

Thai Families' Caring Practices for Infants with Congenital Heart Disease prior to Cardiac Surgery

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Abstract : This focused ethnographic study aimed at exploring how the Thai socio-cultural context influenced the perceptions and practices of Thai families caring for infants, 3 months to 17 months, with symptomatic, acyanotic or cyanotic, congenital heart disease (CHD), prior to cardiac surgery. Purposive sampling was used to recruit twelve parents and two family members, from eight families, who brought their infant with a CHD, to two university hospitals in Bangkok. Data were collected through in-depth interviews, participant observations and field notes, from September 2006 to October 2007, and analyzed through use of content analysis.

Family care practices were characterized by the phrase: "doing our best to get our child ready for surgery." Families understood their infants may not survive and would be difficult to care for. All the infants required pharmacological management, followed by surgery, and needed weight gain and strength to withstand and recover from surgery. Families prevented their children from getting worse, as well as managed their respective infant's care under significant constraints.

Findings indicated the families' perceptions and practices were influenced by the socio-cultural contexts, which included Buddhist teachings, cultural beliefs, financial constraints, hospital services, and support from family members and significant others. The results provided health professionals with an understanding of perspectives and practices of Thai families providing care, prior to surgery, for infants with CHD, and highlighted the context-dependent nature of family care and need for new and creative ways to provide culturally congruent professional care.

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Background

Congenital heart diseases (CHDs) are among the most frequent and severe chronic diseases of childhood. The incidence of congenital heart disease (CHD), in Thailand, is eight to ten infants of every 1000 live births.^{1, 2} Half of the infants with CHD have been reported to be symptomatic, and require both medical and surgical treatment.^{1, 3} The timeframe before surgery, however, is problematic since infants face

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health-related issues, i.e. congestive heart failure (CHF) and pneumonia.⁴ Although less than 2,500 infants with CHD, 0–2 years of age, undergo cardiac surgery yearly,¹ approximately 5% die awaiting surgery because of secondary complications.^{4, 5} The goal for health care professionals is to ensure parents are able to care for their infants with CHD in a manner that will maximize their functioning and maintain their lives throughout the preoperative phase.

In Western cultures, parents of young children have been found to be significantly affected when their children have been diagnosed with CHD,^{6, 7} and have expressed concern about the magnitude of their caring responsibilities. These include: interpreting their children's symptomatic behaviors; minimizing physiologic demands when their children are crying; difficulty feeding their children; maximizing their children's nutrition and weight gain; administering medication to their children; preparing their children for surgery; and, understanding their children's health conditions, including signs and symptoms, as well as ramifications of the diagnosis.^{8, 9} Thai parents also have been found to have parenting responsibilities similar to parenting practices in Western countries.^{10, 11}

Parents of children with CHD need sufficient knowledge to provide care for their children. However, parental informational needs are not being met, thus potentially compromising parents' ability to care for their sick children.^{12, 13} Prior studies have found that family members experience psychological and social changes, including stress, difficulty coping and decreased quality of life, when one of their children has CHD.^{14–20} No studies, however, could be located, in English or Thai language publications, which explored day-to-day practices of families providing care for young children with CHD, during their children's preoperative period.

Most studies, reported in Thai literature, have focused upon demographics and maternal factors of mothers' of children with CHD, with respect to their

children's care.^{21–23} In addition, previous research has found health education programs and self-help groups to be effective ways to provide support for mothers' child caring behaviors.^{24–27} Only one study, regarding the perspective of Thai parents of children with CHD, could be located. Although Nukulkiy:¹⁰ found parents of children with CHD view heart disease as dangerous and life-threatening, she questions if they appropriately are providing care and feels they do not treat their children in a typical manner. Thus, there is a need to explore, especially within the socio-cultural context, the day-to-day practices of Thai families providing care for their children with CHD who are awaiting cardiac surgery. Subsequently the aims of this study were to describe: 1) perceptions of Thai families regarding their infants' illnesses and treatments; 2) daily practices of Thai families in caring for their infants; and, 3) Thai cultural context influences on the practices of families caring for their infants.

