EFFECTS OF A SUPPORTIVE-EDUCATIVE NURSING SYSTEM ON PRIMARY CAREGIVER BEHAVIOR IN CARING FOR CHILDREN WITH CYANOTIC HEART DISEASE AT RISK OF CYANOTIC SPELLS AND THE OCCURRENCE OF CYANOTIC SPELLS

ONCHIRA THEANNAMNGIAN

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Miss Onchira Theannamngian
Candidate

Asst. Prof. Renu Pookboonmee, D.N.S.
Major-Advisor

Assoc. Prof. Pairoj Chotiwittayatarakorn, M.D.
Co- Advisor

Assoc. Prof. Rassmidara Hoonsawat, Ph.D.
Dean
Faculty of Graduate Studies

Assoc.Prof. Yuwadee Luecha, Ed.D.
Chair
Master of Nursing Science
Faculty of Medicine,
Ramathibodi Hospital

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on
October 16, 2003

Miss Onchira Theannamngian
Candidate

Assoc.Prof. Panwadee Putwatana, D.Sc. (Nutrition)
Member

Asst. Prof. Renu Pookboonmee, D.N.S.
Chair

Asst. Prof. Wanida Sanasuttipun, Ph.D.
Member

Assoc. Prof. Pairoj Chotiwittayatarakorn, M.D.
Member

Assoc. Prof. Rassmidara Hoonsawat, Ph.D.
Dean
Faculty of Graduate Studies
Mahidol University

Prof. Prakit Vathesatogkit, M.D., ABIM., FRCP.
Dean
Faculty of Medicine,
Ramathibodi Hospital,
Mahidol University

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ONCHIRA THEANNAMNGIAN 4436604 RAPN/M

M.N.S. (PEDIATRIC NURSING)

THESIS ADVISOR: RENU POOKBOONMEE, D.N.S.,
PAIROJ CHOTIWITTAYATARAKORN, M.D.

ABSTRACT

The aim of this study was to determine effects of a supportive-educative nursing system on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and the occurrence of cyanotic spells. The supportive-educative nursing system is a nursing system to promote appropriate primary caregiver behavior in caring for children, and it consisted of educating, guiding, supporting, and establishing an appropriate environment. This study was conducted in a pediatric cardiology clinic in Bangkok. Thirty primary caregivers participated in the supportive-educative nursing system. Primary caregiver behavior was assessed by using an interview questionnaire, adapted to the issue of cyanotic spells. The occurrence of cyanotic spells was assessed by using an assessment form.

This study revealed that the mean scores of primary caregiver behavior after participation in the supportive-educative nursing system (Mean=53.00, SD=1.89) was higher than before participation (Mean=37.20, SD=5.18). The frequency of the occurrence of cyanotic spells after primary caregivers participated in the supportive-educative nursing system (Mean=6.33, SD=8.90)was lower than before participation (Mean=8.63, SD=10.52).

In conclusion, the supportive-educative nursing system seems to promote appropriate primary caregiver behavior in caring for children at risk of cyanotic spells and decrease the occurrence of cyanotic spells. So, it may be useful for member of the health care team.

KEY WORDS : PRIMARY CAREGIVER BEHAVIOR, CHILDREN WIYH CYANOTIC HEART DISEASE, CYANOTIC SPELLS, SUPPORTIVE-EDUCATIVE NURSING SYSTEM

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ผลของการพยาบาลระบบสนับสนุนและให้ความรู้ต่อพฤติกรรมของผู้ดูแลหลักในการดูแลผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหันและการเกิดภาวะเขียวกะทันหัน (EFFECTS OF A SUPPORTIVE-EDUCATIVE NURSING SYSTEM ON PRIMARY CAREGIVER BEHAVIOR IN CARING FOR CHILDREN WITH CYANOTIC HEART DISEASE AT RISK OF CYANOTIC SPELLS AND THE OCCURRENCE OF CYANOTIC SPELLS)

อรจิรา เทียนน้ำเงิน 4436604 RAPN/M

พย.ม. (การพยาบาลเด็ก)

คณะกรรมการควบคุมวิทยานิพนธ์ : เรณู พุกบุญมี, D.N.S., ไพโรจน์ โชติวิทยธารากร, M.D.

บทคัดย่อ

การวิจัยก่อนทดลองแบบวัดซ้ำในกลุ่มเดียวกันนี้ มีวัตถุประสงค์เพื่อศึกษาถึงผลของการพยาบาลระบบสนับสนุนและให้ความรู้ต่อพฤติกรรมของผู้ดูแลหลักในการดูแลผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหันและการเกิดภาวะเขียวกะทันหัน โดยใช้ทฤษฎีระบบการพยาบาลของโอเร็มเป็นแนวทางในการศึกษา กลุ่มตัวอย่างเป็นผู้ดูแลหลักที่ดูแลผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหันซึ่งมารับการรักษาที่แผนกผู้ป่วยนอกเด็กโรคหัวใจ โรคพยาบาลจุฬาลงกรณ์สภากาชาดไทย ระหว่างเดือน มกราคม ถึง มิถุนายน 2546 คัดเลือกกลุ่มตัวอย่างแบบเฉพาะเจาะจงตามคุณสมบัติที่กำหนด จำนวน 30 ราย โดยผู้วิจัยวัดพฤติกรรมการดูแลของผู้ดูแลหลักด้วยแบบสอบถามเกี่ยวกับพฤติกรรมการดูแลผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหันที่ผู้วิจัยสร้างขึ้นโดยใช้ทฤษฎีการดูแลตนเองของโอเร็มและความรู้ทางการแพทย์เกี่ยวกับภาวะเขียวกะทันหันเป็นพื้นฐาน และใช้แบบประเมินการเกิดภาวะเขียวกะทันหันที่ผู้วิจัยสร้างขึ้นเพื่อให้ผู้ดูแลบันทึกจำนวนครั้งของการเกิดภาวะเขียวกะทันหันของผู้ป่วยเด็ก วิเคราะห์ข้อมูลด้วยโปรแกรม SPSS/FW โดยใช้สถิติ pair t-test

ผลการวิจัยพบว่าผู้ดูแลมีคะแนนพฤติกรรมการดูแลเด็กสูงขึ้นภายหลังได้รับการพยาบาลระบบสนับสนุนและให้ความรู้อย่างมีนัยสำคัญทางสถิติ ($p<.01$) และผู้ป่วยเด็กมีจำนวนการเกิดภาวะเขียวกะทันหันลดลงอย่างมีนัยสำคัญทางสถิติ($p<.05$) ผลการวิจัยได้แสดงให้เห็นถึงประสิทธิภาพของการพยาบาลระบบสนับสนุนและให้ความรู้ต่อพฤติกรรมการดูแลเด็กที่เหมาะสมของผู้ดูแลและลดการเกิดภาวะเขียวกะทันหันในผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน ดังนั้นจึงเป็นระบบการพยาบาลที่มีประสิทธิภาพและทีมสุขภาพสามารถนำไปใช้ในการดูแลผู้ป่วยเด็กกลุ่มนี้ต่อไป.

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INTRODUCTION

Background and Significance of the Study

Congenital heart disease is the most common congenital anormalies in children. (Boonchob Pongpanich, B.E.2542: 23). Congenital heart disease is a chronic illness, and it needs continuous caring in the long term. About 50% of the newborn with congenital heart disease have the symptoms in the first year of life, and they have to be cured. The incidence of congenital heart disease is about 7.4 in 1,000 newborn infants (Hoffman, 1990 cited by Wong, 1991: 1593). In The United States of America, 31% of children younger than eighteen years have a chronic illness, and two-thirds of the children with a chronic illness have congenital heart disease. In Thailand, the incidence of congenital heart disease is about 7.4 in 1,000 newborn infants (Jul Tisayakorn, 1999: 233).

Cyanotic heart disease accounts for 18% of congenital heart disease. Thailand has about 1 million newborn infants each year, and 1,200 of them suffer from cyanotic heart disease. They have to be referred to hospitals which have cardiologists, and each of these hospitals has to take care of up to 120 of the children with cyanotic heart disease in a year. (Pantonglaptavee, et al., 1992: 183-190). The symptoms of cyanotic congenital heart disease are more severe than those with acyanotic heart disease. Severe cyanosis, heart attack, or a combination of both are the main causes of death. Therefore, they need surgical correction. However, most children have to wait for a long time for an operation. So, these children need special care (Pantonglaptavee, et al.,1992: 183-190; Pongpanich, et al., 1996: 62-65; Laohaprasitiporn, et al., 1999: 23-82).

Hypoxic spells or cyanotic spells are the most common critical problems in the cardiovascular system. It results in an inadequate blood flow to the lungs. Cyanotic spells mostly occur in the Tetralogy of Fallot, a type of cyanotic heart disease. The symptoms include restlessness, crying, cyanosis, hyperpnea, unconsciousness and seizures. The severity of symptoms may occasionally lead to death (Tanarat Layarngkoon, B.E.2539: 237). These symptoms usually resolve spontaneously. The symptoms may last for 15-30 minutes. The frequency of the occurrence of cyanotic spells is varied. As an illustration, some children may experience cyanotic spells once a day while others may suffer once every fortnight (Jul Tisayakorn, B.E.2542: 237). Although, there is no ratio of the occurrence of cyanotic spells, it can affect the growth, development and the lives of children. Moreover, if children do not receive the appropriate care when cyanotic spells occur, the symptoms may be aggravated and they may eventually die (Duangmanee Laohaprasittiporn, B.E. 2540: 234).

The mechanism of cyanotic spells begins with a sudden decrease of the blood volume to the lungs. Subsequently, the blood volume from the right ventricle will be shunted to the left ventricle through the septal defect. As a result, the patients will appear very blue due to a lack of oxygen (Gevitz & Vetter, 1993: 567-572). A primary cause of cyanotic spells is pathology, and many researchers are paying great attention to the factors that trigger the occurrence of cyanotic spells. Sun et al. (1997: 6-12) found that there is a positive correlation between children's excitement, activities, and cryng and the onset of cyanotic spells. This finding suggests that several factors can trigger the occurrence of cyanotic spells. Consequently, these children are in great need of total care that minimizes these aggravating factors. Since the care given to these children is an important issue, we need to ascertain that children receive appropriate care.

