

# Support Program for Thai Mothers of Toddlers with Congenital Heart Disease: A Randomized Control Trial

Thitima Suklertrakul\*, Wilawan Picheansathian, Usanee Jintrawet, Jutamas Chotibang

**Abstract :** The health status of toddlers with un-repaired congenital heart disease relies on maternal care behaviors. This randomized control trial investigated the effects of a Dependent Care Support Program on maternal care behaviors. Participants were 50 mothers of toddlers with non-cyanotic congenital heart disease waiting for surgery. They were randomly assigned to either the experimental group (n = 25) or the control group (n = 25). The experimental group received the usual care plus the program. The control group received only the usual care. Data were collected by using the Maternal Care Behaviors for Congenital Heart Disease Toddlers Scale and the Incidence of Illness Recording Form. Data were analyzed using descriptive statistics, Chi-square test, Fisher's exact test, independent t-test, and dependent t-test.

Results indicated that the maternal care behaviors in the experimental group at week 6 after program implementation were significantly higher than mothers in the control group and were significantly higher than those before attending the program. The incidence rate of illnesses among children in the experimental group (40%) at week 6 was significantly lower than children in the control group (80%). Nurses may implement the 6-week program to improve maternal care behaviors and their children with congenital heart disease to gain optimum health for surgical treatment as planned. Further study should evaluate the effectiveness of the program in long-term follow-up.

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**Keywords:** Care Behaviors, Congenital Heart Disease, Dependent Care Support, Mother, Orem's Self- Care Model, Randomized Controlled Trial, Toddler

## Introduction and background of the study

Congenital heart disease (CHD) is a leading cause of birth defect-associated children's morbidity and mortality. The birth prevalence of CHD worldwide occurs in approximately 6.9–9.3/1000 live births, and the most common subtype is acyanotic CHD with increased pulmonary blood flow, particularly ventricular septal defect (VSD), atrial septal defect (ASD), and patent ductus arteriosus (PDA).<sup>1</sup> Currently, CHD in children continues to be a global health issue worldwide,

**Correspondence to:** Thitima Suklertrakul\*, RN, PhD (Candidate)  
Faculty of Nursing, Chiang Mai University, Muang District, Chiang Mai, Thailand. **E-mail:** thitima.suk@cmu.ac.th

**Wilawan Picheansathian**, RN, DN. Associate Professor, Faculty of Nursing, Chiang Mai University, 110 Intawaroros Road, Muang District, Chiang Mai, 50200 Thailand. **E-mail:** wiawan84@gmail.com

**Usanee Jintrawet**, RN, PhD. Assistant Professor, Faculty of Nursing, Chiang Mai University, 110 Intawaroros Road, Muang District, Chiang Mai, 50200 Thailand. **E-mail:** ujjusanee@gmail.com

**Jutamas Chotibang**, RN, PhD. Associate Professor, Faculty of Nursing, Chiang Mai University, 110 Intawaroros Road, Muang District, Chiang Mai, 50200 Thailand. **E-mail:** chotibang.coact@gmail.com

including in Thailand.

Acyanotic CHD affecting children usually requires either medical or surgical treatment.<sup>2</sup> The majority of children with un-repaired acyanotic CHD are toddlers.<sup>3-5</sup> Due to the nature of the defects and the developmental stage of the toddlers, they are often faced with health-related problems before surgery, including the common cold, pneumonia, bronchiolitis, congestive heart failure (CHF), and infective endocarditis.<sup>6-8</sup> Consequently, these illnesses may lead to the postponement of cardiac surgery and increased mortality.<sup>9</sup> Therefore, monitoring the health status of children with CHD and providing appropriate care to reach optimum health for planned surgical treatment is necessary.

Toddlers with CHD require both general and special care from their caregivers, including care for promoting nutrition and dental health, taking cardiac medications, preventing illness, and monitoring signs and symptoms of CHF.<sup>10</sup> Mothers are the primary caregivers who spend most of the time in providing both general and special care.<sup>11-12</sup> As such, mothers act as dependent care agents in performing care actions for children with CHD who are their dependents, according to Orem's Self-Care Deficit Nursing Theory (SCDNT).<sup>13</sup>

Caring for children with CHD can affect the physical, psychosocial, and social state of mothers.<sup>14-15</sup> These combined effects result in difficulties in performing their care taker role.<sup>11</sup> Several studies have reported improper care behaviors by mothers, particularly care related to nutritional, dental, and respiratory care.<sup>16-18</sup> For example, they failed to offer feeding on demand,<sup>17</sup> provide a low-salt diet, or avoid crowded places.<sup>18</sup> As a result, pre-surgery illness in children with CHD still occurs.<sup>19-20</sup>

A literature review has shown that the factors found to be positively associated with maternal care behaviors for young children with CHD are family income,<sup>3</sup> health perception,<sup>18</sup> self-efficacy,<sup>3</sup> social support,<sup>3</sup> and knowledge,<sup>18</sup> while parenting stress<sup>3</sup> was found to be negatively associated with maternal care behaviors. However, self-efficacy was found to be the only strong predictor of maternal care behaviors

for toddlers with CHD.<sup>3</sup> In addition, the factors related to improper care among mothers included lack of knowledge,<sup>16-17</sup> lack of confidence,<sup>21</sup> and lack of coping skills.<sup>10,22</sup> Thus, interventions designed to help the mothers of children with CHD should focus on the above factors.

