

# Factors associated with mothers' knowledge of children with congenital heart disease in Bangkok, Thailand

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## Abstract

**Purpose** – This study aimed to determine mothers' knowledge of children with congenital heart disease (CHD) and to examine the relationship between types of CHD, the duration of treatments, the perception of the severity of illness and the mothers' knowledge.

**Design/methodology/approach** – A correlation study was conducted among 84 mothers of children (from infancy to six years old) with CHD who had attended pediatric cardiology clinics and pediatric units in three tertiary hospitals in Bangkok, Thailand. The two questionnaires aimed to evaluate the mothers' knowledge and perceptions of the severity of illness. Descriptive statistics, Spearman's rank-order correlation and Fisher's exact test were used to analyze the data.

**Findings** – Knowledge levels of mothers of children with CHD were at a high level with a mean score of 34.79 (SD = 8.23), but the knowledge domain of preventing complications was at a low level with a mean score of 14.95 (SD = 5.28). The types of CHD and the perceptions of illness were not correlated with the mothers' knowledge, but the duration of treatments was significantly correlated ( $r = 0.271, p < 0.05$ ).

**Originality/value** – Healthcare professionals, especially nurses, should emphasize proper health education on complication prevention and the duration of treatments for children. Moreover, mothers should be supported to nurture children with CHD to reduce possible complications and prepare for cardiac surgery where needed.

**Keywords** Types of congenital heart disease, Duration of treatment, Perception of the severity of illness, Mother's knowledge, Children with congenital heart disease, Thailand

**Paper type** Research paper

## Introduction

Congenital heart disease (CHD) is the most frequently encountered chronic disease existing at birth. The incidence of CHD in Asia is 6-17 infants [1–3] and eight infants per 1,000 live births in Thailand [4]. CHD is divided into two types — acyanotic CHD (67-80%) and cyanotic CHD (20-33%) [2, 3]. According to the Pediatric Cardiology Clinic, Siriraj Hospital, the number of children with CHD from infancy to 15 years old who were admitted for diagnosis and



treatment (2015-2017) was approximately 1,400 patients per year. The majority of them were children with CHD from infancy to 6 years old. In Thailand (2006-2018), 50-70% and 30-50% children with CHD required cardiac surgery and therapeutic cardiac catheterization, respectively [5]. Hence, cardiac surgery and therapeutic cardiac catheterization are necessary for treating children with CHD.

Before cardiac surgery and therapeutic cardiac catheterization, some children with CHD are seen to have other cardiac pathologies apart from those two types of CHD. Children with acyanotic CHD and cyanotic CHD, with increased pulmonary blood flow, usually have pneumonia and congestive heart failure, while those with cyanotic CHD, with decreased pulmonary blood flow, have hypoxic spells including brain abscess. Both types of CHD have a high risk of infective endocarditis [4]. These complications cause the children to consume less, lose weight, have malnutrition and become easily infected. Because of infection and growth failure, children must not receive cardiac surgery and therapeutic cardiac catheterization according to the schedule [6-8]. Additionally, some children, unfortunately, pass away due to complications while awaiting surgery.

Mothers are the main caregivers of children with CHD. Essential knowledge about caring for children with CHD consists of three domains including (1) the child's heart disease and its treatments, (2) the prevention of complications and (3) general care [9-13]. However, according to the literature reviews, mothers were not able to accurately respond to their children's heart defects, reactions and side effects of medication, proper food and exercise and infective endocarditis [9-16]. Based on the researchers' experience in caring for children with CHD, the mothers of children with CHD had improper childcare behaviors. Some mothers did not acknowledge the decent caring of children with CHD – they could not distinguish the abnormal symptoms of the defect, that is, how to manage their cyanosis, the complications including their preventions, the intake of medications and their side effects. Some inquired about appropriate and inappropriate diets and the purpose of taking the children to dentists. Due to bad oral health, the children also had cavities resulting in infective endocarditis. Thus, it is assumed that should the mothers have comprehensive knowledge of the defects, the children would receive efficient care [9, 10, 13].

