring the affected child. Under limited advice and care, parents were very gracious and framed this in positive way, admitting the situation and realized that it was the parents' duty to care for children. In addition, they tried to find information from others and adjusted themselves to the hospital service. Nevertheless, limited information and care affected their child care when they were at home.

Some parents revealed that they did not receive much information and advice from physicians and nurses. Bank's mother said that physicians usually used technical terms and did not give easy-to-understand explanations, while she did not get any information from nurse, as she explained:

> *During the echo, doctors told me to hold my child, but both of them spoke doctor language that I can't understand. The test was shown on the monitor. I saw it all, but they didn't explain it to me. They said they would explain later but finally they didn't. And I've been confused until now. I didn't have a chance to talk with nurses, and doctors didn't explain things to me. I know it's impossible to get good service. The best I can do is taking care of my child best. (P7 Int2/55-58, Int3/822-828)*

Parents described that they were likely to have brief conversations with doctors, rather than nurses. They perceived that nurses' advice was general such as giving medicine and limiting food and water of children. Parents revealed that physicians gave more specific and important advice and data, which were related to

the condition and treatment of children directly. They also realized that nurses could not answer or clarify as clearly as physicians, as told by Fah's mother about her faith and belief in the physician's treatment. She talked about advice from health care professionals that:

> *I got more advice from doctors than nurses. At an investigating room, a nurse only called my child's name, but I would get a chance to see a doctor and then I could consult him. Also, the nurses at the ward where my child was admitted didn't give me much advice, only general information and I myself didn't want to ask them rather than doctors. They couldn't answer all my questions; they only give general information. If I want to know something specifically, I would rather ask doctors who could give simple and deep explanations. (P4 Int 4/633-659)*

However, one parents dared not to ask physicians, felt "*Kreng Jai*" **(**เกรงใจ**,** felt considerate to ask a question, as told by Bank's mother:

> *I want to know if this disease can be cured and how the surgery will be operated, but I dare not to ask physicians. And I forgot to ask when seeing a doctor, but when I was about to ask, he already went way. Then I intended to make a note of my questions, but I forgot it. And I also felt too considerate ("kreng jai") to ask him while he was teaching his students. I didn't want to interrupt them. (P7 Int1/372-374)*

Six parents mentioned that they did not receive information regarding caring for children provided by nurses either at the out-patient department or at the ward. They were very gracious and framed this in a positive way, admitting the situation and realizing it was the parents' duty to care for the children. At the pediatric wards, mothers were allowed to stay with the hospitalized child. The mothers provided total care for their child, while nurses did not. Parents, however, admitted the situation and realized it was the mother's duty to care for children. They accepted the limitations of not getting advice and care from nurses as Pim's mother said:

> *Nurses didn't give me any information (she shook her head and said with strong voice). Never….. When the nurse came in the room to provide medicine, she just put it on the table and I fed it to my kid myself. They just came to ask how many times my child had a poo and pee. That's all. They didn't give me advice about how to care for my child at home or talk with me. Anyway, I don't think too much. I know nurses are busy. It's my duty as well. (P1 Int1/367-369, Int3/870—875, 892, 896-914)*

Likewise, Bank's mother told while her son was receiving treatment at the hospital, she took care of everything for him, daring not to ask for help from nurses when she need to go outside the ward. She decided to wait for her husband to take a turn. She realized that nurses had many responsibilities and it was mother's duty to care child, as she told that:

> *I feel considerate to leave my child with the nurse because she is already busy. She has never talked to me. She is not quite available. If I need to run an errand, I'll wait for my husband to take turn. I feel really considerate. I don't think she will do for us while I can and must do by ourselves. (P7 Int1/634, 652)*

Due to insufficient advice and care from nurses, mothers turned to seek information about child care from other children's mothers at the ward. Pim's mother explained how she found information regarding caring for the child in the hospital :

> *On the first day I went into the ward, I had to ask a woman whose child was sleeping besides my child's bed where I could get the clothes. Nurses didn't come out to help me, making me to ask others while my kid was hungry. But how could I make milk? Where is hot water? They didn't care about us, so I thought I was nobody and my 30 baht (30 baht health scheme) was meaningless. But later I gave up that thought. I just followed others without waiting for the nurse's advice. If I don't know, I'll ask others. (P1 Int3/901-909)*

Due to limited advice and care from health care professionals, parents provided wrong dose of medication to the children. Parents described that they did not receive information about side effects or irregularities after being given medicine

from physicians and nurses. As a result, they have neither known how to observe abnormal signs, nor how serious it is when their children take an overdose of medicines. Nurses would advise how to feed and store medicine before discharge, with some demonstrating of the method of medicine preparation, but some giving explanations only. However, parents did not have a chance to practice, only being given information that medicine could make the heart work better. Therefore, they fed over dose of medicine, thinking that when the child took more medicine, the child's heart worked better, and would feel regret for dumping the remaining drug, leading to a wrong medication.

An observation of medicine preparation by Pim's mother showed she mixed one fourth of a Captopril pill with 3 c.c. of water and fed her child with 1.8 c.c. of mixed medicine, as advised by doctor. She dropped a white tablet—one fourth of a Captopril pill— into a plastic glass, poured water, which she claimed was cool boiled water) into the glass, used a 5-c.c syringe to suck up 3 c.c. of water, and poured it into the medicine glass. Then she used the tip of syringe to crush the tablet, sucked all the powdered medicine and then sucked much water to the level of 1.8 c.c., without dissolving or disintegrating the drug before sucking. (P2, FN3, 3 December 2006).