The analysis of existing interventions from previous studies<sup>4,21,23--24</sup> revealed that mothers of young children with CHD who received training, had enhanced self-efficacy, modified perceptions, improved social support, and developed coping skills. It was found that these interventions significantly increased maternal care behaviors at 4-8 weeks within three to five sessions, and they also improved child health outcomes. However, some maternal care behaviors did not improve<sup>16-18</sup> which might have resulted in an increased incidence rate of illnesses among their children and led to postponement of surgery. This might be because each intervention did not address all of the factors influencing maternal care behaviors. All of these interventions were based on theories that emphasized modification of only one or two factors, such as enhancing self-efficacy<sup>21</sup> or modifying perception and improving social support.<sup>23</sup> Orem's SCDNT<sup>13</sup> provides a structure to help improve maternal care behaviors through multiple factors.<sup>3,4</sup> Thus this study, aimed to test the Dependent Care Support Program (DCSP) to enhance maternal care behaviors for toddlers with CHD awaiting surgery using SCDNT<sup>13</sup> as a framework.

## **Theoretical Framework for the Intervention**

The DCSP, developed for this study, was based on Orem's SCDNT,<sup>13</sup> which proposes relationships among the four major concepts namely; self-care (SC), self-care agency (SCA), therapeutic self-care demands (TSCD), nursing agency (NA) and peripheral concepts of basic conditioning factors (BCF). According to Orem<sup>13</sup> SC is the practice of activities that persons initiate and perform for themselves to maintain life,

health, development, and well-being. SCA is the capabilities of persons to engage in self-care to meet TSCD,<sup>13</sup> which are the actions sequences necessary to meet all of the self-care requisites at specific times.<sup>13</sup> NA is the capabilities of nurses to design nursing systems to meet TSCD by enhancing SCA and modify BCF.<sup>13</sup> BCFs are factors that affect both SCA and TSCD.<sup>13</sup> However, this study focused on dependent care agency (DCA) instead of SCA, since children with CHD have to depend on their mothers, who are their dependent carer, to meet their TSCD. Orem states that DCA and BCF affect care behaviors.<sup>13</sup> In this study, DCA focused on capabilities for dependent care operations, namely estimative and transitional operations. Estimative operation is seeking knowledge and meaning of the conditions and factors significant for dependent care.<sup>13</sup> Transitional operation is making judgments and decisions about what can and should be done.<sup>13</sup> Estimative operation and transitional operation were conceptualized as knowledge and self-efficacy in this study, respectively. BCF in this study were health state and resource availability and adequacy. Health state is a factor that can constitute an obstacle to meet TSCD.<sup>13</sup> Resource availability and adequacy is a factor that affects the selection of means to meet TSCD.<sup>13</sup> Health state and resource availability and adequacy were conceptualized as parenting stress and social support in this study, respectively.

To enhance maternal care behaviors, the first component focused on providing knowledge, which was achieved using the six principles of adult learning from Knowles and colleagues:<sup>25</sup> the need to know, the learners' self-concept, the role of the learners' experiences, readiness to learn, orientation to learning, and motivation.<sup>25</sup> Enhancing knowledge would increase estimative operation of DCA because it plays an important part in investigating conditions that are significant for maternal care behaviors. It can help the mother to better understand CHD overview and the child's demands. The second component, enhancing self-efficacy, was achieved by developing four major sources of information from Bandura:<sup>26</sup> enactive mastery experience, vicarious experience, verbal persuasion,

and physiological and affective states.<sup>26</sup> Enhancing self-efficacy would increase transitional operation of DCA because it plays an important part in helping the mother to exercise good judgment about her capacity to perform care behaviors. The third component, decreasing parenting stress, was achieved using problem management and emotional regulation from Glanz and Schwartz<sup>27</sup> to develop strategies for coping skill training. Decreasing parenting stress would improve health state in BCF because it can reduce the obstacles on maternal care behaviors. The last component, enhancing social support, was achieved by providing four supportive acts from House:<sup>28</sup> emotional, informational, instrumental, and appraisal support.<sup>28</sup> Enhancing social support can increase resource availability and adequacy in BCF because it can aid the mother in meeting the child's TSCD. Improving DCA and BCF through the four components in the program may enhance maternal care behaviors. Thus, mothers of toddlers with CHD who participated in this program would have enhanced knowledge, enhanced self-efficacy, decreased parenting stress, and enhanced social support, which would help them improve care behaviors for toddlers with CHD and decrease the incidence of illnesses of the toddlers. The following hypotheses were proposed:

1) Maternal care behavior mean scores in the experimental group would be statistically significantly higher than those in the control group and higher than before attending the program as measured at the sixth week, and

2) The cumulative incidence rate of illnesses in toddlers with CHD whose mothers attend in the experimental group would be statistically significantly lower than those attending in the control group.

