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A CONTINUING CARE PROGRAM AT HOME ON CAREGIVER'S ROLE FOR CHILDREN WITH CONGENITAL HEART DISEASE: A PILOT STUDY

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ABSTRACT

Caregivers should have adequate caring roles knowledge of children to increase the quality of life of children with congenital heart disease (CHD). Aim: To develop and evaluate the effect of a home-based continuing care program on the role of caregivers for children with CHD. This pilot study was a quasi-experiment with one group pre-posttest without control group design and conducted between October 2018 and September 2019 in Narathiwat, Pattani, and Yala. Thirty caregivers were recruited using a multistage random sampling technique. The program covered teaching, demonstration, and feedback equipped with a manual of CHD for six weeks. The self-developed caregiver role questionnaire was provided to evaluate caregiver care roles. The paired t-test was applied to evaluate the different scores of the caring roles before and after the program with the significant p value < 0.05. The scores of the caregivers' roles for children with CHD after receiving the program were significantly higher than the scores before receiving the program (t = 6.20, p < 0.00.001). Continuing care programs enhance caring roles related knowledge of children with CHD. This program is recommended to apply continuously for caregivers of children with CHD at the outpatient or as part of discharge planning.

Keywords: Caregivers; caring roles; children; congestive heart disease; continuing care program

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INTRODUCTION

Congenital heart disease (CHD) is an abnormal formation of the heart or major blood vessel structures, which causes birth defects associated with children's morbidity and mortality (Mahmoud et al., 2020; Poudel & Malla, 2017; Suklerttrakul et al., 2018). The incidence of CHD is 8-10 per 1,000 live births, representing nearly 25% of all congenital malformations (Mahmoud et al., 2020). CHD can be classified as non-cyanotic CHD of ventricular septal defect, atrial septal defect, patent ductus arteriosus, pulmonary stenosis and coarctation of the aorta, and cyanotic CHD of tetralogy of Fallot, transposition of the aorta, and pulmonary atresia.

Children with CHD require specific care from medical experts and their caregivers, including nutrition care, development, dental health, receiving prescribed cardiac medication, prevention of pneumonia, and monitoring of signs and symptoms of congestive heart failure (CHF) (Musiksukont, 2010; Suklerttrakul et al., 2018a). Some children with CHD did not receive adequate care, such as not getting vaccinated by appointment, eating a low-energy diet, not taking medication as prescribed, or having untreated (Suklerttrakul et al., 2018) dental problems (Wangsawat, Jaisomkom, et al., 2019; Wangsawat, Phiban, et al., 2019). Most of these children receive treatment in the outpatients and the family plays the role of the caregiver to manage the children's problems (Amakali & Small, 2014). The caregiver may experience complications of caring at home in terms of malnutrition, delayed development, congestive heart failure, hypoxic spell, respiratory infection, and pulmonary hypertension. About 20-30% of children with CHD have physical problems, delayed development, or cognitive

disorders that require specific care and treatment (Mahmoud et al., 2020). Children with CHD also have a higher risk of inhospital mortality and morbidity when admitted to the hospital due to influenza and have lower health-related quality of life compared with healthy children (Mellion et al., 2014).

Children with CHD aged 6-30 months are at a higher risk of developmental delays due to chronic hypoxia induced by underlying CHD so early continuing screenings and interventions are recommended to solve this issue (Lata et al., 2015). Moreover, children aged 0-3 years cannot meet their needs and must depend on caregivers. The mortality rate in children with CHD remained high during the first four years of life, indicating that ongoing surveillance and early intervention may be advantageous. The age range of 0-3 years old of children with CHD is the crucial time for early identification, early diagnosis, accurate assessment, and appropriate treatment for minimizing CHD mortality and improving children's health (Mandalenakis et al., 2020).