Method

Ethnographic methodology was employed because it is an approach to learning about the social and cultural life of people, communities and institutions, peoples' worldviews, social behaviors and ways of life.^{28, 29} In this study 'focused ethnography' was used, since the intent was to concentrate efforts on very specific questions, as well as selected behaviors and their meanings among a specific group of people.^{29, 30} Focused ethnography shares, with classical ethnography, the commitment to carrying out intensive participant observation activities within the natural setting, asking questions to learn what is happening, and using other available sources of information to gain an understanding of people and events of interest. Focused ethnography allows for a better understanding of the complexities of common situations and, therefore, can help researchers uncover daily practices of Thai families in caring for children with CHD.^{28–30}

Participants: Approval, for this study, was obtained from the human research ethical committees of the Faculty of Nursing, Chiang Mai University and two university hospitals in Bangkok where data were gathered. Five informants were recruited from the out-patient pediatric cardiology clinics, while nine were obtained from the cardiology and infectious disease inpatient wards of the hospitals used in the study. Each informant was fully informed about the study, and assured of anonymity and confidentiality. Inclusion criteria involved being a parent and/or family member, with direct experience in providing care for a 0–2 year old child, who had been diagnosed with either acyanotic or cyanotic symptomatic CHD and was: awaiting cardiac surgery; was receiving ongoing medical management; being followed through one of the pediatric cardiac clinics; and residing, in the home, with at least one parent. Informants provided written consent, prior to data collection, to participate.

An equal number of males and females diagnosed with acyanotic CHD (n=4), and cyanotic CHD (n=4), were children of the eight informant families. They ranged in age from 3 to 17 months. Most of the families (n=7, 87%) relied on Thailand's 30 baht scheme for universal coverage of medical expenses.³¹ Three fourths of the infants (n=6, 75 %) had been hospitalized on the pediatric infectious disease ward, while awaiting cardiac surgery, because of having sustained an infectious disease, e.g. pneumonia. Hospitalization of children with CHD who have an infection, on an infectious disease ward, is done to prevent other children with CHD from contracting their infections.

Key informants from the eight families consisted of twelve parents (8 mothers, 4 fathers), one grandmother and one maternal aunt. They were 18 to 63 (mean=32.7) years old. Most were female (n=10; 71.42%), married (n=13; 92%) and lived in a nuclear family (n=8; 57%). All were Buddhist. Seven had completed primary school (six years) and

worked selling goods, i.e. fish, candles or used products collected from the garbage. Although one informant was illiterate, four completed secondary school, one completed high school and one obtained vocational certification. Two were employed in a candy factory, while one worked as a taxi driver. Three were housewives and one female did not work outside the home. These four stay-at-home informants received incomes either from husbands or parents. Although the families' average income was 200–500 baht (6–15 USD) per day, 11 reported their income was insufficient for their living expenses.

The families lived throughout Bangkok. Travel from their homes to the hospital took one to three hours, using public transportation, and 30 minutes to 2 hours, using a taxi. Even though transportation to the hospital was a major expense, they did not feel they could move closer because of the cost of rent and need to be near their workplace, family and friends.

Seven families lived in a 15 to 60 square meter wood and concrete rental home. Ten, due to limited space, did not have a separate kitchen or bedroom. Since they did not have beds, they slept on mattresses on the floor. One family lived in a small community littered with garbage. When it rained, mud formed and the area became uncomfortable and unsafe for children. Although all had water and electricity, and at least one appliance (radio, television, refrigerator or gas oven), none had a washing machine, microwave oven or personal computer. Every home had a Buddhist shrine or spirit house.

Data collection: Once an informant was identified and consented to participate, the primary investigator (PI) scheduled a home visit and requested his/her phone number. One to two days prior to the scheduled interview, the PI called to confirm the interview time and assure the informant would be available.