Pim's mother explained her drug preparation:

> *I don't need to stir the drug to dissolve it. When it begins to disintegrate, I can suddenly use a syringe to suck it without waiting for the disintegration. I regret if the drug is left. I think my child could be much better from taking a lot of medicine as it could help his heart. I fear he won't get the drug fully. He didn't show any reactions. I thought that if he is overdosed, there could be something wrong. But there's nothing irregular, so I think he'll be better. (P1 Int3/34-47, Int4/118-127)*

In addition, most parents did not know they could adjust the medication time. If the time to feed the drug had passed, they would defer to the next dose, preventing children from taking medication fully according to the treatment plan. Bank's mother told that once she fell asleep, so she missed feeding drug to her child for the midnight meal and deferred to the morning meal on the next day. After knowing from the researcher about adjusting the time, she put forward the drug feeding to 9-10 o' clock in the evening, when her child was still awake, so that her child got full medicine. As Bank's mother explained,

> *For midnight meal, I could wake up sometimes to feed drug to him, but there were sometimes I couldn't (she said with laugh). So I let it pass and deferred to the next meal around 8 o'clock in the next morning. I know that was not good. My child won't get full medicine. But I didn't know how to do. I took a nap but didn't wake up to feed him. I didn't know if he could take drugs around 10 or 11 o'clock in the evening, as he's still awake around that time. (P7 Int2/250-264)*

Managing constraints related to the long wait for heart surgery. Parents adjusted themselves while waiting for the heart surgery of their children. During this period, parents felt stress and anxiety over the child's uncertain conditions. They, therefore, tried to accept the waiting situation and try to find ways to accelerate the surgery.

Prior to cardiac surgery, parents who had seen their children suffer serious illness were more stressful and anxious, and wanted their child to undergo surgery early. However, parents coped with stress by thinking positively in the hope that their children would be cured after the surgery, making them wait with patience. Fah's mother told her child was admitted to Hospital A when she was 6 months old and needed a new diagnosis. The girl had to wait until she was 17 months old to have

a first heart surgery, as she had to gain proper weight before the surgery. However, that surgery was not successful, as physicians could not repair the heart defect due to the wrong diagnosis. The girl underwent a surgery again at the age of 20 months, meaning that it took a total of one year and two months to have a surgery. Fah's mother revealed how she went through that period:

> *I hoped she would be cured; it took a long time, though. Everything was slow. I knew doctors already worked hard and were responsible to help us. There were other cases who were serious than my child. The only thing I can do is wait, even though I'm tired of it, but I must wait (she laughed). I must accept it. Waiting is always torturing. Doctors might not think it's slow, but for me, it takes a very long time. (P4 Int 3/395-411)*

In the meantime, some parents tried to rush the process to have their children get the surgery early by getting referred to other hospitals with the help of others. Jing's mother told that she asked the district council member/Bangkok Metropolitan Council member during a local election campaign at that time to help transfer her child to another hospital. She said that:

> *He (a district council member/Bangkok Metropolitan Council member) told me that he could help admit my child to the hospital x. I thought it should be nicer as he knew the surgeon in person. It must be good. He told me that with his help, my child would get the heart surgery in a few months. So, I referred my kid to that hospital. (P3 Int 1/260-261)*

Managing constraints related to the long wait for hospital services. Parents had to deal with problems related to receiving services from the hospital. Parents often met with a long waiting queue for receiving the treatment due to the insufficient number of health care professionals and medical practitioners. However, all parents in this study tried to understand, adjust, and accept that the problem was common among well-known and large hospitals.

Having developed an understanding of the hospital system as well as the treatment procedures, parents adapted and adjusted the way to help their children get the treatment early, as told by Fah's mother that:

> *I usually had to wait for a long time when receiving medicine and waiting to see a doctor. The small number of doctors did not match the great number of children, while the pharmacists at the dispensing unit could not serve all people in time. Anyway, it was slow everywhere. So I let it be! I hurried up myself. I let my husband carry my child and I ran for a queue card (she laughed). (P4 Int 2/453-466)*

Besides a long wait for treatment, parents had to deal with the documents about health care benefits that made them exhausted. They managed to ease the tiredness occurring during the long process by taking turns to be with their child so that the other could be able to proceed with the document process. Doing things this way required both father and mother to go to the hospital in order to take turns to look after the child. Some parents sought help from their relatives such as the grandmother and maternal aunt to take turns to help carry the child or belongings when taking children to the hospital. Fah's and Mai's mother explained as follows:

> *I need someone to go with me to the hospital to help carry the child. Yesterday I went there very early and got home at 6.30 p.m. I needed to deal with the document process so my husband had to go with me…It's better to go there together as we could help each other. (F, P4 Int 4/510, 630-631)*

> *The last time when my child was admitted to the hospital, I asked help from my sister. Without her, I would have been in a terrible trouble. I had to contact many departments and take my child to get an x-ray. She said she was very tired from carrying heavy belongings. So if I go there alone, how tired I'll be. She helped a lot. (P6 Int 3/229-233)*

Managing constraints related to the referral system. Parents explained the constraints related to referral system of the registered primary care hospital in the 30 baht health care scheme to a tertiary care hospital. Seven from eight families in this

study used their health security cards while the other used the health card for the disabled. To be exempt from the medical expenses according to the health security scheme, a referral form by the registered hospital to the tertiary hospital is required.