## **Methods**

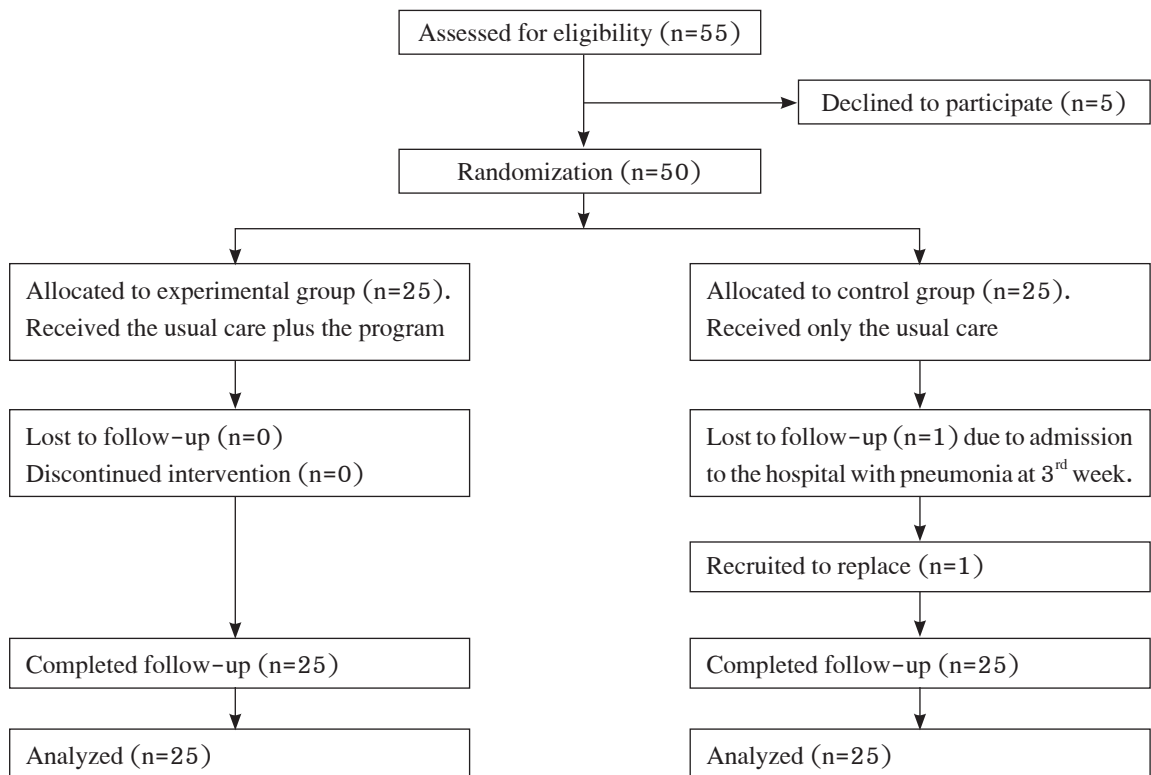
**Design:** The randomized control trial design was used for the study.

**Sample and Setting:** The sample was drawn from all mothers of toddlers with CHD who accompanied their children to the Division of Cardiology and the

Pediatric Cardiology Clinic of a northern Thailand hospital, and who met the inclusion criteria: 1) being a mother of a child aged 1–3 years old diagnosed with a known case of VSD, ASD, or PDA, waiting for surgery at least 7 weeks; 2) The child had no other health problems and needed to be admitted to the hospital; 3) aged 18–45 years old; and 4) having the ability to communicate in Thai language verbally. The discontinuation criteria for the mothers were inability to participate in all of the intervention sessions, such as those whose children with severe complications from CHD, or emergency cardiac surgery during the program implementation, or the researcher’s inability to contact the mother.

The sample size was estimated using power analysis, with a power of .80 and a significance level of .05.<sup>29</sup> The estimated effect size (6.43) was calculated based on the findings of one previous related study.<sup>23</sup>

This effect size was interpreted as a large effect by Cohen.<sup>30</sup> The value of an estimated effect size of .80 was used to estimate the sample size in this study. Thus, the sample size required 50 participants. Participants were randomly assigned with equal probability to the experimental and control groups using permuted-block randomization in a block size of four. 55 mothers of toddlers with CHD who met the inclusion criteria were recruited for the study. Five mothers refused to participate due to being far away from the setting. Therefore, 50 participants joined the study and were randomly assigned into the experimental and the control groups, 25 per group. One participant in the control group dropped out because of the hospitalization of her toddler with pneumonia during the third week of the program. Thus, another participant was recruited to replace. (See **Figure 1**).