To date, few studies focusing on the mothers' knowledge of children with CHD, either acyanotic CHD or cyanotic CHD, before cardiac surgery are available in Thailand and abroad. Based on previous studies, the mothers' knowledge of children with acyanotic and cyanotic CHD had been evaluated by the same questionnaires which might not reveal their actual knowledge. As a result, the researchers decided to evaluate the mothers' knowledge and study for associated factors by deploying specific questionnaires for each group of mothers. The findings are expected to boost nurses to provide sufficient knowledge for mothers so that children with CHD will be appropriately and precisely cared for, along with reducing potential complications before preparing the children for cardiac surgery.

## Methods

### *Study area and study sampling*

This descriptive correlational study was conducted to examine the relationship between types of CHD, the duration of treatments, the perceptions of the severity of illness and the knowledge of mothers of the children. The study period was 4 months, from March to June 2019. The samples were mothers of children with CHD from infant to 6 years old; also, they should never have received either cardiac surgery or therapeutic cardiac catheterization. The children had been diagnosed and treated at the pediatric cardiology clinic and pediatric

cardiology wards at 3 hospitals in Bangkok, Thailand, including (1) Siriraj Hospital (one pediatric cardiology clinic, and 5 pediatric wards), (2) Ramathibodi Hospital (one pediatric cardiology clinic and 3 pediatric wards) and (3) King Chulalongkorn Memorial Hospital (one pediatric cardiology clinic and 3 pediatric wards). The subjects were selected by convenience sampling based on specified qualifications as mothers who are primary caregivers of children (aged 18 years and more) with CHD, and who could speak, read and write in Thai.

In determining the sample size, similar studies were found in the literature review. The duration of treatments among children with asthma was positively correlated with the knowledge of caregivers of children with asthma aged 7–13 years ( $r = 0.30, p < 0.05$ ) [16]. A medium effect size ( $r = 0.30$ ) was obtained with the power of the test at .80 and reliability of the test at the alpha level of .05. When calculated with the G\*power program, the sample size was 84 subjects.

According to studies conducted in Thailand and overseas, 75% of children were found to have acyanotic CHD and 25% of children were found to have cyanotic CHD at a 3:1 ratio [17–19]. Thus, the sample was composed of 63 mothers of children with acyanotic CHD and 21 mothers of children with cyanotic CHD.

### *Research instruments*

The structured questionnaires developed for this study consisted of 3 parts: Part I, the demographic information of the mothers and children with CHD; Part II, the Perceptions of the Severity of Illness Evaluation Form was based on the Perceptions of the Severity of Illness instrument of Chanpa *et al.* [20]. It contained an analog 10-point scale (“less serious” to “extremely serious”). The scale was used for the mothers of the children with CHD reporting their children’s severity of illness. Part III, the Maternal Knowledge Questionnaire of CHD, was developed by the researchers based on literature reviews [9–11, 13, 21]. It consisted of two questionnaires: Question I, for the mothers of children with acyanotic and cyanotic CHD (excessive pulmonary blood flow), and Question II, for mothers of children with cyanotic CHD (deficient pulmonary blood flow). The Maternal Knowledge Questionnaires of CHD were assessed under three domains with 51 items: disease and its treatments (14 items), prevention from complications (25 items) and the general care (12 items). The answers were selected via the checklist pattern rated as “correct,” “incorrect,” and “do not know”.

### *Quality of research instruments*

The questionnaires were checked and verified by three experts who were experienced in the subject of children with CHD and the knowledge evaluation of CHD. The content validity of the Maternal Knowledge Questionnaires was 0.89. The formula of Kuder-Richardson was used to check the reliability of the questionnaires in 30 mothers of children with CHD at Siriraj Hospital, Ramathibodi Hospital and King Chulalongkorn Memorial Hospital. Its reliability of knowledge was 0.91.

### *Data collection*

After formal authorizations were obtained from the Institutional Review Board of three hospitals, the mothers were approached. Following a comprehensive description of the project, background, purpose, data collection, advantages and the effect, mothers signed an informed consent form. Then, mothers were instructed on how to fill out the questionnaires. The researcher who was a master’s student and the principal investigator (PI) stayed with the mothers to provide clarification. The researchers collected the data of 84 mothers of children with CHD, for 45–60 min, within the three aforementioned hospitals.

### Data analysis

The data were checked and analyzed using SPSS version 18; the demographic data of samples were analyzed by descriptive statistics and the data of mothers' knowledge were analyzed by the criteria of the knowledge level. The correlation coefficient and types of CHD were analyzed by Fisher's exact test, and perceptions of the severity of illness and the duration of treatments were analyzed by Spearman's rank correlation coefficient with statistical significance at 0.05.