Otherwise, congestive heart failure-related complications in children may trigger psychological distress among caregivers. Some of the caregivers reported an increased incidence of emotional distress and psychosocial issues, as well as a lack of relationships, insufficient social support, and higher expenses because they had to spend most of their time providing care for children with CHD at home (Amakali & Small, 2014; Lantin-Hermoso et al., 2017; Srichantaranit & Chontawan, 2011). Since some academic knowledge conflicted with the caregivers' beliefs and way of life, caregivers did not apply the knowledge to care for children with CHD. Furthermore, these circumstances cause complex psychological feelings and excessive stress for caregivers with a high risk of complications for children with CHD. Therefore, caregivers need to adapt to their roles through self-study to gain more knowledge regarding the care of children with CHD to increase the quality of life for children with CHD (Ni et al., 2019).

To solve this problem, encouraging caregivers to have effective knowledge and caring roles for their children with CHD is one of the recommended interventions needed. Caregivers need to adapt to their roles and apply the knowledge for caring for children with CHD. However, 94.3% of caregivers had poor knowledge and most of them had a moderate level of caring role for children with CHD (EL-Gendy et al., 2020). In southern border provinces of Thailand, malnutrition and pneumonia were found in 66.6% and 43.4% respectively among children with CHD due to caregivers' lack of knowledge and insufficient caring role at home. Therefore, it is highly recommended to create a home-based education program for caregivers in looking after children with CHD.

A previous study explored a home-based educational program to improve caregivers' knowledge and caring roles. Caregivers who received supportive and educational nursing programs had a higher mean score of knowledge when compared with the control group. However, there was no difference in the mean score of caregiver role after receiving the program observed between the experimental and control groups (Wangsawat, Phiban, et al., 2019). Wangsawat, Jaisomkom, et al. (2019) found language as the limitation of the previous program. Most caregivers used Malay as their first language, while the previous programs mostly used Thai. Therefore, this study developed a continuing care program equipped with a manual of CHD knowledge for caregivers in Thai and Malay containing illustrations that are easy to understand, allowing caregivers to review the knowledge about caring for children with CHD. This study aimed to

develop and evaluate a continuing care program at home for children with CHD aged 0-3 years and compare the caregivers' role in caring for children with CHD before and after receiving the program.

METHOD

Study design

This quasi-experimental research (one group pre-post-test design) was part of the research and development project entitled The Development of Continuing Care Management System and Health Monitoring of Children with CHD Aged 0-3 Years in Primary Care Unit in Southern Border Provinces of Thailand (Wangsawat et al., 2020). This study was carried out from October 2018 to September 2019.

Sample

The minimum sample size per zone for a two-tailed paired ttest analysis was calculated using G-Power software version 3.1.9.4 where the estimated effect size of 0.9 based on the a power of 80% was assumed. The minimum sample size calculated was 17, which was increased to 30 to accommodate incomplete or non-responses and statistical analysis of the t-test requires a sample of at least 30 people (Srisatidnarakul, 2007). The samples were selected using a multistage random sampling technique, including Takbai district in Narathiwas province, Mueang district in Yala province, and Mueang district in Pattani province. The inclusion criteria were family members as main caregivers of children aged 0-3 years old with CHD, willingness to participate in the research, ability to communicate in Thai, and willingness to be contacted by phone. The respondents who did not complete the research phases were excluded from this study.

Intervention

This program was divided into three phases using system theory (Donabedian, 1980): 1) phase I: the focus group discussion invited six caregivers to identify the problem condition and analyze caregivers' problem related to caring roles in children with CHD; 2) phase II: construction of the program that eventually consisted of demonstration, discussion and feedback, and manual of CHD knowledge for the caregivers provided the information related to cause, signs and symptoms, nutritional care, complication prevention, and drug administration for children with CHD. Also, the program was verified for content validity by three experts and was tried out in five caregivers of children with CHD; 3) program evaluation: evaluation of continuing care program at home on caring roles of caregivers of children with CHD using quasi-experimental research design.

Procedures

The continuing care program for caregivers with children with CHD was carried out at home caregivers consisting of teaching, demonstration, feedback, and providing a manual of CHD knowledge for caregivers. The manual included illustrations related to causes, signs and symptoms, nutrition care, complication prevention, and medication use in Thai and Malay. Then, the researchers carried out a follow-up by phone to assess the problems with caring among children with CHD. The program has been verified for content validity by three experts and was tried out on five caregivers of children with CHD who had similar characteristics to the study sample.