Data were collected through participant observations, formal interviews, field notes and review

of clinical documents. Depending upon the situation, participant-as-observer and/or observer-as-participant were the primary methods used to obtain data. Over 13 months, 4-6 home visits (2-4 hours in length) were conducted with each family to observe and engage in the families' daily child care practices. For example, as observer-as-participant, the PI might hold the child while the mother was cooking, dress the child or rock him/her in a cradle. Prior to each formal interview, informal conversation, addressing topics such as life, beliefs and family constraints, was initiated so as to establish rapport and trust among the investigator, the informants and family members. Each informant was formally interviewed 2 - 4 times, in his/her home, for a period of 60 - 90 minutes, using a researcher constructed interview guide with open-ended questions that used informal language and requesting similar information in different ways. Examples of the open-ended questions included: "Could you please tell me about how you do daily care for your child? Please tell me more about what, when and how you do care activities, and why?" The questions were not necessarily asked in the same sequence with every participant. However, all interviews were tape-recorded and addressed, in a probing manner, the study's topics of interest, as well as information related to child caring practices the investigator observed during the visits. All interactions and behaviors observed during the interviews were recorded in field notes. Clinical documents, including the infants' medical records, outpatient records and health records were reviewed. Health records maintained by the parents provided information, since birth, about the children's vaccinations, height and weight, and reflected whether parents were maintaining prescribed vaccination schedules. Data collection and analysis continued until no new information emerged.

Data analysis: Content analysis^{29, 30, 34} was conducted simultaneously with data collection. The analysis process consisted of coding, categorizing and thematic analysis. Data were obtained from individual parents and/or family members as a unit of analysis. So data were confirmed and complete, all data were checked through the use of: triangulation; data collection from different sources at various times; and, different methods. Data analyses were conducted in Thai, since it was the language used by the respondents and PI. Significant statements, relevant to each child's care, were extracted from the respective transcription. The PI translated statements into English, via consultation with a native English editor, who also is fluent in Thai, to retain the meaning and quality of the Thai context.

Results

Findings are presented within two major themes: 1) perceptions of families regarding their infants' illnesses and treatments; and, 2) practices of families caring for infants with CHD, prior to cardiac surgery, and the socio-cultural context influencing these practices. The **two major themes** are underlined and bolded, while the **key categories within the two major themes** only are bolded. ***Subcategories within the key categories*** are bolded and italicized, while the "informants' comments" are italicized and in quotation marks.

I. Perceptions of Families regarding their Infants' Illnesses and Treatments: When parents first were told their children had CHD, they were shocked and feared their children may not survive ("*Pen Laew Arj Mai Rod*"). Parents realized heart disease was serious and a functioning heart was needed to survive. None of the families previously had encountered a family member with heart disease and only knew about it from watching television. The 32 year-mother of an 8 month old girl, with patent ductus arteriosus (PDA), expressed the following:

“Heart disease is dangerous. It’s hazardous to my child’s heart, the most important organ. It sends the blood around my child’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?”

Despite being told CHD had no known causes, parents believed it was **caused by previous karma brought on by karma of parents, karma of the child, or karma of both parents and the child.** Having heart disease, in the present life of the child, is like *“the karma of retribution”* or *“his karma catches up with him.”* A 30 year-mother with four children said:

“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”

A 29 year-mother of a 17 month old girl, with a ventricular septal defect (VSD), believed her child’s CHD was caused by her previous karma, as indicated by her statements:

“I think karma affects my child’s suffering from heart disease. But it’s not her karma, it’s mine. If it’s her karma, it should be her own pain without causing me any trouble. 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.”

Some parents blamed themselves, believing their children’s heart diseases were **caused by the mother’s behavior during pregnancy.** They presumed **consuming certain food and drink**, i.e. grilled pork, canned coffee, Pepsi or M-100 energy drink, could have caused their children’s illnesses. A 28 year old father with a 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.”

Other parents believed **taking certain medicines** (pain pills, migraine medication or drugs for gastritis), **doing certain activities** (sewing or using a hot-steamed rock compress on the mother’s stomach to destroy a uterine tumor) or **being exposed to pollutants** (cigarette smoke or chemical fumes), during pregnancy, could have caused their children to have heart disease. These beliefs persisted despite professional explanations.