### Ethical consideration

This study was approved by Siriraj Institutional Review Board, Faculty of Medicine, as an expedited review on February 14, 2019 (COA No. Si 114/2019), Faculty of Medicine, Ramathibodi Hospital, and Mahidol University as an expedited review on December 11, 2018 (COA No. MURA2018/991) and Institutional Review Board Faculty of Medicine, Chulalongkorn University as an expedited review on January 9, 2019 (COA No. 071/2020).

## Results

Concerning the 84 mothers of children with CHD in this study, the mothers were 18–44 years old with a mean age of 31 years old ( $SD = 6.27$ ). The mothers' perceptions of the severity of the illness had medium severity showing a mean score of 4.6 ( $SD = 2.73$ ). Most of the mothers had no previous experience in caring for children with CHD (97.4%). Most of the mothers had received instructions related to CHD from doctors (96.4%), nurses (61.9%) and the Internet (81%). This study involved 84 female and male children with CHD (50% equally). Of these, 75% had acyanotic CHD. The age of the children was between 5 days to 6 years (0–71 months) with an average of 20.05 months ( $SD = 17.74$ ). Most of them were 0-1 year old (40.5%) and 1-2 years old (21.4%). The children had a mean treatment duration of 16.9 months ( $SD = 16.66$ ). Most of the children were scheduled or waiting for cardiac surgery or cardiac catheterization (90.5%). The children had never been admitted to a hospital due to complications including pneumonia, congestive heart failure, hypoxic spells, and pulmonary edema (67.86%). The children currently received oral medications (64.3%) such as a diuretic (57.1%) and digitalis (39.3%). Most of the children were hospitalized for diagnosis such as cardiac catheterization (72.6%) and for receiving corrective surgeries (16.7%) (Table 1).

### Congenital heart disease knowledge

In the area of overall knowledge of the mothers of children with CHD, the subjects were found to have a mean knowledge score of 34.79 ( $SD = 8.23$ ) and a real scoring range of 9–49 points, indicating high knowledge. When considering the knowledge under those three domains, the mothers scored high in knowledge under the domain of the disease and its treatments with a mean score of 11.24 ( $SD = 1.97$ ), and the domain of general care with a mean score of 8.81 ( $SD = 2.28$ ). However, the mothers had less knowledge (low) under the domain of the prevention of complications with a mean score of 14.95 ( $SD = 5.28$ ) (Table 2).

### The association between the types of congenital heart diseases, the duration of treatments, the perceptions of the severity of illness and the mothers' knowledge

The types of CHD were not correlated with the mothers' knowledge ( $\chi^2 = 0.475$ ,  $p = .49$ ) (Table 3). The mothers' perceptions of the severity of illness were also not correlated with the mothers' knowledge ( $r = -0.206$ ,  $p = 0.058$ ), but the duration of treatments was significantly positively correlated with the mothers' knowledge ( $r = 0.271$ ,  $p < 0.05$ ) (Table 4).

Characteristic	Frequency	Percentage
<i>Maternal</i>		
<i>Age (years)</i>		
18–30	39	46.4
31–40	41	48.8
41–50	4	4.8
<i>Information sources</i>		
<i>Personal</i>		
Physicians	81	96.4
Nurses	52	61.9
Pharmacists	5	6.1
Caregiver of children with heart disease	11	13.1
Family	3	3.6
<i>Material</i>		
No	6	7.1
YES (choose more than 1 choice)	78	92.9
Internet	68	81.0
Manual	15	17.9
Brochure	14	16.7
Television	13	15.5
Video	7	8.3
<i>Children with CHD</i>		
<i>Sex</i>		
Male	42	50
Female	42	50
<i>Age of children (years)</i>		
0–1	34	40.5
>1–2	18	21.4
>2–3	17	20.2
>3–6	13	17.9
<i>Type of congenital heart disease</i>		
Acyanotic CHD	63	75
VSD	33	39.3
ASD	19	22.5
AVSD	3	3.6
CoA	3	3.6
PDA	3	3.6
PS	2	2.4
Cyanotic CHD	21	25
Excessive pulmonary blood flow	10	11.90
Pink TOF	1	1.2
Truncus arteriosus	3	3.6
DORV	5	6.0
TAPVR	1	1.2
Deficient pulmonary blood flow	11	13.1
PA	3	3.6
TOF	7	8.3
TA	1	1.2
<i>Duration of treatment (year)</i>		
0–1	45	53.6