The study showed that three families encountered the inconvenience from the referral as the physician at the registered hospital did not allow the referral and provided no useful advice, making these families worried that their children would not have proper treatments and the heart surgery. Nevertheless, they eventually overcame the obstacle and had their children receive the treatment at the tertiary hospital. Particularly, they had to accept the situation because of financial constraints. Bee's father recalled his memory of suffering from inconvenience of the referral as well as the physician's comments that caused him more worries; however, he tried to follow the steps until his child got the treatment.

> *The worst period was when my child was not yet transferred to Hospital A from Hospital "X & Y" due to their haggle. Both of them denied the responsibility. It was a shock! They said I had to spend as much as hundred thousand baht for the surgery. They later told that I had to be more active for my child. My child should be listed as a disabled person who must register for another type of health security card for the disabled. After calming down, I followed their advice and finally my child was transferred to another hospital. (F, P8/2/470)*

In the meantime, some parents could not deal with the problem of transferring to another hospital after being informed that lots of money is needed. They then decided to have their children receive the treatment at the same hospital. Bank's parents told that their child with pneumonia was admitted to the registered hospital, which was a private one near their house. After two weeks of treatment, the child was not yet recovered; they asked doctors to refer him to Hospital A, which had his patient record. However, the physician denied it. Transferring to Hospital A without the

referral form would cause them to pay all medical costs by themselves. Due to a lack of money, they needed to have their child stay at the registered hospital. During hospitalization, the mother contacted the researcher via telephone over her concern over her child's condition. As Bank's mother said,

> *I told the doctor I needed to transfer my son to Hospital A, as that hospital was not well-equipped, but the doctor asked me if I had money. I wanted the doctor to refer my son, but I had no money (said with sad face and voice). So, I had to pay close attention to my child and worry. (Fm, P7 Int1/378-385, 767-789)*

Even faced with the difficulty of seeking a referral document, parents did not change the registered hospital due to a lack of information and fear that their children might fall sick and need to be admitted to the hospital. They worried that they could not have enough money for medical costs during the change of hospital.

> *I don't know whom I can ask. I know I should change the hospital during waiting for the surgery. But what if something bad happens to my child? Does it take months for the process? I heard it takes 15 days. And what if he has pneumonia during that time? I don't have money for the treatment. I'm afraid of that period. So I decided to wait. (P7 Int3/285-290)*

Thamjai —Making up One's Mind

Apart from various constraints coming from out side, the most significant constraint usually came from parents' emotional stress and strain related to their children's illness as well as difficulties in taking care of the children. Nevertheless, the parents tried to minimize their stress by cheering up and accepting the child's illness.

Accepting the child's illness. Regarding accepting the child's illness, parents confronted the problems by *Tham Jai*, or making up one's mind. Since Buddhist teachings indicate a child's heart disease is caused by karma, they felt they had to accept their children's illness by adjusting their minds. Parents tended to accept that

caring for their children was discouraging and tiring. So they were able to continue caring for their children, they found ways to build encouragement within themselves Parents noted they might find encouragement within themselves from adjusting their ways of thinking (not giving up, comparing themselves to others who they perceived to be worse off than them, thinking positively and following the principles of Buddha). Receiving information and support from physicians also helped parents relieve their stress and feel better. However, most of them accepted it was difficult and took time to accept the real situation, or get through it, as told by New's mother that:

> *I never thought that my child would suffer from this disease. It's strange for me to be anxious when hearing my child has heart disease. I think everyone must be worried. It depends on how much he can accept. For me, my two children are normal, but the third has the illness. That makes me concerned, as I never thought of it. It's difficult to accept it, but I've tried to adjust mind and think my child will be ok. (P5 Int1/712, 1166-1167, Int3/101-105)*

Bee's father had similar feelings to New's mother when he was first told about his daughter, he explained:

> *At first, it was shocking when I was told that my child has a serious heart disease. I was shocked and thought why I met up something like this. But later I composed myself and accepted that the way it is. So I can accept it. (F/P8, Int2/548-550)*

Parents had various individual methods to adjust mind to accept the child's illness such as letting it go, as told by Pim's mother:

> *Let it go when time passed. I had to adjust my mind and must not be stressful. The only thing I can do is calm my mind. I don't think of it and don't express my feelings to others. I have to deal with it by myself. (P1 Int 4/721).*

Thinking positively and accepting the real situation contributed to parents' encouragement, as told by Fah's mother, who is being a good humored, talkative, open and optimistic person, she spoke in a cheerful voice:

> *It's tiring, but I think she was born to be my baby. I try my utmost to care for her. I love her. She's my child. I take care of her completely. I accept that I feel tired. Sometimes when I was alone, I couldn't help complaining about her. But there's nothing better. So I tried to adjust mind and be happy with it. But sometimes I got angry with her, so I hit her softly (she laughed). (P4 Int 4/780)*