Three parents believed taking certain medicines, during pregnancy, could be the cause of the children’s heart diseases. Since she was a teenager and up to the time she was 2–3 months pregnant, one mother had taken medications for migraine headaches, pain and gastritis. She took medications during the early months of pregnancy because 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.”

Two families believed their children's CHD was caused by activities the mothers engaged in during pregnancy. Using an electric sewing machine, one informant earned extra income making clothes until she delivered. 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 to the baby. She stated:

“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 a heart disease, I think it was that cause. The electricity might affect any part of my fetus. It could affect so strongly that it caused heart disease in my baby.”

Three families believed the mother's exposure to pollutants, i.e. cigarette smoke and/or chemical fumes, might have caused their children's CHD. These families learned from the media that exposure to toxic fumes, especially cigarette smoke, was hazardous to health and could lead to heart disease in a fetus. 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 their 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 a house where there is a small aluminum molding 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.”

All parents said their children with CHD were **difficult to bring up (raise)** (“*Leang Yak Toh Cha*”) and experienced growth delays compared to other children. The physicians informed the families their children would be vulnerable to other illnesses, particularly common colds, and experience illnesses that would require a long recovery time. Parents and family members were aware their children with CHD had compromised immune systems, leaving them susceptible to infections, and indicated this partly was related to their children's growth retardation. Therefore, they needed to be vigilant in protecting their children from other illnesses and assist them with a quick recovery when an illness occurred.

The children experienced a loss of appetite and slow weight gain due to frequently catching colds. As a 63 year old Chinese grandmother of a 14 month old girl, with a VSD, stated:

“My granddaughter falls sick quite often. She'll be ill 3-4 times within two months and it takes a half month for her to be cured. Sometimes when she gets a sore throat, she won't eat, but vomit. She's frequently is sick, so she can't eat. When she could eat, for a few days, she would fall sick again. It's like she can eat well for 3 days a month and then 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. It's difficult to raise her because of her frequent sickness."

The children were unable to consume sufficient food or drink adequate amounts of milk, which resulted in them experiencing delayed growth, low weight gain, delayed motor development, frequent colds and slow recovery from illnesses (upper respiratory infections [URI] and pneumonia). From observations and discussions with the physicians, parents recognized the severity of their children's health, and realized they would require medications and surgical interventions.

II. Practices of Families Caring for Infants with CHD, prior to Cardiac Surgery, and the Socio-Cultural Context influencing these Practices: The findings highlight the importance of exploring socio-cultural family context when examining practices of families caring for infants with CHD. After having received information from physicians, families explained: *"Doing our best to get our child ready for surgery"* was their main parenting goal. They revealed their practice patterns included: **a) promoting the child's weight gain and improved health; b) preventing the child from getting worse; c) practicing traditional cultural beliefs; and, d) managing the child's care under constraints or limitations.**

A. Promoting the Child's Weight Gain and Improved Health:

Ten informants acknowledged the importance of providing nourishing food in order to help their children gain weight and be healthy. With appropriate weight, determined by cardiac surgeons and based upon factors such as severity of the heart defect, presence of other health conditions, age and improved health, the children could be ready for heart surgery. Parents believed improvement in their children's health and appropriate weight would decrease their chances of post-surgical complications.

Within this category two practices emerged: **1) feeding sufficient food; and 2) feeding nutritious food.**

1. Feeding sufficient food: Thirteen parents stated their children ate less and had gradual weight gain. In an attempt to have their children eat more, parents frequently fed them small quantities. A mother of a 17 month old girl, who weighed 6100 grams, said:

"My daughter eats gradually. This morning she ate only two tablespoons of rice. So, I mainly fed her with breast milk all 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."

Since they believed rice grain was more filling than other solid foods and would improve weight gain, twelve informants fed their children solid food (cooked rice or soft rice porridge). In addition, five parents believed a bowl of cooked rice was more nutritious than a bowl of soft boiled rice because rice grain could satisfy their children's hunger faster and keep their stomachs full for a longer period of time. They also believed cooked rice was more nutritious than milk. A mother of a 7 month old boy, who had Tetralogy of Fallot, remarked:

"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. I try to feed rice because milk alone is not enough to make him full, while rice can."