According to Orem's Nursing Theory, there are three significant elements which are the theory of self-care, theory of self-care deficit, and theory of nursing system. The self- care theory is the main theory that serves as a guideline for giving complete care. It describes the essential care needed for appropriate self-care, to the stage of development, and the essential self-care need when health is deviated (Orem, 2001: 284- 286), and the concerns that all self-care needs have to met. Under normal circumstances, adults care for themselves, whereas infants, the elderly, the ill and the disabled require assistance with self-care activities. Infants and children are in an early stage of development (Orem, 1991

cited by Somjit Hanucharoenkul, B.E.2540: 23). In particular, children with cyanotic heart disease at risk of cyanotic spells cannot fully perform self-care activities when cyanotic spells occur. With the constraint of children being at a developmental stage, their parents or other family members, who act as primary caregivers, have an important role in taking care of these children. They also act as dependent care agents (Orem, 1995: 242).

According to the review of related literature concerning self-care of children with congenital heart disease, Nilawan Taweekun (B.E.2539: 56-58) stated that the caregivers of children with congenital heart disease have a high level of knowledge regarding have a good medication and approach to deal with the children when their symptoms occur. Nevertheless, they lack knowledge regarding the prevention of complications and oral hygiene. According to Clare (1985: 218), the mothers of children with congenital heart disease fail to take good care of their children in the aspects of growth and development. In addition, they do not know how to take care of children when the symptoms arise. Thus, inappropriate care has an adverse effect on these children. Their symptoms will be aggravated and other complications may occur. These can lead to mortality. In general, primary caregivers such as fathers and mothers need to perform various activities to maintain their children's health. Consequently, the primary caregivers should understand children's illness in order to provide appropriate care.

From the researcher's experience, it was found that there are a great number of children waiting for surgery. Nevertheless, the primary caregivers do not fully recognize the symptoms, the prevention, and how they can help their children when cyanotic spells occur. Despite the fact that they have been informed about these issues by doctors and nurses, they fail to fully understand the total care needed. In addition, the caregivers of these children fail to demonstrate their abilities related to the self-care needs of the children, so they can be regarded as dependent self-care deficit (Orem, 1995). In other words, these primary caregivers have inappropriate child care behavior.

Cyanotic spells result from the pathology of the disease associated with other factors. The statistics of children with heart diseases at King Chulalongkorn Memorial Hospital, Thai Red Cross Society, from January 1999 to October 2002, showed that five to seven cases of children with cyanotic heart disease at risk of cyanotic spells needed to be admitted to the cardiac ward or the intensive care unit per year. Some of them needed emergency surgery. Moreover, a few of them died from their cyanotic spells.

Therefore, cyanotic spells remain problematic and depend on the appropriate behavior of primary caregivers to decrease the factors causing it. Consequently, nursing practice becomes vital in assisting and providing a supportive-educative nursing system which is one of the nursing systems based on Orem's Nursing Theory. Primary caregivers are provided with assistance. Nurses will give knowledge, guidance, support, and provide the environment to facilitate caregivers to give adequate, appropriate, and continuous care to the children (Somjit Hanucharoenkul, B.E.2536: 232-233). The nursing system will serve as a guideline for caregivers to have appropriate behaviors when taking care of children with cyanotic heart disease at risk of cyanotic spells.

The Conceptual Framework of the Study

This research was based on a conceptual framework utilizing a combination of Orem's Nursing Theory which includes

1. Theory of self-care
2. Theory of self-care deficit
3. Theory of a nursing system

and the medical knowledge about cyanotic heart disease and cyanotic spells.

Self-care is the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being. Self-care is a deliberate action that should lead to further insights about deliberate action and about the development and exercise of self-care agency (Somjit Hanucharoenkul, B.E.2536: 22-23, Orem, 1995: 104-228). The aspects of self-care are therapeutic self–care demands (Orem, 1995: 120-121).

Cyanotic heart disease in children is a chronic illness. Children do not have sufficient ability to meet their therapeutic self-care demands, which may be influenced by certain conditioning factors (i.e., age, developmental state, pathology, and complications). These basic conditioning factors result in self-care requisites for therapeutic self care demands. So, they must depend on their fathers, mothers, or members of the family. Orem called these people as dependent care agents. Dependent care agency is the ability to perform action to respond to therapeutic self-care demand and it is need more than normal children because of cyanotic spells.

Therapeutic self care demand of children with cyanotic heart disease at risk of cyanotic spells;

1. Universal self-care requisites means the caregivers' practice which serves the children's basic physical needs and comfort. Great emphasis is placed on minimizing factors which trigger cyanotic spells

2. Developmental self-care requisites means care which corresponds with the developmental stage. Caregivers need to promote children's normal growth, development, and prevent illness.

3. Health deviation self-care requisites refers to the practice which aims to control the symptoms and prevent complications resulting from cyanotic spells. The practice includes seeking and maintaining assistance from health team members or providers, paying attention to the pathology of the disease, compliance to medical management, knowing how to prevent discomfort, and minimizing factors that trigger continuous cyanotic spells.

These elements of self-care are essential to caring for children with cyanotic heart disease at risk of cyanotic spells for therapeutic self-care demands and dependent care agency. Dependent care agency is like self-care. (Orem, 1995: 229, 242-243; Taylor, 1989: 134). It consists of self-care agency which has the capabilities for self-care operation, and a power component, enabling capabilities for self care and foundational capabilities and disposition. If caregivers can not take an action or have an inappropriate and insufficient action, it means the caregivers have a self-care deficiency.

Moreover, according to Orem, self-care is a deliberate action and goal oriented, and it consists of two stages. The two stages of self-care are: 1) the stage of considering action and 2) the stage of actions and outcomes. The first stage shows that the knowledge of self-care and the environment with the belief of action brings on self-care. So, self-care requires knowledge about events, observation, their meaning, and the relationship of events with action. Consequently, they will determine action. The second stage shows that the goal is important to the action of self-care, because the goal is the main focus of action and the criteria to follow outcome (Orem, 1985 cited by Somjit Hanucharoenkul, B.E.2540: 23-25). A supportive-educative nursing system is appropriate to promote the agency of caregivers. Primary caregivers are provided with assistance. Nurses will give knowledge, guidance, support, and provide the environment to facilitate the caregivers to

give the appropriate and continuous care to the children (Somjit Hanucharoenkul, B.E.2536: 232-233). Thus, it may reduce the self-care deficiency and promote appropriate behaviors for taking care of children with cyanotic heart disease at risk of cyanotic spells. However, appropriate behaviors of caregivers depend on the relationship between nurses, patients, and caregivers (Somjit Hanucharoenkul, B.E.2536: 232-233; Orem, 1995: 310-313). When the caregivers have appropriate behaviors, it will promote the control of cyanotic spells and reduce the occurrence of cyanotic spells.

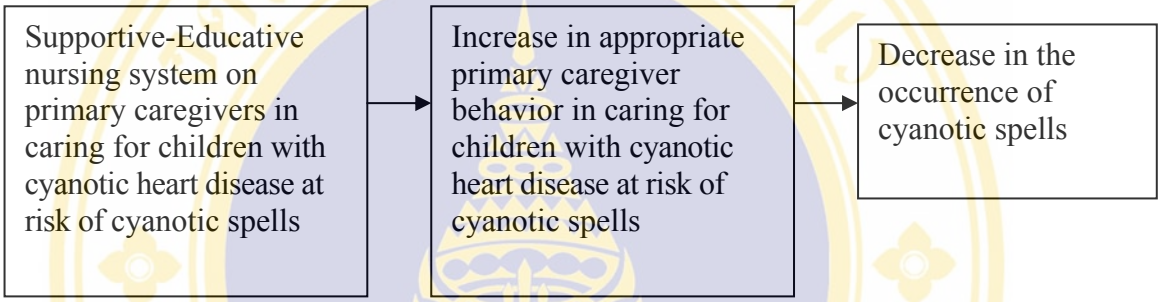

Figure I : The conceptual framework of this study

Research Questions

1. Is the supportive-educative nursing system able to promote primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells ?

2. Is the supportive-educative nursing system able to decrease the occurrence of the cyanotic spells in children with cyanotic heart disease at risk of cyanotic spells ?

The purposes of this study

1. To promote the behaviors of primary caregivers who take care for children with cyanotic heart disease at risk of cyanotic spells by giving a supportive-educative nursing system.

2. To decrease the occurrence of cyanotic spells by giving a supportive-educative nursing system to primary caregivers.

Hypotheses

1. The post-test scores of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells was higher than the pre-test scores.

2. The frequency of the occurrence of cyanotic spells after primary caregivers receive the supportive-educative nursing system was lower than or equal to the frequency of the occurrence of cyanotic spells before receiving supportive-educative nursing system.

The scope of this study

This research aimed to study the effects of a supportive-educative nursing system on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and the occurrence of cyanotic spells. The subjects of this study were 30 primary caregivers of children with cyanotic heart disease at risk of cyanotic spells. These children were two to six years old and were undergoing treatment at the Pediatric Cardiology Clinic, Department of Pediatrics, King Chulalongkorn Memorial Hospital, Thai Red Cross Society, from January to June 2003.

Basic Assumptions

1. Primary caregivers of children with congenital heart disease can learn and improve themselves.

2. Primary caregivers of children with congenital heart disease received training for assessment the occurrence of cyanotic spells, so the data from the assessment form of cyanotic spells are reliable.

Expected Outcomes and Benefits of the Study

1. To be a guideline for nurses in using the supportive-educative nursing system in their nursing care plans to develop capabilities of the primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells.

2. To be a guideline for conducting nursing research to promote self-care among sick children and other caregivers.

3. To be a guideline for nursing practice based on Orem's Nursing Theory, which it can also promote professional advancement.

4. To be a guideline for developing and promoting the nurses' roles in giving nursing care to children with cyanotic heart disease at risk of cyanotic spells.

Definition of terms

Supportive-Educative nursing system refers to the nursing activities which aim to enhance the effectiveness of the care given to children with cyanotic heart disease at risk of cyanotic spells. The researcher designed the activities based on Orem's Nursing Theory. A supportive-educative nursing system gives a framework for teaching, guiding, supporting, and managing environmental conditions, as described below:

A. Teaching is aimed at developing the dependent-care agency of primary caregivers by giving knowledge of cyanotic spells (definition, cause, signs and symptoms, the results of cyanotic spells and self-care practices). The researcher gives information to primary caregivers based on the instruction plan about cyanotic spells for primary caregivers.