Another contribution to parents' positive thinking could be receiving positive information from a competent physician who would treat her child. Mothers told that they felt better and more encouraged after being informed of physicians. In addition, parents revealed that what relieved their stress most was the doctor's explanation and information that the heart disease suffered by their children is curable by the surgery. As two mothers said:

> *The physicians told me not to be frightened. My daughter's heart disease isn't serious. The surgery can definitely save my young kid. She will be cured for sure. So I think it's not frightening and worrying.*
> *(P3 Int3/146-150)*

> *It wasn't a big problem, just a small one, a doctor told me. I was shocked at first, but now I can accept it and don't think of it anymore. The doctor said my child will be cured by the surgery. I was anxious then, but now I'm relieved. I'm not afraid. I'm now happier. (P1 Int3/401-409)*

Cheering themselves up. They also relied on being cheered up by their children, family members, co-workers and neighbors. Parents often became deprived of sleep and had to have patience while caring for their CHD children. Parents gave themselves moral support to help overcome the problem and anxiety related to their children's illness and to continue to care for them. Most parents accepted that caring

for children with heart disease was discouraging and tiring, leading them to find ways to build encouragement for them to keep caring for the child. Encouragement might be provided by themselves by adjusting the way of thinking such fighting, not giving up, comparing themselves with others who are worse off, thinking positively and following the principles of Buddhism. They were also cheered up by their children, family members, co-workers and neighbors.

Almost all the parents revealed that bringing up children with heart disease was a burden, as they were deprived of sleep. It required them to have a lot of patience to care for children, as told by a mother who revealed her feelings towards caring for her child and her way of thinking to cheer herself up:

> *Caring for a child with heart disease is like caring for ten children at the same time. It's difficult and tiring. But I never give up. I do for my child. How could I give up? I gave birth to him. I must fight. It's tiring, but it's worth seeing him grow up and have good health. (P1 Int3/395, 646 4/188, 319)*

Comparing themselves with others whose children have more serious heart disease, and acknowledging others have a harder and more difficult situation than theirs could lead parents to think that their children's condition might not be too serious, making them feel better as told by two mothers:

> *It seems that another child's illness is much more severe than my child's. He suffers lots of diseases. His condition is worse. That child's parents must use more patience than I. Looking back at them, their suffering is greater than mine. Thinking like this makes me feel better. (P1 Int3/ 857-861)*

> *After talking with others, I feel better that my child's illness isn't too serious. Some children are incurable, while some have to undergo the surgeries for several times, causing them lots of pain, taking many medicines, and some had to stay at the hospital for many months. That makes me think my child's condition is not as severe as theirs and I feel better. (P2Int3/ 243-255)*

Another important factor helping many parents feel better, to have encouragement to care for their children, and to accept their illness was to follow the teachings of Buddhism, such as paying respect and praying to the Buddha, making merit, and offering food to monks at a temple. Some parents expressed that:

> *I've recited Katha Chinnabanchorn (คาถาชินบัญชร=a Buddhist praying) every night since my child was sick. I pray for him and for me to feel better and to have encouragement to keep caring for him. (P7 Int1/844)*
> *I took my child to a temple to give offerings to the monks, pay respect to the Buddha, and pray for him to be cured after the surgery. I have nothing to rely on. Making merit makes me feel better and calm down. (P5 Int 1/393-401)*

> *I would offer food to the monks some mornings, and dedicate merit to the enemies from a former life. I also pay respect to the shrines everywhere I meet and beg the holy thing to help protect my child. I believe in superstition. It makes me feel better. (P6 Int 3/530-533)*

Besides cheering up themselves, parents were encouraged by their companions. The most important person who encouraged them to go through the tough period was their child. Nai's mother revealed that "*My child is my encouragement. I've brought him up since he was born. When he has this disease, I must take care of him closely even I feel tired.*" (P2 Int2/245- 258).

All families in this study revealed that assistance, counseling and encouragement came from within the family. Even though some did not have much conversation, their support was expressed via actions, like accompanying mothers to the hospital. Nai's mother told that grandparents gave them a helping hand in everything as well as cheered them up. When the child had the treatment or surgery, the grandmother would go with the mother every time. Nai's mother said:

> *My mom (the child's grandmother) stands by me. She told me to accept the truth, whether my child could be cured or not. My dad also told me to take patience as I gave birth to my child, and I must care for and bring up him well. I've been cheered up by my family. My encouragement is here. (P2 Int1 99, 153, Int3/213-215)*

For a nuclear family, the person counseling and cheering up was generally the father, while a grandmother would come to visit them sometimes. Even if they did not give verbal advice, a mother said she could feel it through their eyes as follows:

> *Although we didn't talk much, I could feel it from their eyes. My husband is not talkative, but I can talk with him when I have problems. I also talk with my mother. She's a good listener; that makes me feel better. (P4 Int 3/461-468)*

Sharing experience with outsiders contributed to their encouragement. Co-workers and neighbors also played an important role in encouraging the parents by giving advice, looking after the child, talking about the child's sickness, showing their concern, listening to problems and visiting. Talking with other cardiac children's mothers at the hospital, knowing each other's problems, exchanging their experience of caring, and receiving positive information about the treatment could also cheer up parents. A mother revealed that:

> *We mostly talk about the treatment of our children. We share the feeling that they'll be cured by the surgery. They told me that their children are cured after the surgery. That makes me feel better and hope that my child will be cured too. That cheers me up. (P4 Int1/585-586, 661-667)*

In summary, even though families had several constraints, they tried their best to deal with the problems in order to provide optimal care for the child as well as to help all in family to live their lives. The findings indicated that parents received support from immediate family and from significant others when dealing with many constraints related to the child's care and daily life. On the other hands, it was appeared that they did not receive information, care, or any support from nurses.