2. Feeding nutritious food: Parents tried to feed their children all five main food group, especially food they believed contained nutrients and vitamins. Bananas were a favored fruit because they helped with weight gain, contained no disadvantages and kept their children's stomachs full for a long time. An 18-year-old mother, with a secondary school education, commented:

"I feed my child nutritional food, like protein from pork, egg yolk, fish and vegetables. Sometimes I feed my son rice and an omelet, as well as a teaspoon 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"

Due to their concern that breast milk had fewer advantages than formula, eight parents gave their children infant formula and instant baby food, in addition to or as a replacement for, breast milk. A mother of a 4 month old child said:

"I supplement my son's diet with infant formula. But some days, I don't breast feed 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 like to feed him with infant formula as advised by the doctor."

B. Preventing the Child from Getting Worse:

Subcategories identified within this category were: **1) preventing the heart from working too hard; and, 2) preventing contraction of other illnesses.** Preventing the heart from working too hard meant the family caring practices included helping to control their children's CHD and enhancing the

effectiveness of their heart function. Preventing contraction of other illnesses meant the parents tried to keep their children from being exposed to contagious diseases (common cold) and consuming unclean or poorly prepared food, which could lead to diarrhea. Parents believed if their children developed infections, or another illness, they would become worse.

1. Preventing the heart from working too hard:

Family members tried to reduce physical strain on their children's hearts by having them avoid activities that required their heart to work harder. Informants indicated they avoided activities deemed likely to make the heart work 'too hard.' These practices evolved from the parents' perceptions of what it meant to be afflicted with heart disease, and fear their children could not live if their heart could not work. Parents' direct experiences with child care let them witness their children's terrifying and frightening symptoms related to cardiac pathology (cyanosis, and increased respiratory and heart rate). They believed improving heart function could prolong life, while making the abnormal heart work 'too hard' could cause it to cease beating and bring on death. The specific family caring practices identified in this sub-category, **preventing the heart from working too hard**, were: a) providing correct dosages of medications and not skipping medication doses; b) ensuring sufficient sleep; and, c) preventing tiredness.

a) Providing correct dosages of medications and not skipping medication doses: All parents acknowledged the importance of medications in helping to keep the heart functioning, controlling symptoms of heart disease and assisting their children's heart to work efficiently. They believed following the physicians' treatment plans would

prevent progression of their children's illnesses and pre-operative complications. Therefore, they 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, parents tried to follow physicians' directives regarding administration of pre-operative medications. With a perception and understanding that medications could improve a child's heart, a 31 year old mother, who was a garbage collector with a primary school education, stated:

"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."

Two families whose members worked away from their home prepared medications for the child care center personnel or their relatives to administer to their children as prescribed. The families provided detailed written information about the dosing and attached it to each of the syringes to be used. For example, a mother, who sold mackerel at a Sunday market, wrote for the grandmother: *"This syringe of medication must be given after lunch"* and *"Don't forget to give the drug, in this syringe, with the red sweet drink."*

b) Ensuring sufficient sleep: Based on their perception their children had difficulty sleeping and that sleep was the best rest for the heart, family members sought to assure their children's sleep was comfortable and lengthy. Thus, they focused on childhood bedtime routines (bathing, dressing in clean clothing and a diaper, and consuming sufficient milk and food) and soothed their children by singing a lullaby, while rocking or holding them; touching them in a gentle manner before placing them in bed;

and, quickly responding to them when they cried or were restless. When they realized perspiration was a common effect of CHD, even in cool temperature, parents 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 or mosquito netting to ensure comfortable sleep.

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."