**Figure 1.** Flow chart of the participant recruitment procedures

**Ethical Considerations:** Study approval was obtained from the Research Ethics Committee of the Faculty of Nursing, Chiang Mai University, (approval no. 177/2014) the Research Ethics Committee of the Faculty of Medicine, Chiang Mai University, (approval No. 109/2015), and Lampang Hospital, (approval No. 015/2015). All participants received a complete explanation and written description of the purposes and processes of the study, the methods, the potential risks and benefits of participation, and the protection of their right to withdraw from the study at any time, without any adverse personal impact. Before signing the informed consent form, participants were assured about confidentiality and anonymity and had a chance to ask questions about the study.

**Intervention Program:** The program was an individualized intervention developed by the researchers

and based on Orem's SCDNT<sup>13</sup> for mothers of toddlers with CHD. The four components of the program included providing CHD knowledge, enhancing self-efficacy, decreasing parenting stress, and enhancing social support. The 6-week program was based on previous studies.<sup>4,21,23</sup> Also, corrective surgery for a child with CHD is typically scheduled approximately seven weeks after physician recommendation. The DCSP spanned four consecutive weeks, with four sessions total, once per week, plus two weeks for follow-up (Table 1). The program content was validated by five experts and modified according to their recommendations. Then it was evaluated on face validity by four mothers of toddlers with CHD for practicality of the program, and its readability and understandability to the participants before full implementation.

**Table 1:** Schedule and Content of DCSP Intervention Protocol

Component	Session	Content	Method	Material
<b>Providing knowledge</b>	1 (wk. 1) (25 min.)	<ul style="list-style-type: none"> <li>- Providing general knowledge of CHD,</li> <li>- Providing knowledge related to universal, developmental and health deviation of self-care requisites,</li> <li>- Providing handbook,</li> <li>- Training in self-recording for monitoring child's health status.</li> </ul>	<ul style="list-style-type: none"> <li>- Active participation</li> <li>- Questioning and answering</li> <li>- Discussion</li> <li>- Feedback</li> </ul>	<ul style="list-style-type: none"> <li>- Lesson plan</li> <li>- Handbook</li> <li>- Power point</li> </ul>
<b>Enhancing self-efficacy</b>	1 (wk.1) (35 min.)	<ul style="list-style-type: none"> <li><i>Enactive mastery experience</i></li> <li>- Developing skills about how to assess and care for the child with CHD.</li> <li><i>Vicarious experience</i></li> <li>- Observing role model</li> <li><i>Verbal persuasion</i></li> <li>- Strong verbal encouragement</li> <li><i>Physiological and affective states</i></li> <li>- Training on relaxation techniques</li> </ul>	<ul style="list-style-type: none"> <li>- Demonstration</li> <li>- Return-demonstration</li> <li>- Discussion</li> <li>- Feedback</li> </ul>	<ul style="list-style-type: none"> <li>- Lesson plan</li> <li>- Videotape</li> <li>- Maternal practice checklist</li> </ul>
<b>Decreasing parenting stress</b>	1 (wk. 1) (60 min.)	<ul style="list-style-type: none"> <li>Coping skill training</li> <li>- <i>Problem management:</i> teaching problem-solving strategies using scenario discussion.</li> <li>- <i>Emotional regulation:</i> encouragement of ventilation of feelings, and discussing concerns and showing a video about coping's model.</li> </ul>	<ul style="list-style-type: none"> <li>- Active participation</li> <li>- Discussion</li> <li>- Feedback</li> </ul>	<ul style="list-style-type: none"> <li>- Lesson plan</li> <li>- Scenario</li> <li>- Videotape</li> </ul>

**Table 1:** Schedule and Content of DCSP Intervention Protocol (Continued)

Component	Session	Content	Method	Material
<b>Enhancing social support</b>	2, 3, 4 (wk. 2, 3, 4)	<i>Informational support</i>	- Counseling	- Telephone support form
	(15-30 min/s for each call)	- Telephone support for counseling and reminder, and other types of communication (Line, Facebook) : discuss mother’s problem in care, and ways to solve the problem : remind about providing the child with good care, recording of the incidence of illness of the child using the recording form, making an appointment for telephone call : review the knowledge and skills <i>Emotional support</i> - Mailing a post-card for providing empathy, caring and trust to participants <i>Instrumental support</i> - Providing thermometer <i>Appraisal support</i> - Providing feedback for self-evaluation	- Reminders - Active participation - Discussion - Positive feedback - Encouragement of the participant to ask questions.	- Postcard - Reviewing knowledge and skills form

Note. wk. = week, s = session, min = minutes

**Usual care:** Usual care refers to the activities usually provided for children with CHD by the pediatric cardiologist and nursing team at the study setting. The care activities included providing information by verbal explanation about CHD and its treatments, preventing complications from the defect, and caring for their children at home.

**Preparing the research assistants (RA):** Two registered nurses (RNs) were trained to collect the care behaviors data by telephone at the baseline (week 1) and week 6 after completing the program. They were blinded to the participants’ allocation status in the experimental and control groups.

**Instruments:**

*The Demographic Data Form (DDF)* was developed by the principal investigator (PI) to collect information about the characteristics of mothers and toddlers.