B. Guiding is the encouraging part that can enable primary caregivers to make their own decisions concerning the children's care. Nurses provide suggestions and alternative practices to primary caregivers; then they assess these choices through talking and discussing and make decisions on what is suitable for them and their children.

C. Supporting is the promotion to maintain the primary caregivers effect on the performance of activity for the children's care by the creation of relationships among the nurses, primary caregivers and the children and the families, and enhancing morale by touching, words, and sympathetic expressions. This will make primary caregivers believe and trust which will enhance than in caring for children with cyanotic heart disease at risk of cyanotic spells.

D. Managing environment conditions is a means to promote dependent-care agency by encouraging to primary caregivers in sharing and exchanging their experiences or opening a venue to have a closure relationship with doctors and nurses to express themselves and ask their questions and to provide rooming-in between primary caregivers and children.

Primary caregiver behavior refers to the primary caregiver behaviors in caring for children with cyanotic heart disease at risk of cyanotic spells related to the self-care needed. These behaviors were assessed by using the questionnaire. The researcher developed this questionnaire based on Orem's Self-Care Theory (Orem, 1991) and it included;

1. Primary caregiver behavior that specifically aim to respond to the universal self-care requisites in caring for children with cyanotic heart disease at risk of cyanotic spells

2. Primary caregiver behavior that specifically aim to respond to the developmental self-care requisites in caring for children with cyanotic heart disease at risk of cyanotic spells

3. Primary caregiver behavior that specifically aim to respond to the health deviation self-care requisites in caring for children with cyanotic heart disease at risk of cyanotic spells

The questionnaire was composed of questions which covered ten aspects as follows: (1) anemia (2) preventing hyperviscosity (3) rest, activities, and interaction (4) preventing constipation (5) relieving fever (6) preventing infection (7) taking medicines (8) assessing cyanotic spells (9) assistance when cyanotic spells occur and (10) regular follow – up.

When considering the scores obtained from the questionnaire, higher scores indicate higher appropriate behaviors.

The occurrence of cyanotic spells refers to the frequency of the occurrence of cyanotic spells on children with cyanotic heart disease at risk of cyanotic spells, which were assessed and recorded by primary caregivers. The assessment form was developed by the researcher. There were 5 items in the criteria which covered a wide range of symptoms. They were constructed to give information about all of the related signs and symtoms of cyanotic spells. These items consist of 1) crying with or without restlessness, 2) hyperpnea, 3) sudden severe cyanosis, 4) unconsciousness, and 5) seizures. Based on the criteria, children will appear severely blue around the lips and under the fingernails whenever the cyanotic spells occur. Other symptoms included in the assessment form

may also be present. Therefore, the criteria of assessment were sudden severe cyanosis or sudden severe cyanosis with the other signs from the assessment form of cyanotic spells.

Pre-test score refers to an assessment of primary caregivers' behaviors and the occurrence of cyanotic spells in the pre-intervention period. Primary caregivers' behaviors were assessed by the researcher at 8th week , and the questionnaire about primary caregiver behavior in caring for children with cyanotic spells was the instrument for assessment. The occurrence of cyanotic spells were assessed by primary caregivers. They received training about assessment from signs and symptoms of cyanotic spells and recorded them by the assessment form of cyanotic spells on the 1st day of the pre-intervention period. After that, the primary caregivers assessed and recorded the occurrence of cyanotic spells from 1 to 8 weeks.

Post-test score refers to an assessment of primary caregiver behavior and the occurrence of cyanotic spells in the post-intervention period. The researcher assessed primary caregiver behavior by the same questionnaire at the 16th week. The occurrence of cyanotic spells were assessed and the occurrence of cyanotic spells were recorded by primary caregivers from 9 to 16 weeks.

CHAPTER II
LITERATURE REVIEW

The purpose of this study was to study the effects of a supportive-educative nursing system on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and the occurrence of cyanotic spells. The researcher reviewed related literature and existing studies based on the following topics:

1. Cyanotic heart disease and cyanotic spells in children
2. Primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and related factors
3. Supportive-educative nursing systems

Cyanotic heart disease and Cyanotic spells in children

Congenital cardiac defects are the most common category of structural malformation, occurring in a little less than 1% of live births. The congenital defects are usually divided in to cyanotic and acyanotic lesions, with the acyanotic lesion further divided into those with left-to-right shunts and those with pressure overload without intracardiac shunting. The term right-to-left shunting is usually applied to cyanotic lesions, when desaturated blood from the systemic venous circulation enters the systemic arterial circulation without oxygenating in the lungs (Gewitz, 1995: 145).

Cyanotic spells or hypoxic spells, anoxic spells, hyperpnea, paroxysmal hyperpnea, cyanotic attack, syncopal attack, and tet spell, are the most common serious problems in the cyanotic heart disease. Cyanotic spells may occur with those cardiac defects in which there is pulmonary stenosis or atresia in combination with an intracardiac communication (Garson et al.,1990: 673). Mostly they occur in the Tetralogy of Fallot (Park, 2002: 115). Moreover, the cyanotic spells may be found in the severe cyanosis, and they are tricuspid atresia, transposition of great arteries with pulmonary stenosis, Eisenmenger's syndrome (Gessner & Victorica,1993: 101).

Cyanotic spells begin with a sudden decrease of the blood volume to the lungs. Subsequently the blood volume from the right ventricle will be shunted to the left one through the septal defect. As a result, the patient will appear very blue and hypoxemia will occur due to metabolic acidosis. The body compensate by hyperpnea and ventilation to decrease carbondioxide (Chang et al.,1998: 257). As a result, the patients have sudden brain anoxia, and cyanotic spells mostly occur and are associated with crying, eating, sucking, play and exercise, or elimination (Chumpol Wongprateep, B.E.2535: 310; Wanida Senasuttipan,1995: 310). Precipitating causes include bowel movements, crying with hunger, or medical intervention (Fyler, 1992: 75). In addition, the other factors of cyanotic spells, include consecutive coughing, physical hurt and stress (Jul Tisayakorn, B.E.2542: 237), and the cyanotic spells more commonly occur in the morning but may occur during the day, especially following a nap when systemic resistance is low (Garson et al., 1990: 1079). The symptoms include restlessness, crying, blueness, hyperpnea, and exchange with stopped breathing. This state usually resolves spontaneously after 1 to 5 minutes or it may last for 20 to 30 minutes, and the long-duration spells may end in death (Garson et al., 1990: 673). The hypoxemia can be severe enough to result in an altered mental status and even death (Moller & Hoffman, 2002: 394). A severe spell may lead to limpness, convulsion, or cerebrovascular accident (Park, 2002: 193).

Cyanotic spells may occur especially during the first two years of life (Gewitz, 1995: 180). The frequency of the occurrence of cyanotic spells is varied. For example, some children may experience cyanotic spells once a day, while others may suffer once every fortnight (Jul Tisayakorn, B.E.2539: 705). These symptoms usually resolve spontaneously, for the patient who has few symptoms. If the children do not receive the appropriate care when cyanotic spells occurs, the symptoms may aggravate. They may develop severe spells, unconsciousness may be prolonged and lead to convulsions, hemiparesis, or even death (Gewitz, 1995: 180). Also, the patients can have brain death, a complication from severe cyanotic spells (Jul Tisayakorn, B.E.2539: 705). The mechanism of cyanotic spells begins with an increase in catecholamine. Thus, the heart is pumping, the pulmonic infundibulum under the pulmonic valve is contracted, and the blood volume of the right ventricle to the lungs is decreased and the pressure increases. Subsequently, the blood volume from the right ventricle will be shunted to the left one through the septal defect.

As a result, the oxygen saturated in the artery is decreased, and the patients have hypoxia and metabolic acidosis, so the breathing increases to speed up respiration. As the resistance of the blood circulation system is suddenly decreased, the venous blood flow to the right atrium increases and leads to the rapid increase of venous blood flow to the right atrium and the rapid increase of oxygen consumption in the muscle. This causes the patients to develop cyanosis and hypoxia (Chumpol Wongprateep, B.E.2535: 310; Wanida Senasuttipun, 1995: 310). The mechanics of cyanotic spells can be summarized that when the infundibulum of the right ventricle is pressed, hyperventilation, tachycardia and the variance of sensitizations on respiratory center occur. However, the cause of the occurrence of cyanotic spells is varied by one cause or more as to shown in figure I.

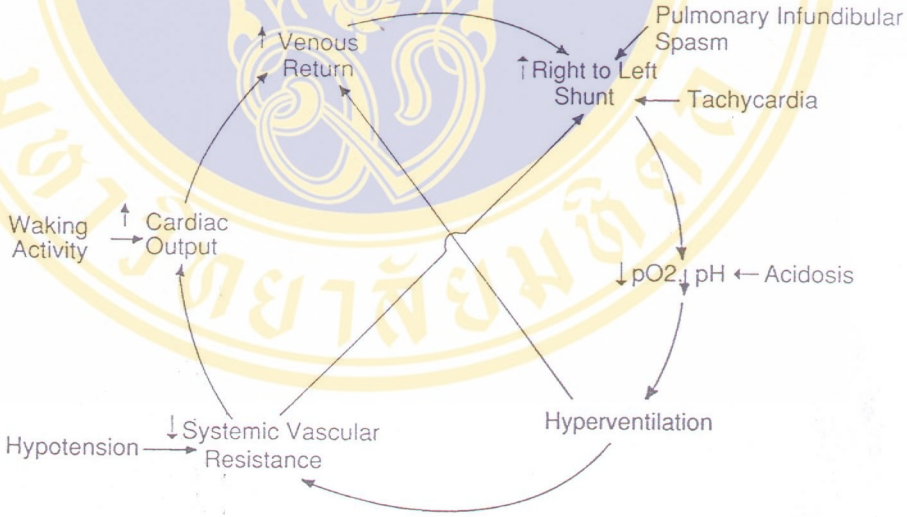

Figure I: the mechanism of the occurrence of cyanotic spells.