Discussion of Practices of Families in Caring for Children with CHD

The practices of the families in caring for infants and young children with CHD prior to cardiac surgery were characterized by the phrase "Doing our best to get our child ready for surgery." This phrase encompassed the practices based on the families' perceptions and interpretations while waiting for the child's cardiac surgery. The day-to-day practices of families were grounded in socio-cultural aspects of Thai life, and supplemented by western biomedical culture, which informed their particular approach to care for the children.

As discussed in a previous section, parents perceived heart disease to be a fatal illness, and cardiac surgery was seen as a very complicated procedure and stressful event. However, parents believed that cardiac surgery was the particular treatment that would be able to extend the life of the child with CHD. With negative perceptions of the child's illness, families tried their best to find all possible ways to help their child be ready for surgery. Through closely observing the child's conditions and after being informed by physicians, parents realized that the period prior to cardiac surgery was a critical period for their child. During this time, the child could not eat much food or drink enough milk, had low resistance, and as a result, was susceptible to other illnesses. For the families, the preoperative period was the most difficult time, as the child had the most uncertainty of the illness, and all family members had the highest stress. The families wanted the child to have surgery as soon as possible. This finding supported an early qualitative study (Carey, 1999) that found parents of a child with CHD who was symptomatic and required surgery wanted their child to be ready for surgery as soon as possible.

It was clear from the findings in this study that much of the energy and attention of families was focused on preparing their child to be ready for surgery. They understood that the child needed to gain weight and strength to withstand and recover from surgery. Parents realized that their infants and young children relied on the parents and others in family to provide care. Infants and young children aged 0-3 years are the most important group of children that develop their physical, psychological, cognitive, and emotional development (Soonthorndhada, Kanugsukkasem, Punpueng, & Tangchonlatip, 1999).

Because the parents believed that they and their child shared karma in a former life together, allowing them to live together as a family in this life, love and help for one another were especially important in this present time, and "doing our best to get our child ready for surgery" in particular. Many families recognized the role of parents as "the fate of karma," by which they meant the ways that actions of the parents affected others. Therefore, the idea of karma let them continue to live under the present conditions, and also warned them to do good things, hoping that good deeds would return good results both to their child and to the family (Mulder, 1994). The idea of previous karma stresses "do well and receive well, do evil and receive evil" (Chunuan, Vanaleesin, Morkruengsai, & Thitimapong, 2007).

The study found that an important pattern of practices in families preparing for their child's surgery, grounded both in socio-cultural aspects and in western biomedical culture, could be characterized as "Promoting and Preventing"—promoting the child's weight gain and strong health, and preventing the child from getting worse. Parents tried their best to feed sufficient and nutritious food to the child, perceiving that infants or young children were too young to have the resistance

needed for surgery. They all understood that insufficient food or malnutrition, by itself, apart from CHD, could adversely affect the immune system and thus the host's response to infection either pre- or post-surgery. Also, they knew from the physicians that children with low body weights were at highest risk for complications or dying during both the pre- and post-operative phases. Therefore, they tried to increase to an optimal level of nutrition as an important goal in their child's care, despite their limited knowledge and understanding about nutritious food. The parents also applied several methods to help the child eat more, such as feeding small quantities frequently, feeding various foods of different types, and so on. They understood that they should feed their children good meals composed of five main groups of food. Personal experiences, recommendation of grandmother and neighbors, advertising media, and information board in the hospital all informed the mothers to select kinds of nutritious food for their children. Similarly, a previous study found that nutrition requirements were the major concerns of parents for determining the outcomes of cardiac surgery (Carey, 1999). Interestingly, all mothers in this study fed their children food supplements, including infant formula, special formula milk such as Pediasure brand milk, and manufactured baby food such as Cerelac. These supplements were in addition to or instead of breast milk.

Many cultural influences are at play in the lack of breastfeeding among Thai mothers. First, the mothers are influenced by social policy and personal reasons. Even though they are informed about breastfeeding from health care professionals when they come to the hospital (ante-natal and postpartum care), and know that breastfeeding is best for infants, they still stop too early. Children need to be breast fed until two years of age (UNICEF, 1009). Hospitals have "exclusive breastfeeding"

policies, which mean that babies should be fed only breast milk, no water and no infant formula milk in the postpartum wards in the hospital (Informal Data from Hospital A, 2009). However, it was found that Thai mothers discontinue breastfeeding because of policies related to occupational leave during the postpartum period for three months, or due to inconvenience, or having little or no breast milk.

Second, mothers are influenced by advertising. They get information about powdered milk from advertisements on TV and from labels on canned milk. Feeding instant formula milk was often the result of influences such as media advertising or health programs from television. Despite the low income level of the families, every house in this study had a television. For low income families in Thailand, television was the one and only form of entertainment (McCarty et al., 1999). Families had to work, and did not have time to read books or could not afford to buy magazines.