*The Maternal Care Behaviors for CHD Toddlers Scale (MCBCHDTS)* was developed by Chaisom and colleagues,<sup>3</sup> and was modified by the PI in this study. The PI modified the construct of individual items based on Orem’s theory,<sup>13</sup> which covered sub-dimensions of three types of self-care requisites for toddlers with CHD: universal, developmental, and health deviation self-care requisites. Some items were added or adjusted in the original scale to be consistent with the maternal care behaviors for toddlers with CHD in current situations. The scale consisted of 39 items with a four-point rating scale ranging from 0 (never experienced the reported behavior) to 3 (always perform the reported behavior). Since some of the reported behaviors were not experienced by some mothers, the final score was calculated by dividing the total score with the number of experiencing items.<sup>3</sup> The possible final scores ranged from 1 to 3

and were classified into three equal levels of low (1.00 – 1.67), moderate (1.68 – 2.34), and high (2.35 – 3.00). Higher scores indicated better dependent care behaviors. An item example was “I keep the child from contact with anyone who had a respiratory infection such as common cold, cough, and sore throat.” The content validity of the scale was determined by five experts. The content validity index was .90. The Cronbach’s alpha coefficient was .83 in the main study.

*The Incidence of Illness Recording Form (IIRF)* was developed by the PI, on which the mothers recorded the incidence of illness of their toddlers with CHD throughout the program. The PI trained participants in the two groups to use this form, which included details of the illness of toddlers with CHD, performance of the help from mothers, and evaluation of help. Illnesses to be recorded were minor illnesses from complications of CHD including fever, common cold, cough, pharyngitis, dyspnea, edema, and diarrhea. The incidence of illnesses was calculated by the cumulative incidence rate of illnesses. The PI monitored and evaluated the mothers’ reporting using this form, as well as reminded them to keep the record continuously.

**Data collection procedures:** Data were collected from June 2015–May 2016. After randomly assigned into the experimental group or the control group, the participants were asked to complete the DDF by self-administering and were trained how to complete the IIRF. Before conducting the first session, the RAs collected data on the MCBCHDTS by phone interviewing, which served as baseline data. The participants in the experimental group received the program conducted by the PI, in addition to usual care, whereas the participants in the control group received only the usual care. At the sixth week, RAs collected data on the same scale by phone interviewing and asked the mothers to mail the IIRF back to the PI. Four participants from the control group completed all sessions in the program, and 21 participated in only the telephone support session.

**Data Analysis:** Descriptive statistics were used to analyze the demographic data. Chi-square, Fisher’s tests, Independent t-test, and Mann Whitney-U were used to examine the differences between the experimental and control groups. The assumption of normality was tested prior to analysis, indicating normal distribution of scores on the care behaviors of both groups. Therefore, independent t-tests and dependent t-tests were used to compare the differences in the mean scores of maternal care behaviors. Chi-square test was used to compare the difference of the incidence of illnesses among the toddlers with CHD between both groups, at the week 6.

## Results

There were no statistically significant differences in all demographic characteristics between the two groups, neither the mothers (**Table 2**) nor the toddlers with CHD (**Table 3**). At the sixth week of the program, the mean scores of maternal care behaviors in the experimental group were significantly higher than the control group (**Table 4**). After attending the program, the mean scores of maternal care behaviors in the experimental group had significantly increased when compared to baseline (**Table 4**).

The cumulative incidence rate of illnesses among the toddlers with CHD whose mothers were in the control group was significantly higher (80%, 20 out of 25) than that of the experiment group (40%, 10 out of 25), ( $\chi^2 = 8.33$ ,  $df = 1$ ,  $p < .05$ ). The CHD in the control group developed the common cold, dyspnea, fever, cough, bronchitis, pharyngitis, cyanosis, edema, or acute diarrhea. Meanwhile, CHD in the experimental group developed the common cold, dyspnea, fever, cough, or acute diarrhea. However, each child of both groups might have developed more than one illness and been ill several times.

**Table 2:** Demographic characteristics of mothers in the control and experimental groups

Characteristics	Control group	Experimental group	p-value
	(n = 25)	(n = 25)	
	n (%)	n (%)	
Age (years)			
Mean (SD)	29.48 (5.83)	31.04 (7.37)	.411 <sup>t</sup>
≤ 20	2 (8%)	1 (4%)	
21-30	13 (52%)	11 (44%)	
31-40	9 (36%)	9 (36%)	
41-50	1 (4%)	4 (16%)	
Educational background			
No school attendance	3 (12%)	2 (8%)	.829 <sup>a</sup>
Primary school	3 (12%)	3 (12%)	
Secondary school	12 (48%)	10 (40%)	
Vocational certificate	3 (12%)	4 (16%)	
Bachelor degree or higher	4 (16%)	6 (24%)	
Occupation			
Housewife	6 (24%)	11 (44%)	.154 <sup>a</sup>
Agriculture	5 (20%)	1 (4%)	
Merchant	1 (4%)	4 (16%)	
Employee	9 (36%)	6 (24%)	
Family income			
Mean (SD)	15,020 (11958.68)	16,680 (13437.26)	
≤ 10,000	14 (56%)	12 (48%)	
10,001-20,000	7 (28%)	8 (32%)	
20,001-30,000	1 (4%)	2 (8%)	
30,001-40,000	2 (8%)	1 (4%)	
40,001-50,000	1 (4%)	2 (8%)	
Characteristics of family			
Nuclear family	10 (40%)	11 (44%)	.827 <sup>a</sup>
Extended family	13 (52%)	13 (52%)	
Other (mother, child, relatives)	2 (8%)	1 (4%)	
Received the knowledge on caring for children with CHD			
Never received	21 (84%)	22 (88%)	1.000 <sup>b</sup>
Have received	4 (16%)	3 (12%)	