Instruments

This study applied the Thai version of a modified questionnaire of caring roles for caregivers from Keawvichit

& Thajeen, (2020). This questionnaire consisted of 40 questions using a Likert scale from 1-4 (1=never practiced, 2=rarely practicing, 3=frequently practiced, and 4=always practiced). The range score of this questionnaire is 40-160, which is categorized with a score of 40-79 = poor level, a score of 80-119 = moderate level, and a score of 20-160 = good level. This questionnaire has a CVI value for content validity which is 0.87. The Cronbach's Alpha Coefficient for the reliability test of this questionnaire is 0.80 (Wangsawat, Phiban, et al., 2019).

Data collection

The research was approved by the ethics committee of Yala Hospital (No 4/2561). The researcher obtained consent from the Respondents who were given the details of participation in the research. Privacy and confidentiality of the data collection were assured, and the Respondents were allowed to withdraw from the study at any time without any consequence (Figure 1).

The first step (week 1): we followed up at primary care unit (researcher and public health staff). The activities were:

- Asking caregivers to take the caring role of caregiver questionnaire before participating in the program.
- Assessing the health status of children with CHD.
- Evaluating and managing the problems.
- Providing education and demonstration about causes, signs and symptoms, nutrition care, complication prevention, and medication use.

The second step (week 2): we visited the caregivers' homes. The activities were:

- Assessing the health status of children with CHD.
- · Evaluating the problems and the caring management of children caregivers.
- Providing education and demonstration about causes, signs and symptoms, nutrition care, complication prevention, and medication use.

The third step (week 4), we followed-up with the participants by phone. The activities were:

- Evaluating the problems and the caring management of children caregivers.
- Encouraging caregivers to take care of their children.

The fourth step (week 6): we visited the caregivers' homes. The activities were:

- · Assessing the health status of children with CHD.
- · Evaluating the problems and the caring management of children caregivers.
- Allowing the caregivers to summarize the appropriate approaches to caring for children with CHD in their family.
- Empowering caregivers to take care of their children.
- · Asking caregivers to take the caring role of caregiver questionnaire after the program ended.

Figure 1. Program stage

Data analysis

Data were analyzed by computer-based data analysis software. The data were displayed using descriptive statistics for respondent characteristics and bivariate analysis using paired T-test to compare the mean scores of caring roles of the caregivers for children with CHD before and after receiving the program. The significance level of this study was p < 0.05.

RESULT

Demographic data of Respondent

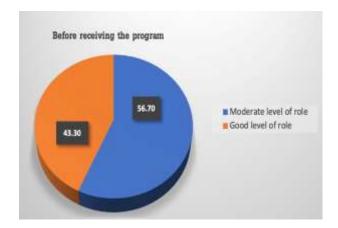
Table 1. Characteristics of Respondent (n = 30)

	n (%)
Age (year) Max = 52, Min = 21, m = 34.8	3, SD = 8.61
Caregiver experience (month)	
Max = 36, Min = 1, m = 22.33, SD = 9.93	3
Caregivers	
Father	7 (23.3)

Variables	n (%)	
Mother	23 (76.7)	
Religion		
Buddhism	3 (13.3)	
Islam	27 (86.7)	
Education level		
Primary school	7 (23.3)	
Secondary school	14 (46.7) 7 (23.3)	
High vocational school		
University or postgraduate	2 (6.7)	
Occupation		
Employer	8 (26.6)	
Farmer	1 (3.3)	
Business	6 (20.0)	
Housewife	11 (36.7)	
Others	4 (13.4)	

Variables	n (%)		
Household income (Bath/month)			
< 5,000	12 (40.0)		
5,001-10,000	8 (26.6)		
10,001-15,000	5 (16.7)		
15,001-20,000	1 (3.3)		
> 20,000	4 (13.4)		
Number of children			
1	9 (30.0)		
2 – 3	16 (53.3)		
4 - 8	5 (16.7)		
Type of family			
Single family	19 (63.3)		
Extended family	11 (36.7)		

This part presents distributions of caregivers studied according to their sociodemographic characteristics. The mean age of caregivers was 34.83 ± 8.61 years (min = 21; max = 52). In this study, 76.7% of caregivers were mothers and 86.7% were Muslims. For education and occupation, 46.6% of the caregivers completed high school and 36.7% were housewives. Moreover, 40.0% of the caregivers had the family income of less than 5,000 baht/month. They had children between 1 to 8 per family and most respondents had children 2-3 per family. Most respondents (63.3%) live in an extended family. The average length to look after children with CHD was 22.33 ± 9.93 months (min= 1; max= 36) (Table 1).