**Table 1.**  
Characteristics of  
participants

(continued)

			Mothers' knowledge of children with CHD
Characteristic	Frequency	Percentage	
>1-2	15	17.9	
>2-3	13	15.5	
>3-6	11	13.2	
<i>Medicine for cardiac treatment</i>			<b>589</b>
No	30	35.7	
Yes	54	64.3	
History of treatment in the hospital about complications (pneumonia, congestive heart failure, hypoxic spells and pulmonary edema)			
No	57	67.86	
Yes	27	32.14	
<i>Treatment</i>			<b>Table 1.</b>
Follow-up (OPD)	61	72.6	
Hospitalization	23	27.4	
Cause			
Cardiac surgery	14	16.7	
Congestive heart failure	4	4.8	
Cardiac catheterization	2	2.4	
Pneumonia	1	1.2	
Hypoxic spells	1	1.2	
Cardiac CT	1	1.2	

Variables	Possible range	Actual range	$\bar{x}$	Sd	Results	<b>Table 2.</b> Knowledge level
Overall	0-51	9-49	34.79	8.23	High	
CHD knowledge						
Domain 1:	0-14	5-14	11.24	1.97	High	
Disease and treatment						
Domain 2: Prevention of complication	0-25	2-24	14.95	5.28	Low	
Domain 3:	0-12	1-12	8.81	2.28	High	
General care						

Type of CHD	Level of knowledge ( <i>n</i> = 84)			$\chi^2$ (df)	<i>p</i> -value	<b>Table 3.</b> Association between knowledge level and type of CHD
	Low level	High level	Total (%)			
Acyanotic	20	43	63 (75%)	(Fisher test)	0.491	
Cyanotic	5	16	21 (25%)			
Total (%)	25 (29.76%)	59 (70.24%)	84 (100%)			

Variable	Duration of treatment		Perception of the severity of illness		<b>Table 4.</b> Correlation between duration of treatment, perception of the severity of illness and knowledge
	<i>R</i>	<i>p</i> -value	<i>R</i>	<i>p</i> -value	
Knowledge	0.271	0.013	-2.06	0.058	
<b>Note(s):</b> <i>n</i> = 84					

## Discussion

The mothers of children with CHD had high knowledge levels with a mean score 34.79 ( $Sd = 8.23$ ). The mothers from three hospitals had similar overall knowledge. Participants from Siriraj Hospital had a mean score of 34.69 ( $Sd = 9.47$ ), from Ramathibodi Hospital had a mean score of 35.25 ( $Sd = 8.24$ ) and from King Chulalongkorn Memorial Hospital had a mean score of 34.73 ( $Sd = 6.78$ ). This might be because the mothers of children with CHD were given information by the three hospitals, which are themselves university hospitals. These hospitals provide systematic service and offer tertiary care with the capacity to provide patients, as well as being well-organized in the areas of medical personnel and instruments. As a consequence, the physicians, nurses and pediatric cardiology specialists provided thorough information to the mothers by assorted media such as posters, leaflets and the hospitals' websites, including the sets of activities such as camps for children with CHD. Most mothers had been informed by professionals in nurturing children with CHD – the physicians (96.4%) and nurses (61.9%). Mothers who received information from the Internet were at 81%. The mothers, thereby, received more information from the professionals and media resulting in their wide knowledge. Although the overall CHD knowledge of the mothers was at a high level, the knowledge on the prevention of complications including the knowledge about infective endocarditis, congestive heart failure, hypoxic spells and pneumonia was at a low level. This may be because half the participants were the mothers (53.6%) of children (aged 0–1-year-olds) with CHD and 67.86% of the children had never been admitted to hospitals, thus making the mothers unfamiliar with the complication details. Also, because the children aged 0–1 years had a lower risk of infective endocarditis [22], the nurses might not be informed about the complications, especially infective endocarditis, causing the low level of knowledge in prevention of complications.