(Jul Tisayakorn, B.E.2539)

Care for prevention of cyanotic spells occurrence, and care during emergency cyanotic spells

Cyanotic spells can be treated, and it depends on the level of severity, especially when it does not accompany diagnoses i.e febrile convulsion, epilepsy, cerebrovascular accidents, brain abscess, Adam-Strokes attacks, breath holding spells, or heart failure (Duangmanee Laohaprasittiporn, B.E.2540: 234). Propranolol is the medicine used to prevent and treat; a beta adrenergic blocking agent group, and it acts to decrease stenosis of infundibulum at the right ventricle. As a result, it increase the blood volume to the lungs. In addition, propranolol acts to decrease the heart rate and increase systemic vascular resistance and decrease hyperpnea, so the blood volume from the right ventricle will be shunted to the left one through the septal defect when the patients have the occurrence of cyanotic spells. In emergency care 1) the patients are prepared into the knee chest position to increase systemic vascular resistance and decrease systemic vascular return 2) oxygen therapy is given 3) the restless patients would have morphine, which decreases deep breathing and blood volume to the heart, so it decreases the blood volume from the right ventricle to the left ventricle by shunt 4) If the patients have continuous cyanotic spells, they would have Sodium bicarbonate 1-2 mEq./kg., which is diluted and given to veins and arteries for correction of metabolic acidosis 5) the propranolol is increased in concentration to 0.1-0.2 mg/kg. 6) The medicine is given to increase blood pressure 7) If the symptoms persist for longer than two to three hours, the patient would need shunt surgery. The prevention of the occurrence of the cyanotic spells includes taking propranolol at 1-4 mg/kg./day and keeping Haematocrit between 60-65%. If the patients have anemia, they would have iron diet and iron medicine. (Jul Tisayakorn, B.E. 2536: 92-93; Chumpol Wongprateep, B.E. 2535: 310-311; Doungmanee Laohaprasittiporn, B.E. 2534: 7-9). However, the most effective position for these children is to be held by a parent over the shoulder, with knees bent or in the knee chest position (Chang et al.,1998: 257). Moreover, Increasing factors of support during the occurrence of cyanotic spells is the main point, and the factors are the varied states i.e. fever, to have a fever.

These factors decrease systemic vascular resistance and change the balance of blood volume from the ventricles, so the blood volume is pressed, and the blood volume to the lungs is decreased. Dehydration from diarrhea, vomiting and fever are other factors

to decrease intravascular volume, intracardiac volume, and stroke volume, while decreasing blood volume to the lungs because the narrow right ventricular cause of the out flow tract, tachycardia, and increased press out. Moreover, anemia and polycythemia are the factors causing hypoxia (Tanarat layangkoon, B.E. 2539: 277). Polycythemia is a normal physiological response to hypoxemia, and in severely cyanotic infants and young children hemoglobin levels may exceed 20 g/dl. and hematocrit levels may exceed 65 to 70%. The viscosity of blood increases rapidly above a haematocrit of 65%, so this may develop severe cerebral anoxia (Moller & Neal, 1990: 652-653). After that, many researcher pay attention to the factor of facilitators in the occurrence of cyanotic spells i.e.

Sun et al. (1997) studied the occurrence of cyanotic spells in children with Tetralogy of Fallot. The study showed that the patients who received Beta-adrenergic receptor (Beta AR) blocking agent had decreased the severity and rate of the occurrence of the cyanotic spells. In addition, it was found that excitement, crying or high activity increased the occurrence of cyanotic spells because the Beta-adrenergic receptor was increased. It was also found that after the experiment, the levels of Beta 1 and Bata 2 were not significant but the cyanotic group had increased Beta AR, so Beta AR stimulated adenylyl cyclase. As a result, the infundibulum was very pressed, becoming the cause of the cyanotic spells.

Takahata et al. (1990) studied five children with Tetralogy of Fallot from 48 children. These patients had the occurrence of cyanotic spells during the operation, and one patient had mutual pulmonary atresia, the experience of cyanotic spells and propranolol therapy. Moreover, they did not have the experience of cyanotic spells and propranolol in the pre-operation period. However, all patients had the occurrence of cyanotic spells during operations, so propranolol was an important medication in the pre-operation level.

Kaulitz et al. (2000) studied the occurrence of the cyanotic spells with a diameter of Pulmonary artery and Pulmonary valve in 62 patients. The subjects were divided in two groups, 37 patients having the experience of cyanotic spells and 24 patients not having the experience of cyanotic spells. The diameters of pulmonary artery and pulmonary valve were not different by echocardiography, so this study supported the occurrence of cyanotic spells from other factors except pathophysiology.

From these studies, it could be seen that the main point is to perform self-care to prevent the occurrence of the cyanotic spells by decreasing factors of cyanotic spells. However, the occurrence of the cyanotic spells could take place and be worsened due to the pathology of the disease, so self-care during cyanotic spells, is also important.

Primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and related factors

In a usual situation, help concerned with self-care activity is really required by infants and children as they are still at the initial stage of growth development, physically, mentally, and socially (Somjit Hanucharoenkul, B.E. 2536: 23; Orem, 1985: 85). Accordingly, children's caretakers must function on caring for their children in order to bring about good health to their children. Interestingly, a definition of the term "care" is given in various aspects as follows:

Blatner (1981: 10) explained that "care" is a process of interaction between a provider and a recipient when they agree to build up the prosperity, satisfaction in their lives, and lift up their healthiness with a special aim to able to perfectly respond to their needs.

Leininger (1987: 9) defined "care" as a kind of activity which mainly deals with a provision of help, support, and facilitation to the individual or groups or a search for whatever their needs are with a special aim to create or improve the human being's way of life and other conditions.

According to Orem (1991: 361-362), the care for dependent persons refers to various activities initiated by anyone who is adult. Therefore, adults really pay special attention to carry out those activities for the ones who are under their responsibility with the aim to save or maintain their lives, as well as to promote better health and security.

According to all the definitions mentioned above, only the focal point of health care behavior is drawn out as it implies the extent of practices for helping, supporting, promoting, and maintaining the individual's life, health, and security.

Orem is broadly accepted as a leader who first introduced a self-care concept to be applied for the development of nursing practice. She has made a strong effort to upgrade this concept to be one of the nursing theories called "Orem's General Theory of Nursing" comprising of the three sub-theories with the presence of their mutual association (Orem, 2001: 141). The concept of dependent care agency is in the process of formalization. Like self-care agency, its broad conceptual structure is formed by capabilities to perform estimative, transitional, and productive operations in knowing and meeting the therapeutic self-care demands of another (or components thereof) (Orem, 2001: 284), including the children who do not have self-care agency, and who are taken care of by adults (Orem, 1991: 361). Thus, the caregivers have enabling power components specific to the operation as the operation is related to knowing and meeting components of the other's therapeutic self-care demand (Orem, 2001: 284). In this study, the caregivers must understand about therapeutic self-care demands of children with cyanotic heart disease at risk of cyanotic spells.

Therapeutic self-care demands of children with cyanotic heart disease at risk of cyanotic spells

Therapeutic self-care demands means all self-care activities which must be carried out at a period of time by each individual in order to respond to his/her need in self-care requisites. Three aspects of self-care need are classified on the basis of health status and the developmental stage (Somjit Hanucharoenkul, B.E. 2540: 27 – 31; Orem, 2001: 224 – 235):

1. Universal Self-Care Requisites refers to the care for individuals which is distinctively involved with promoting and maintaining individuals' health and security. This is considered as an essential element for everybody, but it requires some adjustment to be suitable for all ages, development stages and environments. Those activities are 1) maintaining sufficient air, water, and food 2) maintaining normal excretion and water drainage 3) maintaining a balance between doing exercise and taking rest 4) maintaining

a balance between isolation and interaction with other people 5) preventing dangers that might affect life, duty, and security and 6) providing promotion for doing a duty and development in the extreme under a social system and self-competency.

2. Developmental Self-Care Requisites refers to the care for individuals according to each stage of the development process dealing with human lives including other concerned developments of available living conditions that could help to support the whole living process and development. This enables individuals to promote their progress to maturity from the stages of living in the womb, delivery, being infants, babies, teenagers, adults and aging, as well as prevention of losses during their development. Also it involves coping with stress or any obstacles derived when facing different situations such as lack of education, problems related to social adaptation, loss of loved ones, illness, injury, disability, changes caused by life events, terminal stages of illness, and eventual death.

3. Health Deviation Self-Care Requisites refers to the care for individuals when there is any malfunction of their body, disability, or diagnosis. Those activities are comprised of 1) seeking or maintaining help received from any health personnel 2) perceiving and being interested in the danger and losses that might occur when getting sick 3) following the treatment plan, diagnosis, and doing the rehabilitation and prevention of any existing pathologies effectively 4) realizing and paying attention to all unhappiness or side effects of illness and then adjusting to them 5) adjusting self-perspective and self-image to become able to ask for help with their own health status and requisites for help from the health service system and 6) learning to live with the pathological effects or the existing situation including the result of diagnosis and treatment. Their living pattern must help to promote their self-development under the limitation of their remaining ability.

As mentioned earlier, children are still unable to fully perform self-care due to a limitation of growth and level of development, especially children with cyanotic heart disease at risk of cyanotic spells who mostly require special assistance for self-care practice because it is a chronic illness with the risk of complications. As a result, primary caregivers are accountable as the most significant persons who are playing the role of helper or caregivers of their children by using different approaches such as controlling, caring, guiding, and training their children till they are able to carry out most of the self-

care activities themselves. However, this must be in accordance with the capability of each child and each specific age. These are accepted as very helpful in promoting health survival and security of the children (Somjit Hanucharoenkul, B.E. 2540: 23). Certainly, primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells need to be intentionally initiated as primary caregivers under a systematic approach such as learning to realize only meaningful things for their children. When all the needs of children with cyanotic heart disease at risk of cyanotic spells are responded to, harmful complications and recurrence of sickness can be prevented. There are three major aspects of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells as follows :

1. Universal Self-Care Requisites for primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells

1.1 Caring for sufficient oxygen, food, and drinking water

1.2 Caring for normal excretion and water drainage

1.3 Caring by producing a balance between doing exercise and taking rest including personal activities and interaction with other persons by consideration their age

1.4 Caring for prevention of dangers to their lives, duties, and security.

2. Developmental Self-Care Requisites for primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells

3. Health Deviation Self-Care Requisites for primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells

3.1 Seeking or maintaining help received from healthcare teams such as medical doctor, nurses or health officials.

3.2 Realizing, paying attention to and considering the extent of pathological effects

3.3 Realizing and paying attention to the treatment plan, rehabilitation and prevention of further complications.

All the three aspects of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells are important.