Parents believed their children's heart could rest, not work as hard and have a slower rate, if their children got sufficient sleep. When their children slept they did not turn blue, looked healthier,

breathed slower and their hearts did not beat as fast as when they were awake.

c) Preventing tiredness: 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. They gave appropriate fluid and nutrition (i.e. formula, vegetables, fruits and easily digestible food) so as to help their children defecate without straining, which they believed would cause them to tire. A mother of a 9 month old child, with acyanotic CHD, 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."

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. The aunt of an eight month old, suffering from cyanotic CHD, stated:

"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."

In addition, 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. As a 32 year old mother of an eight month old with cyanotic CHD said:

"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."

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."

2. Preventing the Child from Contracting Other Illness: Twelve informants believed 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. 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.

a. Protecting against common colds and pneumonia: Having been warned, by physicians to protect their children from common colds and pneumonia, while they awaited 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. A 31 year old mother, with a secondary school education, explained:

“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.”

In addition, four informants avoided taking their children to places that suddenly became hot or cold (department stores) out of concern they may not adjust to the heat or air conditioning and, subsequently, develop a cold. A mother of a 9 month old girl, with PDA, who had been admitted to the hospital with pneumonia said:

“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 temperature, she could get a cold”.

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.”

“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.”

These restrictions were a major challenge for families who had limited living space. One family rented a 3 x 5 meter room, which served as their bedroom, dining room and living room. Thus, parents and children had to sleep together. When one of them got a cold, they had no where to sleep separately, so the child with CHD also got a cold. One family lived in the slums where houses were dirty, unstable and always flooded with garbage infested water. Due limitations in obtaining living accommodations, parents could not always alter environmental issues. As one mother stated:

“The doctor suggested I keep my child clean. I know that it’s good for my child. So, I did as much as possible. But you see! Our house is 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 only do the best that I can."

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. A 28 year-mother explained:

"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."

Parents also monitored changes in their children's temperatures. When a thermometer was not readily available, five parents said they touched their children to determine if they had an elevated temperature. If a fever was present, parents provided home care until they felt they needed to see a physician. One parent said:

"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."

b) Protecting against diarrhea: If diarrhea developed, parents were aware their children would lose 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 was a challenge for those who lived without a refrigerator, gas stove or clean water. A mother of a 5 month old boy, with VSD, said:

"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."

c) Ensuring hygiene care: Parents realized 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 wash basin, or a child care area, in their home. Seven families lived in a rented house where the bathroom was outside. Hygiene was a challenge, particularly for the family in the house surrounded with garbage and flood water.

One mother indicated having only two baby bottles with which to feed her child (one for milk and one for water). She washed the bottles with dish detergent and sterilized them each morning. Due to financial problems, she did not own a gas stove and could not sterilize the bottles prior to each use. To clean them, she simply poured hot water into the bottles. She stated:

“I try to clean my child’s bottles as much as I can, but I can’t do it every time before I use it. I don’t have a gas stove. It’s difficult to do.” ^(serious face)

d) Obtaining immunizations. 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. One mother, with a secondary school education commented:

“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.”

C. Practicing Traditional Cultural Beliefs:

As one examines health care practices carried out by these families, the socio-cultural context of their practices must be taken into consideration. In addition to relying on modern medical treatments, families used traditional cultural beliefs in an effort to help their children recover from illnesses and surgeries, as well as to become healthier. Traditional beliefs were based on sacred or supernatural powers, which helped parents feel relief and comfort (“*Sabai Jai*”). They turned to traditional beliefs upon learning their children had CHD. Five parents symbolically gave their children to the former Kings of Thailand. As a way to ask for help for their sick children, nine informants prayed for blessings from sacred images of Buddha, and paid respect to the shrines, spirit guardian houses and monuments of the King. Ten parents took their children with them when they made offerings, gave food to monks and apologized for past wrongdoings.

The aunt of one child 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.”