The types of CHD were uncorrelated with the mothers' knowledge with statistical significance ( $\chi^2 = 0.475$ ,  $p = 0.49$ ), which concurred with the study of 90 mothers of children with acyanotic and cyanotic CHD aged three months to 14 years with and without heart surgery. The mothers of children with acyanotic CHD and those of children with cyanotic CHD had no different knowledge about infective endocarditis ( $p = 0.084$ ) [22]; nevertheless, the types of renal disease (no ESRD and ESRD; end-stage renal disease) were correlated with the knowledge of kidney disease ( $p < .05$ ) of caregivers of children. The researchers reasoned that children with ESRD required increased treatment processes, so physicians and nurses ought to provide information and knowledge to the caregivers to make them more knowledgeable [23]. This is different from the study, while the experience of mothers of children with acyanotic and cyanotic CHD was similar. The children with acyanotic and cyanotic CHD received similar procedures to diagnose, for example, echocardiography and cardiac catheterization; they had planned treatments by cardiac surgery, received oral medications, had similar symptoms such as dyspnea and were treated in the hospital for complications. The mothers of children with the two different types of CHD had the opportunity to receive knowledge from physicians and nurses. Therefore, the types of CHD were not correlated with the mothers' knowledge.

The mothers' perceptions of the severity of illness were uncorrelated with the mothers' knowledge with statistical significance ( $r = -0.206$ ,  $p = 0.058$ ). It might be because the perceptions matched less or more than the actual illness. The perceptions depended on feelings, experiences in caring for children, observations of children's symptoms, the present symptoms and the information received from physicians and nurses. When the children were admitted to hospitals, the mothers received knowledge from the physicians and nurses or from the Internet which increased the mother's understandings of CHD. The mothers' perceptions of the severity of illness were at three levels: low, medium and high. The overall knowledge was high. Therefore, the mothers' perceptions were uncorrelated with the mothers' knowledge. The findings of this study were consistent with the study of factors

correlated with knowledge of 55 parents of children aged 7–13-year-old with asthma and found that parents perceived the severity of the illness to not be correlated with the knowledge of parents of children with asthma ( $r = 0.05$ ,  $p > 0.05$ ) [16].

The duration of treatments was positively correlated with the mothers' knowledge with statistical significance ( $r = 0.271$ ,  $p < 0.05$ ). This might occur as most of the mothers had taken the children for follow-up at the pediatric cardiology clinic for at least one to two months. At each visit, the mothers received more knowledge about heart disease from physicians and nurses. Furthermore, with time, it enabled mothers to gain more knowledge from media such as websites, leaflets and conversations, allowing them to exchange knowledge with mothers of other patients with similar and different experiences. Eventually, these caused the mothers to accumulate more knowledge. The findings from this study correspond with those of a study of the factors correlated with knowledge about infective endocarditis among 90 parents of children with CHD aged from infancy to 15 years, which found the duration of treatment was positively correlated with knowledge in parents ( $r = 0.548$ ,  $p < 0.001$ ) [22]. Similarly, the two studies of the factors correlated with the knowledge of parents of children with asthma, which found that the duration of diagnosis of asthma was correlated positively with the knowledge (Spearman rho 1.232;  $p = 0.044$ ) [24] and ( $r = 0.30$ ,  $p < 0.05$ ), respectively, by reasoning that when children were diagnosed, the parents were instructed by physicians, nurses or other parents with children with the same disease. In addition, the information searches from media caused parents to continually accumulate knowledge, thereby creating more knowledge and understanding [16].

## Conclusion

The overall knowledge of mothers of children with CHD was at a high level, while the domain of the prevention of complications was at a low level. The duration of treatments was positively correlated with the mothers' knowledge of children with CHD. Consequently, healthcare professionals, especially nurses, should emphasize appropriate health education depending on the duration of treatments for the children with CHD which covers the prevention of complications on four topics: infective endocarditis, congestive heart failure, hypoxic spells and pneumonia. Nurses should provide instructions from various media such as handbooks, leaflets or the hospital's websites. The use of the QR code that links to the information sources, for example, the hospital's line official account or reliable websites, is also applicable. In conclusion, mothers of children with CHD should be knowledgeable about taking care of their children to eliminate or at least reduce complications so as to eventually strengthen the children's readiness for future cardiac surgery.

## Strength of study and recommendations

The strength of this study is that tool development specific to mothers of children with CHD, both acyanotic and cyanotic types. Therefore, the aforementioned findings can be used as baseline data to develop a teaching program to improve knowledge for mothers of children with acyanotic CHD or cyanotic CHD with regard to symptoms, complications and duration of treatments according to the child's age.

Conflict of Interest: None

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