1. Universal self-care requisites for primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells

1.1 The maintenance of a sufficient intake of food, water, and air for the children with cyanotic heart disease at risk of cyanotic spells. Food is very important for children with congenital heart disease because a complete variety of food intake with adequate quality is necessary. Children should be fed with iron-rich food in order to prevent anemia which causes inadequate oxygen to the body tissue (Duangmanee Laohaprasittipon, B.E.2540: 8). The children 0-1 year old should have iron 6-10 mg./kg./d., 1-10 years old should have iron 10 mg./kg./d., and older than 10 years old should have iron 12-15 mg./kg./d. Food high in iron, such as, meat, liver, milk, egg yolk, beans etc. should be given to infants and pre-schoolers, and they need high iron-milk. Moreover, the body needs adequate vitamin C to absorb iron in the small intestine, so food rich in vitamin C such as orange, lemon, tomato, pineapple and cauliflower should be eaten. The children 0-1 year old should have 30-35 mg./day, 1-10 years olds should have 40-45 mg./day and those older than 11 years old should have 50 mg./day (Sungkom Jongpipatwanit, B.E. 2539: 604).

Milk feeding of babies and between meal feeding are a cause of high catabolism and high need of oxygen (Caddel, 1989: 750 – 777), so the children should have a small meal with a duration of about 30 minutes. If bottle feeding is being used, the selection of nipple should carefully done to be not too tender or too hard in order to prevent hard sucking by the children. The nipple hole must not be too small because the children might have to put in an effort. During milk feeding, the children should be held at the high position in order to help the children suck and swallow easily, and after feeding, the children should be rested (Suttilak Tungkulboriboon, B.E.2539: 18). Also the children must consume a soft diet, and oral hygiene care is needed (Jul Tisayakorn, B.E. 2542: 233). Congestive cardiac failure is rarely seen in tetralogy of Fallot because the volume load on the heart is usually normal or reduced and the increased right ventricular systolic pressure is well tolerated by the right ventricle of infants or young children (Moller & Neal, 1990: 652-653). As for water intake, an unlimited amount of water is required for children with cyanotic heart disease at risk of cyanotic spells because the appropriate water intake of the children prevents viscosity of blood. It is a cause of cyanotic spells. Primary caregivers should be sure that their children get an adequate quantity of water,

and if they lose water from the body by diarrhea, or vomiting, they need more water for recovery (Park, 1996).

The pathological condition of the disease causes abnormality of the heart function, so they have abnormality of the systemic vascular system. As a result, the blood volume is inadequate and there is low oxygenation in the tissue. Primary caregivers should clean the home to ensure cleanliness and ventilation of the environment. Besides, infection prevention is crucial and patients should avoid close contact with persons with a cold or other infectious diseases. Primary caregivers should not bring the children to a crowded place including supermarkets, theaters, department stores, etc. , because the cyanotic spells can be caused by respiratory infection.

1.2 Caring for normal excretion and water drainage.

Primary caregivers who care for children with cyanotic heart disease at risk of cyanotic spells, need to pay attention to regular excretion, and they should avoid constipation in order to conserve energy and avoid over-straining, a possible cause of cyanotic spells. They should maintain a regular pattern of elimination (Opperman & Cassadra,1998). Another approach that could help the children to have regular excretion is to provide them with food and water such as vegetables, fruits and water i.e. banana, orange, papaya, orange juice, tamarind juice, prune juice, and also motivate exercises (Wanida Senasuttipan, B.E. 2534: 19).

1.3 Caring by producing a balance between doing exercises and taking rest including a balance between personal activities and interaction with other persons

For the children with cyanotic heart disease at risk of cyanotic spells, the pathological condition of the disease causes retarded oxygenation to organs. The children should get rest in order to decrease oxygen consumption. Therefore, children should sleep both day and night as follows (Prakaikeaw Praprettoy, B.E. 2540):

0 – 1	years of age	sleep	14 – 17	hours a day
1 – 3	years of age	sleep	12 – 14	hours a day
over 3	years of age	sleep	8 – 12	hours a day

After the children wake up, the primary caregivers should observe signs of cyanotic spells. Because the cyanotic spells might occur at this period of time, the children had a decrease of systemic vascular resistance in this period (Jul Tisayakorn,

B.E. 2542: 237). Playing and exercise produces personal activities and interaction with other persons, and it motivates creative thinking and imagination (Precha Katetat, B.E. 2527: 295). Primary caregivers should avoid a limitation of activities for the children, and they need to have activities or playing following pathology, with no competition or force i.e. running, climbing, etc. (Doungmanee Laohaprasittiporn, B.E. 2534: 6). Demanding exercise causes an increase in oxygen consumption. As a result, the children have fatigue and cyanotic spells occur. Moreover, the primary caregivers must observe for signs of tiredness during playing or exercise, and they need to stop the activities immediately (Ratchanee Sresawad, B.E. 2520: 44).

1.4 Preventing the occurrence of cyanotic spells from other factors

1.4.1 The children are given Inderal, Propranolol as beta adrenergic blocking agent, to decrease the heart rate and increase peripheral vascular resistance. Moreover, the primary caregivers need to observe side effects of medicines such as bradycardia, or heart failure, cold of peripheral areas or claudication, bronchospasm, semiconciousness, headaches, or hallucination (Jul Tisayakorn, B.E. 2539: 349). If the children get Iron as Fer in sol, Fersolate,or Nutroplex, they should have it right after meals because the side effect is bowel irritation and crying, vomiting, diarrhea (Kampol Sriwattanakul, 2532).

1.4.2 Infection prevention. The pathological condition of the disease causes venous blood in the right ventricle and arterial blood in the left ventricle to go to the aorta because of equal pressure or vicinity leading to right-to-left shunt, so the blood volume is mixed to the aorta, while the partial blood volume does not exchange gas in the lungs. If it does not have it, and it get rid of bacteria, the children can be infected (Sresomboon Musiksukon, B.E. 2543). Infection leads to the the occurrence of fever, resulting in the dilation of arteries, decreased blood vessels, increased cardiac output and increased cardiac input (Tanarat Layangkoon, B.E. 2539: 277). The children with congenital heart disease should have care for the body's cleanliness regularly.

The primary caregivers should take good care of their children's cleanliness by giving them a bath at least two times a day at an appropriate temperature of water because a cold ambient temperature is related to cyanotic spells because of low cardiac output (Gason et al.,1998: 693-694). The primary caregivers should clean their clothes and personal items in order to prevent infection. Having a good oral health care is

also important for the children with congenital heart disease because the infection of dental decay causes the bacteria to circulate in the blood circulation and can cause endocarditis.

Therefore, primary caregivers should take good dental care of their children by having their children brush their teeth at least twice, in the morning and before going to bed, and clean their mouth or brush their teeth after eating in order to get rid of bacteria. In the young children, primary caregivers should do it for them, but in the older children primary caregivers should let them do it regularly and properly. Primary caregivers should also take the children to see the dentist and they must inform the dentist that children are sick with congenital heart disease, so the dentist and can give antibiotic drugs to prevent endocarditis. Prevent infecting by vaccination just the as same as normal children is also needed (Jul Tisayakorn, B.E. 2542: 234).

1.4.3 Avoid continuous crying in the children because it is a factor which promotes the occurrence of cyanotic spells.

2. Developmental self-care requisites for primary caregiver behavior in caring for children

2.1 Maintaining each stage of the development process. Older children, have to realize and participate in a medical plan, and they should practice self-care.

2.2 They must cope with stress from the illness and treatment according to their stage i.e. the older children have knowledge about disease, and practice and follow up include practice similar to normal children (Prissana Suntonchai, B.E. 2535: 9-16).

3. Health deviation self-care requisites for primary caregiver behavior in caring for children

3.1 Seeking and maintaining help from a health care team which includes medical doctors, nurses, and other heath personnel. At the same time, the primary caregivers should be taught about health education or the provided with clarification of suspicions concerning cyanotic spells such as cause of cyanotic spells, symptoms, treatment, and a suitable method to care for children to decrease factors of the occurrence of cyanotic spells and practice when the cyanotic spells occur.

3.1.1 Knee chest position

3.1.2 Oxygen therapy by ventilation and clearance of airway

3.1.3 Immediate request to health personnel if severe symtoms occur and the first occurrence must be examined by doctors for diagnosis and treatment

3.2 Acknowledging and paying attention to the occurrence of cyanotic spells and the treatment plan

3.3 Practicing according to plans for treatment and follow-up including reports on the occurrence of cyanotic spells before follow up

According to the aforementioned care behaviors, it can be seen that caregiving is a distinct action taken by the primary caregiver with the aim to help children with cyanotic heart disease at risk of cyanotic spells to control and prevent the occurrence of cyanotic spells. The primary caregivers need to develop the capabilities for performing estimative and transitional operations of self-care, and these are requirements of a dependent care agency (Orem, 2001: 284-285).

Primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells

Dependent care agency

Dependent care agency is the complex, acquired ability of mature or maturing persons to know and meet some or all of the self-care requisites of children who have health-derived or health-associated limitations of self-care agency (Orem, 1995: 242). The capability of persons who have to be responsible for dependent person, involves not only capability for self-care, but also capabilities to meet the therapeutic self-care demand of another person (Orem, 1995: 229, 242 – 243; Taylor, 1989: 134)

The conceptual structure of dependent care agency consists of three components (Taylor, 1989: 134).

1. Capabilities for self-care operations are the essential and close capabilities for dependent care agency, and the actions are deliberate and goal-oriented.

1.1 Estimative is capabilities for investigation of conditions and factors of self and the environment on dependent care agency for effective regulation.

1.2 Transitional is capabilities to determine which course of self-care should be followed and to decide what to do with respect to self-care.