Third, they are influenced by health care providers' advice. Five of eight mothers mentioned that health care providers at the hospitals suggested they replace breast milk with formula milk. This was not correct practice regarding promoting the child's weight gain. The mothers might not have understood clearly that formula milk should be fed additionally, not as a replacement for their breast milk. When physicians recommended that they feed the infants with some kinds of formula milk, the mothers wanted to follow their recommendation. Also, when they saw that the neighbors' children were big, healthy, and increased weight gain after eating certain powdered milk, they too fed that kind of milk to their child. Even though it is expensive, they buy it for their child.

Thus in spite of efforts such as the hospitals' exclusive breastfeeding policies (which are not always followed), and the International Code of Marketing of Breast

Milk Substitutes (which Thailand adopted nearly 30 years ago), breastfeeding is not practiced widely enough in the country. The reasons for this have to do with social norms, biomedical culture, and the influence of western culture. Many practitioners of western medicine have already tried to bridge the gap between western and traditional health practices —such as doing the research about breastfeeding, and about mother-child attachment during breastfeeding (Lobo, 1992; Marino, O'Brien, & LoRe, 1995; McGrail, 1997). However, it's not only the responsibility of practitioners of western biomedicine, but also of advertising agencies to do better.

Regarding "Promoting and Preventing," it should be noted here that parents managed their child's care while trying to help others in the family live their life normally despite significant constraints. Six of the eight families who participated in this study were low income families, with average incomes from 100-500 baht (3-15 US dollars) a day, and managing financial issues was their main challenge. Even faced with financial problems, the parents tried to give their ill child nutritious or favorite foods to help the child become strong enough for surgery. While other healthy children and the parents never had chances to eat some nutritious food or "good foods," the CHD child was fed with eggs, vegetables, or expensive instant powder milk every day. Doing so was a challenge for the low income families, but because of their unconditional love, parents were more motivated to do what was best for the child. Personal experiences, recommendations of grandmothers and neighbors, advertising media, and information boards in the hospital all informed the mothers how to select kinds of nutritious food for their children.

Traditional beliefs also influenced parenting practices regarding feeding solid food. The parents brought their personal beliefs and knowledge, as well as the

traditional practices of elders in the family, regarding the feeding of solid food (mashed bananas in particular) at an early age. They believed that bananas could fill up the infants and potentially help them gain weight, as opposed to milk, which they believed would simply be eliminated as urine. This finding was consistent with one ethnographic study of Pouwilai and her colleagues (2003), who found that mashed banana was the most popular food for Thai families to feed infants aged more than one month. In addition, parents fed their children either Thai traditional medicine, or Chinese herbs, believing that they could help the child have a bigger appetite. This practice was influenced by parents' personal beliefs, as well as the recommendation of grandmothers and other neighbors. These findings were consistent with a qualitative study of Klunklin (2003) that nutrition provided to HIV-infected children matched their primary caregiver's beliefs, or beliefs of the community elders regarding taboo foods for certain diseases.

To prevent the child from getting worse, families tried their best to prevent the child's heart from working too hard using several practices based on their beliefs and direct child care experiences. The practices began at the child's diagnosis and continued throughout the course of cure, until the child's operation. Such traditional beliefs were often based on supernatural powers rather than on modern medicine, or on wishing their children would recover from illness and be healthy and safe from the heart operation. For instance, many families offered food, made merit, and prayed to and asked for blessings from Buddha, Buddha images, or other supreme beings to cure the child, to keep the child safe, and to protect the child from bad things. As previously mentioned, importance was placed on karma related to causing suffering to animals or people in the previous lives. Buddhist people use different cultural

approaches to lower their karmic effects, such as asking forgiveness from the spirit to whom they owed their life (*Jao Karma Nai Wein*, *เจ้ากรรมนายเวร*.) If they believe that they caused suffering to another human life, that human will be the spirit they ask for forgiveness (Junda, 2002; Phra Saneh Dhamavaro, 2003). Although western evidence-based medicine is becoming accepted as the standard for cardiac treatments, the Thai parents did not have a single or consistent theory about the cause of disease in general, nor did they totally rely on any single therapeutic approach (Jintrawet, 2005; Klunklin, 2003). Their practices supported some existing studies that reported Thai parents using non-western treatments to help the recovery of their ill children based on their beliefs (Nukulkij, 1993).

Feeding the right dose and not skipping doses of medicine were important practices of families concerned about that preventing the progression of the child's illnesses and any complications. Parents found that after the child took a certain medicine called lanoxin, the child's heart rate was not as strong and rapid as before. (Lanoxin is also called "*Ya Hau Jai*," or ยาหัวใจ and is used for maintaining the heart's function, improving its ability to pump while decreasing its workload (Laohaprasitiporn, 1991).) Some parents found that when lanoxin was skipped or was not fed to the child, the child had worsened symptoms such as more restlessness and a more rapid and stronger heart rate. Therefore, they tried to keep feeding the child's all types of medicine and did not skip doses of medicine, even though they failed to administer the drug on time every time. They put this care practice as their first priority. Despite limited knowledge and understanding about medicines, all parents tried to keep feeding all of the child's medicines and did not skip doses of medicine.