Note: <sup>t</sup> = t-test, <sup>a</sup> = Chi-square test, <sup>b</sup> = Fisher's Exact test.

**Table 3:** Demographic characteristics of the toddlers with CHD in the control and experimental groups

Characteristics	Control group	Experimental group	p-value
	(n = 25) n (%)	(n = 25) n (%)	
Age (months)			
Mean (SD)	21.08 (7.52)	19.52 (8.24)	.488 <sup>t</sup>
13-18	11 (44%)	15 (60%)	
19-24	5 (20%)	3 (12%)	
25-30	5 (20%)	3 (12%)	
31-36	4 (16%)	4 (16%)	
Age at first diagnosis of CHD (months)			.572 <sup>m</sup>
Mean (SD)	3.96 (6.93)	2.4 (4.56)	
< 1	13 (52%)	13 (52%)	
1-6	7 (28%)	8 (32%)	
7-12	3 (12%)	3 (12%)	
> 12	2 (8%)	1 (4%)	
Duration of diagnosis with CHD (months)			.634 <sup>t</sup>
Mean (SD)	17.44 (9.37)	16.24 (8.28)	
1-12	8 (32%)	7 (28%)	
13-24	11 (44%)	14 (56%)	
25-36	6 (24%)	4 (16%)	
Type of CHD			.580 <sup>a</sup>
VSD	15 (60%)	18 (72%)	
ASD	7 (28%)	4 (16%)	
PDA	3 (12%)	3 (12%)	
Medications for treatment of CHD			.758 <sup>a</sup>
No	7 (28%)	8 (32%)	
Yes	18 (72%)	17 (68%)	
Illness during the past month			1.000 <sup>b</sup>
No	4 (16%)	3 (12%)	
Yes	21 (84%)	22 (88%)	
Type of illness			.506 <sup>a</sup>
Common colds	15 (71.43%)	19 (86.36%)	
Pneumonia	2 (9.52%)	3 (13.64%)	
Dyspnea	8 (38.10%)	8 (36.36%)	
Fever	8 (38.10%)	5 (22.73%)	
Cough	1 (4.76%)	1 (4.55%)	
Diarrhea	4 (19.05%)	2 (9.09%)	
Infective endocarditis	1 (4.76%)	0 (0.00%)	
Hospitalization			1.000 <sup>a</sup>
No	18 (72%)	18 (72%)	
Yes	7 (28%)	7 (28%)	

Note: <sup>t</sup> = t-test, <sup>m</sup> = Mann-Whitney test, <sup>a</sup> = Chi-square test, <sup>b</sup> = Fisher's Exact test.

**Table 4:** Comparison of mean scores of maternal care behaviors between the experimental and control groups at baseline and at the sixth week

Maternal care behaviors	Control group (n = 25) mean ± SD	Experimental Group (n = 25) mean ± SD	t-test	p-value
Baseline	2.55 ± 0.19	2.53 ± 0.14	0.356	.723
6 <sup>th</sup> week	2.56 ± 0.17	2.85 ± 0.09	-7.726	.000 <sup>t</sup>
t-test	-.272	-11.179		
p-value	.788	.000 <sup>d</sup>		

Note: <sup>t</sup> = Independent t-test, <sup>d</sup> = Dependent t-test

### Discussion

The findings from this study indicated that the DCSP was effective in improving maternal care behaviors and reducing the incidence of illnesses of toddlers with CHD. These results were consistent with the findings of previous studies and support educative supportive nursing system programs using Orem’s theory as the theoretical framework.<sup>4,31</sup> Thus, the DCSP that included providing knowledge, enhancing self-efficacy, decreasing parenting stress, and enhancing social support could promote the maternal care behaviors.