1.3 Productive is capabilities to perform self-care operations.

2. Ten power components of dependent care.

2.1 Ability to maintain attention and exercise requisite vigilance with respect to self as self-care agent and internal and external conditions and factors significant for self-care

2.2 Controlled use of available physical energy that is sufficient for the initiation and continuation of self-care operations

2.3 Ability to control the position of the body and its parts in the execution of the movements required for the initiation and completion of self-care operations

2.4 Ability to reason within a self – care frame of reference

2.5 Motivation (i.e., goal orientation for self-care that is in accord with its characteristics and its meaning for life, health, and well-being)

2.6 Ability to make decisions about care of self and to operationalize these decisions

2.7 Ability to acquire technical knowledge about self-care from authoritative sources, to retain it, and to operationalize it

2.8 A repertoire of cognitive, perceptual, manipulative, communicative, and interpersonal skills adapted to the performance of self-care operations.

2.9 Ability to order discrete self-care action or action systems into the relationships with prior and subsequent actions toward the final achievement of regulatory goals of self-care.

2.10 Ability to consistently perform self-care operations, integrating them with relevant aspects of personal, family, and community living.

3. Foundational capabilities and dispositions. These are capacities for deliberate action and goal-orientation

3.1 ability and skill of knowledge

3.2 sensory motors
3.3 perception
3.4 self value
3.5 characteristics
3.6 determination
3.7 perspective of the individual
3.8 worry of the individual
3.9 acceptance of the individual
3.10 setting of priorities

The three components of capabilities that affect their abilities to engage in self-care or affect the kind and amount of self-care required are named basic conditioning factors. It is the basis of the ten power components of dependent care, and it is the basis of capabilities for self-care operations (Gast, Denyes & Carmbell et al., 1989, cited in Somjit Hanuchareankul, B.E. 2536: 33). Moreover, a specific power component depends on basic conditioning factors of the dependent care agent (Orem, 1991 cited in Somjit Hanucharearnkul, B.E. 2536). In summary, if the persons have an adequate power component, they have capabilities for self-care operation.

Moreover, factors that demand regulatory action and are expressed as self-care requisites are associated with the age and gender of individuals, their developmental and health states, their environments, and their patterns of living (Orem, 1991: 136). These factors include age of primary caregivers, the level of education of primary caregivers, occupation of primary caregivers, income of the family, and the period of time in caring for the children.

Age of primary caregivers

Age is related to dependent care agency because it means related experience and personal maturation. Mature persons have good adjustment to caring for the patients, and dependent care agency increases following age, but it decreases until the period of old age when it begins to decline (Orem, 1991: 239). Hurlock (1980: 271) pointed our that the mothers who have not completed caring for children when they enter old age need to complete caring for children. Markland & Duran (1976: 169) found that the mothers who

care for the children for complete immunization are the old age mothers, as opposed to young age mother. Moreover, Nalawan Taweegan (B.E. 2539: 82) found that age of guardians was related to self-practice of children with congenital heart disease in taking medicine. The study of Aagchareeya Pratumwan (B.E. 2534: i) discovered that the age of mothers had a positive relationship with capabilities in caring for children with acute lymphoblastic leukemia. In addition, the study of Prakit Rachawat (B.E. 2536: 75) found that the age of mothers had a positive relationship with caring for first-year children with or without acute respiratory infection. Finally, the study of Rungtip Weerakul (B.E. 2539: 79) found that the age of mothers was related to maternal behavior in caring for children with thalassemia.

Education

Education is an experience of life, and it involves a thinking process to solve problems. Orem (1985: 175) believes that it is necessary for the development of knowledge, skills, and positive attitudes related to self-care, health, and dependent care agency. In general, the persons with high education would have knowledge and good behaviors leading to more appropriate care when compared to the persons with a lower education who lack opportunity for health education (Janya Suwannatat, B.E. 2527: 838). The persons with high education have a chance to learn about health, so they have appropriate practice based on good decisions, while the persons with low education would have limitations to learn, seek information, and experience health behavior (Pender, 1987: 161-162).

Becker et al (1978: 274) found that the mothers with high education would have better knowledge and pay more attention to the health of children including collaboration in taking medicine to prevent bronchial asthma in children than the mothers with low education. The study of Wallapa Piewtone (B.E. 2527: 108) found that the level of education of mothers had a relationship with participation in taking their school-age children to get immunization. Also, the study of Aagchareeya Pratumwan (B.E. 2534: i) found that duration of study time of caregivers on children with acute lymphoblastic leukemia had a positive relationship with dependent care agency. Finally, the study of Sagawrat Poungchan (B.E. 2538: 58) found that level of education had a positive relationship with capabilities of mothers in caring for children with thalassemia.

Occupation

Primary caregivers have responsibility in caring for children and other members of the family. Moreover, they have household duties and high responsibility. If they have to work outside their house, they have an increased role, and they can easily because tense and tired. The study of Ozer (1993) discovered that the mothers who had many roles suffered effects on the roles of a mother, especially in the families with ill children who needed more care than normal children. The study of Wanida Younyong (B.E. 2538: 37) found that the occupation of mother was related to adjustment in caring for the children with asthma.

Family income

Family income is a resource which is related to dependent care agency (Orem, 1985: 175) because the persons who have high income would have more opportunity than the persons with low income to seek things that benefit health such as nutritional food and public health care (Penderk, 1987: 161 – 162). Morover, the ideas about health and illness of persons with low income would be different form those of persons with high income, so they have different health behavior. For instance, the low income family take children to hospital when the children have a serious illness because they think that the children are ill when they can not move their body or do any activity (Juenker, 1971, cited in Sagaundrat Poungjan, B.E. 2538: 41)

Duration of time in caring for the children

A period of time means experience of primary caregivers with illness. Orem (1985: 120) believes that dependent care agency depends on the experience of persons which may affect their judgment and primary caregiver behavior in caring for the children. In addition, treatment planning and a period of time for caring have an effect on appropriate primary caregiver behavior. From the study of Venters (cited in Sagoundrat Poungjan, B.E.2538: 42), it was discovered that after the children had been diagnosed with chronic illness for about one year, the mothers can perform care and plan the goal for the future. Aagchareeya Pratumwan (B.E. 2534: i) found that the caring period was positively related to dependent care agency of caregivers of children with acute lymphoblastic leukemia

Moreover, there were a number of studies about the factors of primary caregiver behavior in caring for the children with congenital heart disease. For instance, Uboal Asumpinthupya (B.E. 2540: 81) studied the relationship between disease perception, some other factors, and maternal behaviors in caring for children with congenital heart disease, aged 3-6 years. It was found that disease perception, mothers' education, and family income were related to maternal behaviors in caring for children with congenital heart disease.

From the factors related to primary caregiver behavior in caring for the children previously mentioned, it could be concluded that these factors have effects on primary caregiver behavior in caring for the children, so a dependent care deficit always occurs.

Dependent care deficit

Dependent care deficit arises from inadequate dependent care agency to meet the needs of therapeutic self-care demands (Orem, 1995). Therefore, caregivers who cared for children with cyanotic heart disease at risk of cyanotic spells were assessed for dependent care agency relate to therapeutic self-care demands of the children in this study. Through the assessment, caregivers practiced caring for the children to meet the needs of therapeutic self-care demands. If they had appropriate behaviors in caring for children, the children would not have self-care deficit, meaning that the caregivers could perform care for the children. If the caregivers did not practice, or practiced wrongly or inadequately, the caregivers had dependent care deficit, affecting health status, development, and the life of children. Nurses have an important role in helping caregivers decrease dependent care deficit though a supportive-educative nursing system.

Nursing system

Nursing system is an activity, and it results from the capabilities of nurses to balance between self-care practice and therapeutic self-care demand of the patients or clients. It occurs from finding problems or needs in care and practicing to meet the needs of self-care including adjustment and development of the patients for self-care and the caregivers for dependent care agency. The nursing system is a dynamic system following needs and capacities of the patients. (Somjit Hanuchareurnkul, B.E. 2536: 37).

A nursing system consists of three basic variations, and it requires controlled ambulation and manipulative movements (Orem, 1995: 306 – 311).

1. Wholly Compensatory Nursing System is the inability to engage in those self-care actions requiring self-directed and controlled ambulation and manipulative movement. In this system, nurses have responsibility to meet all three types of therapeutic self-care demand.

2. Partly Compensatory Nursing System is appropriate to the patients who can contemplate and decide about self-care, but have limitations from disease, treatment, and lack of knowledge and skill. The method of help follows the capability of patients. Nurses practice some self-care activity for patients, and they develop increased capabilities of self-care.

3. Supportive-educative nursing system is for situations in which the patients, are able to perform or can and should learn to perform required measures of externally or internally oriented therapeutic self-care but can not do so without assistance. Valid helping techniques in these situations include combinations of support, guidance, provision of a developmental environment, and teaching.

Nurses must assess the primary caregivers, who have to develop capability to meet the needs of therapeutic self-care demand. Nurses would have to consider the role of the primary caregivers, who are mostly mothers or fathers, including their responsibilities for the protection of patients. Thus, the supportive-educative nursing system is an appropriate nursing system for child patients and their relatives. The objectives are contributions to the design of a dependent-care system and planning for their operation to respond to their need.

Supportive-educative nursing system

The promotion of patients for cooperation in self-care is a method to develop self-care capabilities of patients. This important method is the participation and exchange of the patients and the nurses about data required for the program of therapeutic self-care demand. This includes, setting the goal for the patients who determine the self-care needed to attain the goal (Somjit Hanucharenkul, B.E. 2537: 315). The method of

promotion is the main point for nurses who help the patients or clients to develop the capabilities of self-care or dependent care agents. According to Orem (1995), the supportive-educative nursing system for primary caregivers consists of teaching or educating, guiding, supporting and establishing an appropriate environment for the family or the dependent care agency for consideration and determination about caring for dependent care agent (Somjit Hanucharoenkul, B.E. 2536: 232 – 233).

Supportive-educative nursing system for primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells

1. Guiding: It is another appropriate method, which should be applied when the primary caregivers have already made a decision to choose one available self-care method and have practiced the self-care activity in caring for their children under the advice and supervision of nurses. Nurses have to provide a chance for the primary caregivers to have interaction, so they could obtain support.