They thought that if the child did not take medicines, the child's conditions would get worse, to the point of perhaps not living long enough to undergo the heart surgery. However, two mothers gave their children the wrong dose of medicine, thinking that feeding more medicine would help the heart function better. This finding confirmed existing knowledge about Thai parents of children with CHD, regarding their limited knowledge and understanding of their child's medications as well as their poor ability to monitor the side effects of the medications (Nukulkij, 1993).

In addition to feeding medicines and not skipping dose of medicine, families avoided any actions that would make the child cry, or cause them fright or fatigue, in order to prevent the heart from working too hard. After playing hard, hearing loud noises, or being exposed to cold water, the child had a stronger, more rapid heartbeat. Parents realized that sleeping is the best rest for mind and body. However, the parents found that their CHD children could not sleep 10-12 hours a night, as recommended for children (Wong, Hockenberry-Eaton, Wilson, Winklestein, & Schwartz, 2001) because their children had difficulty to sleep, were sensitive to hot weather, and easily became sweaty even when the weather was not hot. Parents realized that having enough sleep is good for health, particularly good for the heart. Therefore, they tried to help the children get enough sleep by getting the child ready to go to bed (making sure they were full and clean), organizing a place and environment where the child could sleep in a cozy, quiet, and safe place, and accompanying and soothing the child.

Apart from reducing the heart workload, families tried to keep the child away from other illnesses. Based on their belief and direct child care experiences, parents realized that if the child was afflicted with any disease, the conditions would be more serious. Consequently the child might not live through the critical pre-operative

phase. Through closely observing the child's conditions and being warned by physicians, they recognized that the child was vulnerable to other diseases. The children had frequent colds and slow recoveries. The parents tried to protect against common colds and pneumonia, and to keep away from contacting people with URIs. In general, based on informal communication with nurses at a pediatric cardiovascular ward in Siriraj Hospital, parents whose CHD children were admitted to the hospital would receive advice from physicians or nurses about keeping the child away from URIs, avoiding taking the CHD child to crowded places, and so on.

However, although parents tried to prevent the child from contacting people with URIs, sometimes they were still reluctant to tell their neighbors with colds not to get close to or carry the child. In line with Thai culture, they were concerned about their friends and neighbors' feelings more than their own feelings, an attitude known in Thai as "*krengjai*." For Thai people, *krengjai* is a daily element of social interaction, a self-conscious way of behaving and thinking. *Krengjai* is a Thai verb that combines two distinct words: *kreng* (to fear something or be afraid to act), and *jai* (of the heart or mind). Thus, *krengjai* is having consideration for another person's feelings, being reluctant to disturb or offend, or being fearful of approaching someone. It draws on the Buddhist beliefs of the majority of the Thai people (of whom around 95% are Buddhists). In particular, *krengjai* reflects the idea of karma that guides one's actions towards others in the expectation that one will receive the same thing in return (Chitrada, 2004).

To keep the child away from other illness, parents also focused on the child's and their personal hygiene and environments as much as possible to prevent disease transmission. Most parents took their CHD children to receive standard vaccines, just

as normal children do. This practice was correct, as children with CHD should receive the same healthcare maintenance, particularly full-dose vaccines as healthy children do (Saenz, Beebe, & Triplett, 1999; Smith, 2001). In addition, parents in this study gave great attention to the cleanliness of the child's utensils because they believed that this could prevent illness related to bad sanitation. However, hand washing was rarely found among families in the study. Parents would wash their hands only after going to the toilet, coming back from outside, or when they were visibly dirty. They perceived that hand washing was the best way to prevent infection, but would do so only depending upon convenience and possibility. In this study, none of families had a washbasin in their house or child care area. As the bathroom was located outside the house, mothers would wash their hands only after the child passed stools, but did not go to wash their hands before preparing medicines. Hygiene was a challenge for low-income families. Due to limitations on living spaces for financial reasons, some families could not avoid problems that occurred due to close quarters. For example, families renting a 3 x 5 meter room that was home for 3 to 5 family members could not prevent the children from contracting common colds when another family member was ill. Despite this major challenge for families who had limited space in their houses, the parents tried to arrange a sleeping place to prevent the CHD child from sleeping close to the URI child. Sometimes the parents would sleep in the middle between the CHD child and the elder child who had caught a cold. Living space was also a major constraint for families who wanted to keep the child away from crowds of people. For example, one family stayed opposite the market, and so could not prevent the child from contacting common colds when other people in the crowded market were ill. However, that mother tried to avoid taking the child

outside. The mother also told her neighbors that the child had low immunity, and asked the ones who had URIs to avoid holding the child. Keeping the child's utensils clean to prevent diarrhea was also a particular challenge in some of the homes. For instance, families often did not have a refrigerator to keep milk and food, nor enough clean water, or no gas oven. Boiling water as often as necessary was inconvenient.