D. Managing Child Care under Constraints:

Multiple constraints affected parents’ ability to care for their children and carry out everyday family life. Their most serious influences were financial limitations, child care and housework responsibilities. Six parents either lost or had a decrease in income after their children were diagnosed with CHD. This was because they worked less overtime or had to take leave without pay in order to care for or take their children to the hospital. Their main expenses were transportation to/from the hospital and accommodations during their children’s hospitalizations. Even having financial constraints, parents sought to provide optimal care for their children. For example, since they believed formula contained more nutrients than breast milk, they asked health service centers to provide formula so as to reduce expenses. As a mother of four children said:

“I went to ask for powdered milk from the Wat Ta Klum Center and I got one can per month. An officer said my child could 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 the Pak Kred Center, but I did not tell the office that I got one can of milk from the Wat Ta Klum Center.” ^(laughing)

Six parents struggled to deal with the constraints of hospital services, especially the limited advice they felt they received from nurses

and physicians. Parents said nurses only played a minor role in providing advice and care for their children, and they were more likely to have conversations with physicians than with nurses. However, they framed complaints about nurses in a positive manner, saying they recognized parents were responsible for caring for their children. As one informant remarked:

"Nurses didn't give me any information (she shook her head and said with strong voice). Never..... 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."

Parents expressed having emotional stress related to their children's illnesses, as well as having difficulties providing their care. They tried to minimize stress by "*cheering themselves up*" and "*accepting their children's illnesses*" through use of "*Tham Jai*" (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). 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. Seven mothers revealed raising CHD children was a

burden. One mother explained:

"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."

Discussion

The results demonstrate how the nature of families' beliefs and perceptions of their children's heart disease and treatments shaped caring practices. Families initially felt: "*Our child may not survive.*" Then, they learned about the causes, symptoms and treatments for their children. Their understanding about the illness was formed via a combination of biomedical and traditional Thai knowledge. From the biomedical aspect, parents believed their children's CHD was caused by the respective mother's behavior during pregnancy. This belief may have been strengthened by the fact that all mothers, in this study, received antenatal care from the hospitals, and were informed about helpful and harmful actions that may affect their fetuses. From a traditional Thai perspective, their children's heart disease was caused by previous karma. Because all informants were Buddhist and believed in karma,³⁵ they used these reasons to explain CHD in a way they could accept. The findings were consistent with those of prior studies conducted in Thailand.^{10, 35-38}

The day-to-day caring practices of families, "*doing their best to get the child ready for surgery,*" were grounded in socio-cultural aspects of Thai life and supplemented by Western biomedical cultural thought, which informed their particular approach to care for their children. The families' main caring practice pattern was "*promoting and preventing,*" which translated into promoting their children's

weight gain and health, while preventing their children's health from getting worse. Parents managed their children's care while trying to help other family members, despite significant constraints, live a normal life. Since six families had a low income [average = 200–500 baht (\$6–15 USD) daily], management of financial issues was their main challenge. Although faced with financial problems, parents tried to provide their children nutritious food to help them become strong enough for surgery. However, living space constraints could not be managed. For example, when a 3 x 5 meter rented room was home for 3–5 family members, the child with CHD could not be kept from exposure to germs when another family member became ill. Caring practices, such as feeding their children formula, were influenced by televised advertisements and health programs. When their children were in the hospital, parents felt they did not receive sufficient information or hands-on care from nurses. However, they tried to think positively, took responsibility for providing daily care for their children and remarked, “due to having an overload of patients,” nurses were busy. Finding informants taking responsibility for their children's basic care, during hospitalization, was congruent with Pongjaturawit's findings.³⁹

Due to discrepancies in the quality of care among government hospitals,³ eight parents believed their children could receive better care from the larger governmental hospitals in Bangkok, compared to the two university hospitals involved in this study. In addition, they acknowledged health professionals had limited time to give advice and provide basic care for their children. Congruent with previous findings,^{36–38,40} parents in this study received support from family members and significant others, which helped them deal with constraints related to their children's care and daily life.

Conclusion and Recommendations

Although the families' perceptions and caring practices were influenced by traditional Thai Buddhist culture, they also were influenced by Western hospital-based biomedicine, folk medicine and global media advertisement. Informants appeared not to feel conflict between traditional Thai practices and biomedical perspectives. They successfully integrated new knowledge into their existing way of life.