First, in regards to developing knowledge of CHD, individual mothers were educated by a power point presentation, techniques of active participation, questioning and answering, discussion, and feedback. Also, they received a handbook on how to take care of children with CHD at home prior to surgery, and their knowledge of CHD was monitored through telephone calls. These educational strategies help mothers to better understand of their child’s conditions and needs, as well as how to interpret information about caretaking, which can lead to providing correct and appropriate care of their children. The findings were consistent with previous studies that showed education through the computer and a handbook as strategies that could improve maternal care behaviors for children with CHD<sup>4,31-32</sup> and children with thalassemia.<sup>33</sup>

Second, self-efficacy in this study including an enactive mastery experiences, vicarious experiences,

verbal persuasion, and physiological and affective states that were enhanced by training on how to assess and care for the ill child, and how to prevent infective endocarditis through return-demonstration, observing role models from a video, strongly positive verbal persuasion, and training on relaxation techniques. These strategies of altering efficacy beliefs related to the judgment of mothers’ capabilities are educational through cognitive processing, which can enhance their performance.<sup>26</sup> The findings of this study were congruent with previous studies that used four sources of information to enhance self-efficacy that could significantly improve maternal care behaviors for children with CHD<sup>21</sup> and children with asthma.<sup>34</sup>

Third, increased care behaviors are also explained by reducing parenting stress through coping skill training of emotional regulation and problem management. In this intervention protocol, emotional regulation was achieved by encouraging mothers’ ventilation of their feelings, discussing their concerns, and watching a video showing role models of coping. Furthermore, problem management was achieved by training in problem-solving skills with a scenario discussion. These strategies facilitated the coping abilities of mothers and decreased parenting stress, which resulted in better care behaviors. These findings were congruent with the findings of previous studies in that coping skill training increases the feeding practice of mothers of infants with CHD and also improves child development.<sup>24</sup>

Finally, maternal care behaviors were increased by enhancing social support. In this study, the PI acted as the health professional source of enhancing social support to mothers by using four supportive acts: informational, emotional, instrumental, and appraisal support. Our findings confirmed that mothers in the experimental group could perceive and receive social support from the PI, which covered all aspects of support including a handbook, a digital thermometer, positive feedback, telephone support, and a postcard mailing. These findings were consistent with previous findings regarding mothers of children with CHD<sup>4,35</sup> and children with cerebral palsy<sup>36</sup> that showed significantly increased caring behaviors scores.

Although mothers in the experimental group showed improvement of their care behaviors for toddlers with CHD, the mean score of maternal care behaviors differed from the control group only 0.29. This might be because the statements of some items of the MCBCHDTS are general care behaviors for the children such as “I give my child three meals a day.” Therefore, the participants in both groups might have answered in the same way. In addition, the mean score of some items of maternal care behaviors increased slightly at the sixth week in terms of providing nutritional meals on demand (i.e., fruits, vegetables, and meat) and assessing the pulse before giving Lanoxin, when compared with the baseline. This might be because their children with CHD were in the toddler stage when they often refuse to be fed and only want to eat their favorite food.<sup>37</sup> Additionally, overprotective behaviors of mothers might result in performing improper care. In terms of checking the pulse before giving Lanoxin, some mothers reported that they had difficulty in checking the pulse due to the activeness of their toddler or their child crying. Thus, the MCBCHDTS may have to have some items of care behaviors refined.

The cumulative incidence of illnesses in toddlers with CHD whose mothers attended the experimental group was statistically significantly lower than those

attending the control group at week 6. Provision of proper care can lead to a decrease in the incidence of illnesses. These findings were also supported by prior studies which found that mothers who received education and training significantly decreased health problems for their children with CHD<sup>23-24,38</sup> and premature infants.<sup>39</sup>

On the contrary, toddlers with CHD whose mothers received only the usual care continued to have health problems, and suffered more frequently from various illnesses, especially respiratory and gastrointestinal problems. This might be because mothers in the control group that had poor care practices in terms of nutrition, taking cardiac medications, dental care, sleeping, and monitoring of complications. They reported at the end of the program that they needed more information, and counseling from health care providers, especially on how to promote their child’s weight gain, prevent the contraction of other illnesses, and correctly provide care when their child had a cardiac problem or an illness. In accordance with Orem’s theory,<sup>13</sup> mothers seek information and secure appropriate medical assistance for their children, especially health care specializing in children with CHD.

The results of this study demonstrated that the DCSP can improve care behaviors among mothers of toddlers with CHD and reduce the incidence of illnesses of children. As a result, children with CHD gained optimum health during the preoperative period and were able to receive surgical treatment as planned.

### **Limitations**

The participants in this study included only mothers of toddlers with CHD who had the ability to communicate in the Thai language, could be contacted by telephone and mail at only two selected cardiology clinics in a provincial hospital, the northern of Thailand. Therefore, it would have limited generalizability to mothers in other countries, or cultures.

## Conclusions and Implications for Nursing Practice

Our findings revealed that the DCSP is effective in improving care behaviors of mother having children with CHD and reduce the incidence of illnesses of children. Thus, nurses can use this DCSP for supportive educative mothers and emphasize on nutrition management, measurement of the pulse before giving Lanoxin, dental care, and monitoring signs and symptoms of CHF. Additionally, nurses should integrate this program with discharge planning for those mothers and a referral care system to their community settings by providing a handbook, telephone support, and using the IIRF. However, the DCSP needs further testing of its application to other participants, such as mothers of children with cyanotic CHD or complex CHD. Further study should evaluate the effectiveness of the DCSP over a longer duration to sustain the maternal care behaviors, and it should consider other methods for measuring the maternal care behaviors to assess the actual behaviors, and for recording the illness of the child with CHD. Also, the MCBCHDTS should be refined for some items of care behaviors regarding avoiding excess sodium consumption, and offering extra calories intake.