2. Provision of Support: It is an essential method for promoting primary caregivers to be able to practice self-care for children while they are under stress, due to having to live with illness. The support is probaby a speech or action of nurses such as looking, touching, or physical assistance. However, nurses have to choose the most appropriate approach for each situation and each primary caregiver as well. Accordingly, primary caregivers are able to make a strong effort to conduct child self-care activity for children including recollection of past situations, they encountered and decision making. Support is also included as a form of assistance to facilitate the primary caregivers to receive some articles from the social workers who are working for an institute or organization.

3. Arrangement of environment to help the primary caregivers have a chance to develop their self-care capability. This is a motivational method, needed to be delivered to the primary caregivers with the aim of alerting them to set an achievable and proper goal as well as change their behaviors until they can accomplish the desired result. Environment probably refers to development, change of attitute, and value of applying

ability for management of a creative activity, change of vision, and physical development. Nurses have to provide a chance for the primary caregivers to have interaction with other people, so they could obtain advice and support. This method has to accompany other methods such as teaching, etc.

4. Teaching: This is a very appropriate mothod to enchance knowledge and skill of the primary caregivers and is essential in building self-care capability in caring for children. Primary caregivers need to hold to on the principle to increase their sense of dignity and self-esteem in caring for children. Problems sometimes occur when the primary caregivers' attitudes and beliefs are quite different from those of the nurses. However, nurses have to recognize that the primary caregivers are the only one to decide what to do and how to in caring for their children when they go back home. So, they probably need to choose to do whatever activities make them feel happy. As a result, teaching techniques with an emphasis on giving honor and acceptance to the primary caregivers as they are individuals involved in the decision making process of self-care practice for their children is strongly recommended. This will be helpful for the primary caregivers in learning and having a better attitude towards the health service system.

Research concerning the supportive-educative nursing system model for knowledge of diseases has been conducted. For example, Garding et al. (1988: 355-361) studied the supportive-educative nursing system and knowledge in 51 patients with sudden myocardial infarction with a discharge at 6-8 weeks. The subjects were divided into the experimental group (25) and the control group (26), and the experimental group recovered follow-up assessment and knowledge via the telephone every two weeks. Results showed that the experimental group had more knowledge about therapeutic self-care demand than the control group. Furthermore, Walla Tantayotai (B.E. 2525) studied the knowledge of disesease and control of diabetes in adult diabetic patients, but they did not have control after they received teaching, followed by supportive system. This method followed Orem's Nursing Theory. The research was conducted with subjects who had three tests before, immediately after, and two weeks after the teaching, and a supportive program every two weeks totaling six times. The results, showed that the knowledge about disease of the patients were statistically significantly increased after the intervention and at 12 weeks, but the knowledge was not correlated with the control of

disease. It can be explained that the control of disease was recognized as self-care if they had knowledge, but they did not practice it, so they had self-care deficits.

The supportive-educative nursing system was tested for its efficiency in adults, and studies showed that the supportive-educative nursing system could increase self-care in the patients (Reisch, 1988: 257 – 273; Folden, 1993: 162 – 167 ; Waraporn Rupee, B.E. 2536: i; Charatsri Terakulchai, B.E. 2536: 51; Suwanna Tadapipat, B.E. 2538: 50). Studies about the supportive-educative nursing system on self-care deficit, showed that the supportive-educative nursing system could decrease the self-care deficit of the patients. Kanittha Hanprasittikam (B.E. 2535) studied the effects of the support on the participation in self-care of the patients with chemotherapy. The 54 subjects were divided into the experimental group (27 persons) and the control group (27 persons). The experimental group received the supportive program in participation of self-care and normal nursing care. The results indicates that the experimental group had higher mean scores of uncomfortable signs in day 2 after chemotherapy, and they had the same mean scores of uncomfortable signs in days 1 and 3 after chemotherapy.

Furthermore, Doungkamol Watradul (B.E. 2537) studied the effect a supportive and promotive program on self-care practice of 43 patients with AIDS in decreasing self-care deficit and increasing quality of life and the supportive and promotive program on self-care included teaching, guiding, supporting and an encouraging environment inclusive of consultation by telephone and mail. They had to speak at least 2 times in the first day and at 4 weeks. The researcher collected data by semi-structured interview questions about self-care for analysis of self-care deficits. The efficiency of the project and the quality of life were assessed by interview on the first day and at eight weeks. It was discovered that the patients who received the supportive and self-care participation had a statistically significant mean score on the topic of self-care deficit and higher mean scores on the quality of life. The result of qualitative data also showed that the patients with AIDS developed the 3 way self-care method, and they made an effort to have health promotion and control symtoms i.e. fever, diarrhea, etc. This result was in line with Orem's Nursing Theory, so the nursing system could decrease the self-care deficit of persons and increase capabilities of self-care to meet the need of self-care. The examples of studies on supportive-educative nursing system in children are as follows:

Yupaporn Pongsing (B.E.2540) studied the effect of a supportive-educative nursing system to decrease self-care deficit in thalassemic child patients. The 60 subjects were equally divided into the control group and the experimental group. Both groups got a self-care handbook, but the experimental group also received the supportive-educative nursing system a few times during the period of eight weeks. It was discovered that the subjects who received the supportive educative nursing system had statistically significantly lower mean scores on self-care deficit after the intervention.

Suchada Prasongtansakul (B.E.2544) studied the effect of a supportive-educative nursing system on self-care deficit on school aged patients with rhumatic heart disease. The 46 subjects were equally divided into the expermental group and the control group. The experimental group received supportive-educative nursing system from the researcher and rhumatic self-care documents for school aged children including supportive-educative nursing system 2-3 times in 12 weeks. It was discovered that the patients who received the supportive-educative nursing system had statistically significantly lower scores on self-care deficit after the intervention.

A review of relevant literature revealed that the supportive-educative nursing system could be used with children, but the children did not have capabilities to perform all of therapeutic self-care demand, so the primary caregivers were crucial in conducting and caring for dependent care agents.

Kresana Kramsang (B.E.2539) studied the effects of a supportive-educative nursing system to decrease self-care deficit of primary caregivers who took care of chidren with cancer treated by chemotherapy. The subjects were 57 primary caregivers, 29 in the control group, and 28 in the experimental group. They received pamphlets, teaching, guidance, support and a good environment from the researcher. The experimental group had 2-5 interventions lasting about three months at an out-patient clinic. It was found that the experimental group had statistically significantly lower mean scores of self-care deficit after the intervention.

Supha Sirisonthi (B.E.2535 : i) studied the effects of a supportive-educative nursing system provided to the guardians towards self-care practice of students with chronic otitis media in primary schools affiliated to B.M.A. It was discovered that the guardians who received the supportive-educative nursing system had statistically significantly higher mean scores on the topic of chronic otitis media and of supportive behavior for self-care practice of the children after the intervention.

Examples of the research related to the effects of supportive-educative nursing system on knowledge of primary caregivers in caring for the children are as follows:

Wantanee Thongmee (B.E.2543) studied the effects of a supportive-educative nursing system on maternal behaviors in caring for infants with respiratory infections. In this study, there were 20 cases, in the expermental group and 20 cases in the control group. The findings of this study showed that the scores related to maternal behavior in caring for infants with respiratory infections of the group with a provision of supportive educative nursing system were statistically significantly higher than that of the group with normal nursing service from the health care team.

However, there was no research particularly conducted on the effects of a supportive educative nursing system on maternal knowledge in caring for children with cyanotic heart disease at risk of cyanotic spells.

Somporn Shotiwitayatarakorn (B.E.2543) studied the effects of maternal development knowledge capacity in caring for children with congenital heart disease. This research was conducted with 30 subjects, and it used repeated evaluations in a one study group. The subjects received the program including guidance, demonstration, practice, experience sharing, a record of health and motivating mail. The subjects were evaluated at one week and twelve weeks. It was discovered that the mothers who received the program had statistically significantly higher mean scores on the topic of maternal knowledge capacity of caring for children with congenital heart disease.

Sasichol Kamporch (B.E.2544) studied the effects of a health education program on maternal behaviors in caring for children with ventricular septal defects at Queen Sirikit Institute of Child Health applying the Protection Motivation Theory and Social Support as the conceptual basis for organizing health education. Fifty mothers were in the experimental group and another 50 were in the comparison group. The eight-week health education program consisted of the following activities: lectures with slide shows and pamphlets, group discussion, positive modeling, demonstration, practice, stimulation through telephone service, and postcard mailing. The result of the study showed that after the experiment, the mothers in the experimental group gained significantly higher levels of perceived severity, perceived vulnerability of getting complications, perceived response efficacy, perceived self-efficacy, behavior intention and behaviors on caring for children than before the experiment. And it was also found that after the experiment, the average frequency of getting respiratory infection decreased significantly among the children whose mothers were in the experimental group.

From the concepts, theories and related literature reviewed, it can be concluded that the occurrence of cyanotic spells in children with cyanotic heart disease at risk of cyanotic spells is caused by various factors. Self-care needs to be specific and complete due to specific therapeutic self-care demand because age, development, health status, and the maternal behaviors influence health status of children. However, primary caregiver behavior depend on other factors: foundational capabilities and dispositions such as age, education, income, and period of time in caring for children. These factors have effects on primary caregiver behavior, so they may have dependent care deficits, and they are dependent care agents. The nurses who are public health personnel will be effective in encouraging primary caregivers to practice appropriate behaviors. Therefore, the researcher was interested in a supportive-educative nursing system consists of teaching, supporting, guiding, and an intense environment, so this system is appropriate in changing primary caregiver behavior in caring for their children and promoting health status of their children with cyanotic heart disease at risk of cyanotic spells.

CHAPTER III
METHODOLOGY AND MATERIALS

This study was a pre-experimental research aiming to identify the effects of a supportive-educative nursing system on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and the occurrence of cyanotic spells.

The research design

This was a single-group pre-test/post-test design. The sample consisted of primary caregivers having children with cyanotic heart disease at risk of cyanotic spells and who were receiving treatment at the Pediatric Cardiology Clinic, Department of Pediatrics, King Chulalongkorn Memorial Hospital, Thai Red Cross Society. The thirty primary caregivers, who participated in the supportive-educative nursing system program were provided by the researcher.