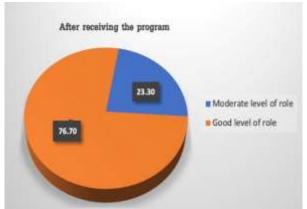


Figure 2. Caring role level of caregivers before and after continuing care program

Before the intervention, most caregivers of children with CHD had a moderate level of caring roles (56.70%), while after the program, 76.60% of the caregivers had a good level of caring roles (Figure 2). The mean scores of caring roles in caregivers of children with CHD before and after receiving the

program were 127.07 (SD = 10.89) and 135.57 (SD = 8.66) respectively. There was a significant increase in the score of caring roles of caregivers after receiving the program compared to the mean score of caring roles before the program (t = 6.20, p < .001) (Table 2).

Table 2. Comparison of the scores of caring roles in caregivers of children with CHD before and after receiving the program (n = 30)

Variable	Before		After		t	р
	m	SD	m	SD	-	
Caring role in caregivers of children with CHD	127.07	10.89	135.57	8.66	6.20	.001***

Note: m = mean; SD = standard deviation; *** P value is significant at p < .001

DISCUSSION

More than half of the caregivers in this study had a moderate level of caring roles before obtaining the continuing care program due to the information about children with CHD, including diagnostic, treatment guidelines, and nursing problems, was not adequately transferred by the hospital and the primary health care units. Even though the caregivers received knowledge and advice from doctors or nurses during the scheduled visits to the hospital, they received a lack of stimulation to put knowledge into practice. The caring role of children with CHD was not clear and might not be achieved as expected. It might be also supported by the educational background gained by caregivers who were senior high school. Caregivers might have limited knowledge to access information about CHD through internet sources.

However, after receiving the program, the number of caregivers with caring roles at a good level increased

significantly to the higher scores. The result was consistent with the study by Songthip et al., (2015) and Wangsawat, Phiban, et al., (2019) which found that mothers of children with CHD who received the education program under the concept of a supportive-education nursing system program had higher knowledge of caring for children with CHD than mothers who received usual care. Continuing education programs including parent mentors are a promising evidence-based strategy for lowering social determinants of health and increasing outcomes for children with CHD and their families (Davey et al., 2021).

The significant increase in caring role score was due to several possible reasons. Most caregivers of this study were mothers of children with CHD and were housewives. They could manage time to take care of their child closely and continuously. In addition, the content of the program is comprehensive including the causes, signs and symptoms, nutrition care, medication use, and prevention and care of

complications. According to Khouenkoup et al. (2022), caregivers of children with CHD should understand three domains, including cardiac disease and therapies, preventing complications, and providing general care. The teaching activities in this study consisted of lectures, demonstrations, re-demonstrations, discussion, and feedback. This program also provides a handbook for caregivers. These methods could help caregivers to learn, understand, and remember more accurate knowledge and behavior so they become more confident in caring for children with CHD (Wangsawat, Jaisomkom, et al., 2020; Suklerttrakul et al., 2018).

The manual of CHD knowledge for caregivers with illustrations and narration in two languages allowed the Respondent to review when they became insecure or forgot the content. According to Gramszlo et al. (2022), parents also expressed the need for greater information about social, emotional, and financial support and direction to credible online resources during education. Therefore, broader topics related to support systems for parents should be provided in the next education project.

Home visits and health assessments of children with CHD were performed by primary healthcare personnel who had the same context as caregivers. Mentoring and educating parents of children with CHD is recommended by community health workers who have or have no child with a specific ailment (e.g., CHD) and are trained to assist other parents with similar conditions (Davey et al., 2021). Public health staff who truly understand the context and lifestyle of children with CHD and caregivers can approach problems and advise caregivers accurately and in accordance with the culture, beliefs, and lifestyles of children with CHD.