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# โปรแกรมการสนับสนุนสำหรับมารดาไทยที่มีบุตรวัยหัดเดินที่เป็นโรคหัวใจพิการแต่กำเนิด: การวิจัยเชิงทดลองแบบสุ่ม

ฐิติมา สุขเลิศตระกูล\* วิลาวณีย์ พิเชียรเสถียร อุษณีย์ จินตะเวช จุฑามาศ โชติบาง

**บทคัดย่อ :** ภาวะสุขภาพของเด็กวัยหัดเดินที่เป็นโรคหัวใจพิการแต่กำเนิดและยังไม่ได้รับการผ่าตัดซ่อมแซมขึ้นอยู่กับพฤติกรรมดูแลของมารดา การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อทดสอบผลของโปรแกรมการสนับสนุนการดูแลแบบพึ่งพาต่อพฤติกรรมดูแลของมารดาที่มีบุตรวัยหัดเดินที่เป็นโรคหัวใจพิการแต่กำเนิด กลุ่มตัวอย่างเป็นมารดาที่มีบุตรวัยหัดเดินที่เป็นโรคหัวใจพิการแต่กำเนิดชนิดไม่เขียวและรอการผ่าตัด จำนวน 50 ราย ทำการสุ่มตัวอย่างเข้ากลุ่มทดลอง 25 ราย และกลุ่มควบคุม 25 ราย กลุ่มทดลองได้รับการดูแลตามปกติและโปรแกรมการสนับสนุนการดูแลแบบพึ่งพา กลุ่มควบคุมได้รับการดูแลตามปกติเพียงอย่างเดียว รวบรวมข้อมูลโดยใช้แบบสอบถามพฤติกรรมดูแลของมารดาและแบบบันทึกอุบัติการณ์ความเจ็บป่วย วิเคราะห์ข้อมูลโดยใช้สถิติเชิงพรรณนา สถิติไคร์ สแควร์ สถิติทดสอบฟิชเชอร์ และสถิติทดสอบค่าที ผลการวิจัยพบว่า พฤติกรรมดูแลของมารดาในกลุ่มทดลองหลังจากเข้าร่วมโปรแกรม 6 สัปดาห์ สูงกว่ามารดาในกลุ่มควบคุมและสูงกว่าก่อนเข้าร่วมโปรแกรมอย่างมีนัยสำคัญทางสถิติ อัตราอุบัติการณ์ของความเจ็บป่วยของเด็กในกลุ่มทดลอง (40%) หลังจากเข้าร่วมโปรแกรม 6 สัปดาห์ ต่ำกว่าเด็กในกลุ่มควบคุม (80%) อย่างมีนัยสำคัญทางสถิติ พยาบาลควรนำโปรแกรมการสนับสนุนการดูแลแบบพึ่งพานี้ไปใช้ในการดูแลเด็กที่เป็นโรคหัวใจพิการแต่กำเนิดในระยะก่อนผ่าตัดหัวใจระยะเวลา 6 สัปดาห์ เพื่อส่งเสริมพฤติกรรมดูแลบุตรของมารดา และทำให้เด็กมีสุขภาพแข็งแรงเพื่อรับการผ่าตัดตามแผน การศึกษาครั้งต่อไปควรประเมินประสิทธิผลของโปรแกรมในระยะยาว

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**คำสำคัญ:** พฤติกรรมดูแล โรคหัวใจพิการแต่กำเนิด โปรแกรมการสนับสนุนการดูแลแบบพึ่งพา มารดา ทฤษฎีการดูแลตนเองของโอเรียม การทดลองแบบสุ่มและมีกลุ่มควบคุม วัยหัดเดิน

**ติดต่อที่:** ฐิติมา สุขเลิศตระกูล\*, RN, PhD (Candidate) คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่ 110 ถนนอินทาทโรส อำเภอเมือง จังหวัดเชียงใหม่ 50200.  
**E-mail:** thitima.suk@cmu.ac.th  
**วิลาวณีย์ พิเชียรเสถียร**, RN, DN. รองศาสตราจารย์, คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่ 110 ถนนอินทาทโรส อำเภอเมือง จังหวัดเชียงใหม่ 50200.  
**E-mail:** wiawan84@gmail.com  
**อุษณีย์ จินตะเวช**, RN, PhD. ผู้ช่วยศาสตราจารย์, คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่ 110 ถนนอินทาทโรส อำเภอเมือง จังหวัดเชียงใหม่ 50200.  
**E-mail:** ujusanee@gmail.com  
**จุฑามาศ โชติบาง**, RN, PhD. รองศาสตราจารย์, คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่ 110 ถนนอินทาทโรส อำเภอเมือง จังหวัดเชียงใหม่ 50200.  
**E-mail:** chotibang.coact@gmail.com