Since six of the eight families who participated in this study were low income families, managing financial issues was their main challenge. Financial problems were increased directly through the various expenses associated with the child's care including food, transportation, and costs of daily living. In addition, some mothers had to work less overtime, or take deductions in daily wages because they had to take leave to take care of the child, or to take the child to the hospital. Others could not go to work or earn money at all. As mentioned earlier, the families in this study averaged 100-500 baht per day, or 3000 to 15000 baht (85 to 480 US dollars) a month. However, parents tried to deal with their financial problems in order to provide optimal care for the affected child. They tried to give their ill child nutritious or favorite foods to help the child become strong enough for surgery. To manage the child's care under financial constraints, the parents needed to adjust their ways of caring for the child, by asking for financial support from family members, or by borrowing money from neighbors and or co-workers. Two families had to borrow money from informal loan providers, at 10-20% interest.

The findings indicated that parents had to deal with the constraints of hospital services, especially the limited advice from physicians, who tended to use technical terms that were not easy to understand. Even though they wanted to ask a question about the child's illness, and had even prepared questions on paper, some parents

hesitated to ask the physicians, or felt *krengjai*. They were reluctant to disturb and were fearful of approaching physicians. For Thai people, both in rural and urban areas, physicians are respected because their roles give them responsibility for helping patients to improve health. Particularly in the big hospital settings, the ratio of physicians to patient is very high and the interaction between health professionals and patient is normally formal (Vong-Ek, 1994). The parents strongly acted in accordance with the physicians' advice, thinking that their suggestions would be best for the child's health.

The findings also indicated that parents did not receive much information or hands-on care from nurses when their child was in hospital. They mentioned that nurses were busy all the time, walked quickly, back and forth, and generally were working with several documents rather than talking with patients, families, or providing any advice related to caring for the child. However, the parents tried to think in a positive way and took on the responsibility of providing daily care for their child, saying that nurses were busy with an overload in the number of patients in the hospitals. They accepted that it was the parents' responsibility to provide basic care for their child during hospitalization. This finding was consistent with the qualitative study by Pongjaturawit (Chang & Hsu, 2007; Jintrawet, 2005; Prasomsuk, Jetsrisuparp, Ratanasiri, & Ratanasiri, 2007).

The quality of care varies widely among government hospitals, and many parents believed that their children could receive better care from larger hospitals in Bangkok, in particular, the two university hospitals involved in this study. Yet these facilities were busy, seeing about 250 walk-in pediatric patients per day, or more than 90,000 per year. A clinic specifically aimed at children with cardiovascular problems

saw 2,686 children in a recent year. Every Tuesday morning, 7 to 10 pediatric cardiologists and two nurses served 60-80 children. In the pediatric ward, 3-4 nurses provide care for 20-25 ill children in the morning shift, while 2-3 nurses take the night shift (Informal data, Annual Statistic Report, Department of Pediatric, Hospital A, 2008).

Parents therefore accepted that health professionals had limited time to provide much advice and basic care for their child. However, it seemed that while nurses said they work hard, their work was viewed by parents as not helpful or necessary for their children. Hospital accreditation requirements meant that nurses worked with several documents, and that these documents needed to be completed on time. Thus, parents could see that nurses were always busy, but not busy working with their child. However, this finding was based only on families' views. Nurses may have their own reasons why they could not provide information, or to explain what made them rushed enough that they had no time to talk with patients. Even though both hospital settings are large university hospitals, it appeared that formalized education systems for parents were not in place, either at the OPD or with hospitalized children with CHD. This is a particular area that nurses can have a significant impact. This gap needs to be addressed so that families can be properly supported during the most demanding caregiving phase.

Religion is one of the most important factors influencing families' beliefs, perceptions and practices regarding caring for the children. In this study, Buddhist teaching provided psychological support for parents and family members having an ill child with heart disease. It was clear from the data that Buddhist beliefs could help families to accept the child's illness, because they thought that the disease was caused

by their wrongdoings committed by the child in a previous existence. Buddhist teaching could help them make up their mind, accept their fate, adjust themselves to the real situation, and let it be. In Thai, families expressed this decision making process as *Tham Jai*, or following the heart. This finding was similar to many findings in Thailand, in which families thought that they had done everything in their power to help the ill child or affected family member. They accepted that responsibility for the outcomes lay beyond their power, connecting the idea of *Tham Jai* with the idea of karma. *Tham Jai* reflected the way of life of Buddhists (Chandra-ngam, 2001).

The evidence from the findings indicated that parents did receive critical support from immediate family and from significant others in dealing with the many constraints related to child care and daily life. This study also supports findings from previous studies showing that social support, support from family, friends, and neighbors, was important for families with chronically ill children (Jintrawet, 2005; Junda, 2002; Klunklin, 2003). Practices of families in caring for children with CHD integrated western biomedical culture, Thai traditional culture, Buddhist belief, folk medicine, media advertising, as well as recommendations of family members and neighbors.

Summary

This chapter described the perceptions and practices of Thai families in caring for children with CHD aged 0-3 years prior to cardiac surgery. These perceptions and practices are based on their understanding that heart disease is a dangerous and life-threatening disease, and that the child may not survive. Through receiving physicians'

information and closely observing the child's conditions, parents believed that the child could be cured by surgery. Therefore, they tried to do their best to get the child ready for surgery. The pattern included promoting the child's weight gain and strong health, preventing the child from getting worse, and managing the child's care under constraints. It was clear that socio-cultural context was the most important factor that deeply influenced the perceptions and practices of Thai families in caring for the child with CHD.