The findings should help health professionals become more aware of how Thai socio-cultural context influences family perceptions and caring practices related to CHD. Nurses should assume active roles in promoting culturally appropriate nursing care and facilitating support programs, as well as provide emotional support for families. Healthcare professionals need to be flexible, listen to what families say, understand their situations, and be ready to share information and learn from those who have children with CHDs.

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การปฏิบัติของครอบครัวไทยในการดูแลเด็กโรคหัวใจพิการแต่กำเนิดในระยะก่อนผ่าตัดหัวใจ

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บทคัดย่อ : การวิจัยเชิงชาติพันธุ์วรรณานี้ มีวัตถุประสงค์เพื่อศึกษาอิทธิพลของบริบททางสังคม วัฒนธรรมต่อการรับรู้และการปฏิบัติของครอบครัวไทยในการดูแลเด็กอายุ 3-17 เดือน ที่เป็นโรคหัวใจพิการแต่กำเนิดทั้งชนิดเขียวและไม่เขียวที่มีอาการในระยะก่อนผ่าตัดหัวใจ คัดเลือกกลุ่มตัวอย่างแบบเฉพาะเจาะจง กลุ่มตัวอย่างคือพ่อแม่ จำนวน 12 คน และสมาชิกครอบครัว จำนวน 2 คน จาก 8 ครอบครัว ที่พาเด็กมารับการรักษาที่โรงพยาบาลมหาวิทยาลัย 2 แห่งในกรุงเทพมหานคร เก็บข้อมูลโดยการสัมภาษณ์แบบเจาะลึก การสังเกตแบบมีส่วนร่วม และการจดบันทึกภาคสนาม จากเดือนกันยายน 2549 ถึงเดือนตุลาคม 2550 วิเคราะห์ข้อมูลโดยใช้วิธีการวิเคราะห์เชิงเนื้อหา

การปฏิบัติดูแลของครอบครัวได้รับการอธิบายจากถ้อยคำที่กล่าวว่าทำดีที่สุดเพื่อช่วยให้เด็กพร้อมที่จะได้รับการผ่าตัด ครอบครัวเข้าใจว่าเด็กที่เป็นโรคหัวใจอาจไม่รอดชีวิต และเป็นเด็กเลี้ยงยากและเติบโตช้า เด็กที่เป็นโรคหัวใจทุกคนต้องได้รับการรักษาทางยาตามด้วยการผ่าตัดและต้องการนำหนักตัวที่เพิ่มขึ้นและสุขภาพที่แข็งแรงเพื่อฟื้นตัวจากการผ่าตัด ครอบครัวป้องกันไม่让孩子มีอาการเลวลงพร้อมทั้งจัดการดูแลเด็กภายใต้ข้อจำกัดต่างๆ

ผลการศึกษาบ่งชี้ว่าการรับรู้และการปฏิบัติของครอบครัวได้รับอิทธิพลจากสังคมวัฒนธรรม ได้แก่ คำสอนทางพุทธศาสนา ความเชื่อทางวัฒนธรรม ข้อจำกัดทางการเงิน บริการของโรงพยาบาล รวมทั้งการได้รับความช่วยเหลือจากสมาชิกในครอบครัวและบุคคลภายนอกครอบครัว ผลการศึกษาครั้งนี้ให้ความเข้าใจกับแพทย์และพยาบาลเกี่ยวกับการรับรู้และการปฏิบัติของครอบครัวในการดูแลเด็กโรคหัวใจพิการแต่กำเนิดในระยะก่อนผ่าตัด และยังชี้ให้เห็นธรรมชาติในการดูแลของครอบครัวที่มีความเกี่ยวข้องกับบริบท รวมทั้งความต้องการบริการสุขภาพรูปแบบใหม่ที่สร้างสรรค์และสอดคล้องกับบริบททางสังคมวัฒนธรรม

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คำสำคัญ: โรคหัวใจพิการแต่กำเนิด การวิจัยเชิงชาติพันธุ์วรรณนา ทารก การปฏิบัติดูแล ครอบครัวไทย

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