The continuing care at home program developed in this study is expected to provide nurses with skills, especially in caring for children with CHD, by integrating the knowledge with the beliefs and culture of children with CHD and caregivers. Nurses in primary health care units who have specific skills and understanding in the caregiver context teach the caregivers by demonstrating caring skills in children with CHD, such as nutrition care, oral hygiene care, assessment of hypoxia condition, stimulation of development, taking medicine, protection of respiratory infection and infective endocarditis, and the care of congestive heart failure (Wangsawat, Pongjaturawit, et al., 2020).

In this study, caregivers received appropriate practical guidelines for caring for children with CHD and could perform their role continuously. Healthcare staff monitored, evaluated, and solved the problems. As a result, caregivers were more confident in their roles. This is in line with the goals of the home service system, which focuses on families and communities to have the potential to care for and manage health to cover all dimensions holistically (Chaikongkiat et al., 2016). Moreover, education plays an important role for parents, especially the knowledge of caring for children with CHD. Therefore, parents who received the program in this study had higher levels of knowledge and practice scores in caring for children with CHD, allowing the children with CHD to have a better quality of life (EL-Gendy et al., 2020). A study reported that toddlers with CHD whose mothers received a supportive and educational nursing program had a lower cumulative incidence rate of illnesses when compared with caregivers who had not received an education program (Suklerttrakul et al., 2018a).

Moreover, the data of children with CHD were shared between the primary health care staff and physicians so caregivers of children with CHD can receive continual and consistent care and this reduces the confusion of caring for their children (Wangsawat et al., 2018). Caregivers with good knowledge, understanding, and performance in the caring role can improve children with CHD health conditions, reduce the chance of complications, and have a better quality of life. According to Jackson et al. (2016), an effective home-based support program for families with chronic diseases should focus on general skills in children's caring, support caregiver's well-being, and collaborate with trained health professional staff. This continuing care program at home provides caregivers for children with CHD with increased access to patient care advice and increases the chance for help when patients have health problems that require specialist care. This program delivers the confidence and roles for caregivers in caring for children with CHD properly. In addition, care by public health staff who understand the caregiver context will reduce burden, anxiety, and stress in caregivers. Therefore, hospitals should implement continuing care at home programs to prepare caregivers before discharging patients and home visits for children with CHD to receive continued and effective care.

As technology evolves, continuing care programs could be combined with other methods, such as telehealth education for follow-up programs. Telemedicine is commonly applied to manage chronic diseases (such as CHD) at home, improve patient outcomes, improve family care, and prevent complications (Chang et al., 2018; Mao et al., 2019). Zhang et al. (2023) reported telehealth education via WeChat significantly improved parents' awareness of the disease and home care ability following CHD surgery, as well as lessened their home care burden, hence lowering the frequency of complications and loss to follow-up after discharge.

This study faced several limitations. Most caregivers who participated in teaching activities, demonstrations, and home visits were mothers, but in the culture in this study area, the father served as the head of the family. Essential care for children with CHD, such as taking patients to visit the dentist, visiting the doctor for catheterization or surgery, and cost planning for children with CHD care is not yet fully practicable. This is because some fathers do not allow their children with CHD to be cared for by this caring. This may be due to a lack of understanding of the reasons for the treatment. In addition, primary health care units lack a pulse oximeter for infants and young children, which makes assessing the patient's health status during home visits less effective, and nursing care of patients is inefficient.

CONCLUSION AND RECOMMENDATION

The continuing care program increased the caregivers' knowledge of caring for children with CHD. The continuing care at home program consisted of teaching, demonstrations, and feedback with consistent content through the manual of CHD knowledge for caregivers, encouraging caregivers to have better knowledge and play a role in caring for children with CHD. The continuing care program could be used as a community-based intervention and a guideline to facilitate caregivers of children with CHD to lessen the home care burden and increase the QoL of children with CHD. This program is also recommended to apply continuously for caregivers of children with CHD at the outpatient or as part of discharge planning and combined with telephone and telehealth to provide broader health information thus helping caregivers gain confidence and maintain an effective caregiver role.

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CONFLICTS OF INTEREST

The author declares that there is no conflict of interest.

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