Population and Selection of Primary Caregivers and Children in the Sample Group

In this study, the population consisted of 2 groups:

1. Children with cyanotic heart disease at risk of cyanotic spells, who attended the Pediatric Cardiology Clinic, King Chulalongkorn Memorial Hospital, Thai Red Cross Society.

The inclusion criteria for the sample of children were:

1.1 diagnosed with cyanotic heart disease at risk of cyanotic spells;

1.1.1 Tetralogy of Fallot,

1.1.2 Pulmonary stenosis with Ventricular septum defect,

1.1.3 Pulmonary stenosis with Transposition of great arteries with Ventricular septum defect,

1.1.4 Pulmonary stenosis with Double outlet right ventricle, and

1.1.5 Pulmonary stenosis with Single ventricle.

1.2 2– 6 years old,

1.3 had never undergone any palliative operation or total correction; and were

1.4 free from febrile convulsions, epilepsy, cerebrovascular accidents, brain abscess, breath holding spells, and heart failure.

2. Primary caregivers, who have children with cyanotic heart disease at risk of cyanotic spells, and who came to the Pediatric Cardiology Clinic, Department of Pediatrics, King Chulalongkorn Memorial Hospital, Thai Red Cross Society.

The criterion for exclusion was:

Subjects who had undergone any palliative operation or total correction during the experiment.

The inclusion criteria for the sample of primary caregivers were:

2.1 a person who took responsibility in caring for children response to therapeutic self-care demand, and mostly cared for the children while they received a supportive-educative nursing system. The primary caregivers might be a father, a mother or a relative of the children.

2.2 lived with the children.

2.3 were able to read or listen in the Thai Language,

2.4 willing to participate in this study, and

2.5 able to communicate with the reseacher by telephone.

The researcher estimated the sample size according to Polit & Hungler's recommendation (1983: 426-427). In a quasi-experimental design, it is generally recommended that a sample size of at least ten people, though preferably twenty to thirty people, be selected for every subdivision of data, or cell design or the number of studied variables. In this study, a one group design compared the performance of an individual under a different pathology of disease using the individual as his/her own control to reduce the influence of inherent variables. Thirty subjects are suitable for this study because all subjects would be placed with a different pathology of disease. Therefore, the sampling technique of the study was a purposive method, which was used to gain a qualified population. The subjects were recruited from those determined eligible based

on a review of their medical record in King Chulalongkorn Memorial Hospital, Thai Red Cross Society.

Duration of the study

The period of the data collection was from January to June 2003. Records were kept during of working hours between 1.00 - 4.00 p.m. on Wednesday and Friday.

Research Setting

This study was conducted at the Pediatric Cardiology Clinic, Department of Pediatrics, King Chulalongkorn Memorial Hospital, Thai Red Cross Society.

The characteristics of the setting are the following:

King Chulalongkorn Memorial Hospital, Thai Red Cross Society provides a Pediatric Cardiology Clinic on Wednesdays and Fridays from 1 to 4 p.m. Nursing activities include measuring body weight and height, preparing the results of laboratory investigation, and taking the patients to a pediatric cardiologist. The clinic was run by three pediatric cardiologists. After diagnosis, new patients would receive medical care and individual instructions about disease from a pediatric cardiologist and these patients would receive further specific investigations. The known cases would receive medical care and individual instructions that are more specific to their problems from the medical personnel. The teaching is informal. After that, the patient and primary caregiver made an appointment for the next follow-up. The regular follow-up is from two to six months. They will receive the follow-up card and medication. If patients are waiting for the operation or have financial problems, they must contact a nurse or a social worker about the operation. The teaching by pamphlets on Tetalogy of Fallot are provided in this area, but there was no health education program of self-care agency developed for children with cyanotic heart disease at risk of cyanotic spells or dependent-care agency developed for primary caregivers. There were about 70-90 children who came to follow-up each day, and there were 3 to 5 cases per week who met the inclusion criteria.

Instruments

Two types of instruments were used in this study.

1. Instruments for data collection
2. Instruments for intervention

The instruments for data collection comprised:

1.1 The questionnaire of children's and caregivers background information consisted of 2 parts: characteristics of children with cyanotic heart disease at risk of cyanotic spells and demographic data of primary caregivers (Appendix).

1.2 The questionnaire of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells. This questionnaire was constructed by the researcher. All of the 19 items were designed to provide client information about primary caregiver behavior that had a specific aim to respond to their needs relevant to the self-care practice for caring children with cyanotic heart disease at risk of cyanotic spells.

This questionnaire was developed by the researcher based on a review of relevant documents and Orem's Nursing Theory. It was classified into the three major parts as follows: (Appendix).

1) Universal self-care requisites for primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells was composed of five items: No. 1, 5, 8, 9, and 11.

2) Developmental self-care requisites for primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells was composed of two items: No. 6 and 7.

3) Health deviation self-care requisites for primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells was composed of 12 items: No. 2, 3, 4, 10, 12, 13, 14, 15, 16, 17, 18, and 19.

All 19 questions were close-ended, and each item had three choices. The primary caregivers would have to respond following the instruction of each item that is you can select only one answer, or you can select more than one answer, and so one.

Scoring criteria

Each item had three scores, that were divided into two types:

Type 1: The questions with one answer, whose scoring was as follows:

Very appropriate behavior was equal to 3 scores.

Appropriate behavior was equal to 2 scores.

Slightly appropriate behavior was equal to 1 score.

The questions were composed of 13 items: No.1, 2, 3, 7, 8, 10, 12, 13, 14, 16, 17, 18, and 19.

Type 2: The questions with three answers. Primary caregivers could select one to three answers that they usually practiced. Each of the answers received one point, so the total score for each item was 3 scores.

The questions were composed of 6 items: No. 4, 5, 6, 9, 11, and 15.

Criteria for interpretation of scores:

The scores of the primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells ranged from 19 to 57.

Validity

The questionnaire was assessed for content validity, sequences, language suitability, and the criteria of measurement and scoring by five experts in the relevant fields were as follows:

- Pediatric cardiologists	2	persons
- Pediatric nurse instructors specialist in Orem's Nursing Theory	2	persons
- Pediatric nurse instructor specialist in cardiology	1	person

These experts ascertained whether the various intruments were appropriate in terms of content for use (Boonjai Sresatitwarakul, B.E.2544: 244). The tool was revised before use in this research.

A pilot study was undertaken among ten primary caregivers who were similar to the proposed sample to check the appropriate of the questionnaire used in data collection. Suggestions and feedback from the pilot study were used to improve the questionnaire for the study.

Reliability

After the questionnaire was validated and revised with special attention to investigate primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells, it was tried out with ten selected primary caregivers who had children with cyanotic heart disease at risk of cyanotic spells, and who possessed characteristics similar to those of the sample group. The Cronbach's Alpha Coefficient reliability was employed to calculate the reliability of the questionnaire, as a reliability of more than 0.70 is required to recognize a new instrument (Burns and Grove, 1977 : 327).

The reliability of this questionnaire was 0.88.

1.3 The assessment form of cyanotic spells was used in assessing for the occurrence of cyanotic spells. This form was developed by the researcher based on a review of relevant documents and medical knowledge about cyanotic spells. All 5 items were constructed to inform about signs and symtoms of cyanotic spells. These items consisted of 1) crying with or without restlessness, 2) hyperpnea, 3) sudden severe cyanosis, 4) unconsciousness, and 5) seizures (Appendix). However, sudden severe cyanosis is the most important sign and symtom of cyanotic spells, because it mostly occurs in children with cyanotic spells. Moreover, it was easy to assess cyanotic spells of children by primary caregivers. Therefore, the criteria of assessment were sudden severe cyanosis or sudden severe cyanosis with other signs from the assessment form of cyanotic spells.

Validity

The assessment form of cyanotic spells was assessed for content validity, sequences, language suitability, and the criteria of measurement and scoring by the same five experts in the relevant fields.

These experts ascertained whether the various intruments were appropriate in terms of content for use. The tool was revised before use in this research.

A pilot study was undertaken among the ten primary caregivers who were similar to the proposed sample to check appropriate of the assessment form of cyanotic spells used in data collection. Suggestions and feedback from the pilot study were used to improve the assessment form of cyanotic spells for the study. After explaining how to use the assessment form of cyanotic spells to ten primary caregivers who had children with cyanotic heart disease at risk of cyanotic spells, and who possessed characteristics similar to those of the sample group, the assessment form of cyanotic spells was tried out with ten selected primary caregivers. They were able to asssess for cyanotic spells.

2. The instruments for intervention

2.1 The instruction plan about cyanotic spells for primary caregivers. This instruction plan explained about cyanotic spells and signs and symtoms when cyanotic spells occur.

2.2 The supportive-educative nursing systems plan for primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells.

2.2.1 An illustration of cyanotic heart disease

2.2.2 The instruction plan about caring for children with cyanotic heart disease at risk of cyanotic spells, explained about cyanotic spells, covering causes, caring for prevention of cyanotic spells, and assistance during the occurrence of cyanotic spells. The content validity of this instrument was verified by the same group of experts, and it was tried out with ten primary caregivers.

2.2.3 Video tape about the ocurrence of and assistance during the occurrence of cyanotic spells was viewed by the primary caregivers

2.2.4 A pamphlet about cyanotic spells

2.2.5 Postcards about assessing and recording the occurrence of cyanotic spells

Validity

All instruments for intervention were assessed for content validity, sequences, language suitability, and the criteria of measurement and scoring by the same five experts in the relevant fields as other research tools.

These experts ascertained whether the various intruments were appropriate in terms of content. The tool was revised before using in this research.

Data Collection Methods

Protection of Human Subjects

The research proposal was submitted and approved by the Department of Nursing, Faculty of Medicine at Ramathibodi Hospital, Mahidol University. The proposal project and informed consent were reviewed and approved by the Ethics Committee, King Chulalongkorn Memorial Hospital, Thai Red Cross Society on March 10, 2003 (Appendix), and Mahidol University on June 25, 2003 (Appendix). Afterwards, the researcher met the head of cardiac children department, head of the pediatrics out-patient ward, the head nurses, nursing staff and relevant physicians in each unit to explain the nature of the study, procedures, and the technique of measurement and to request their collaboration.

The human rights of the subjects were respected in this study. The researcher selected subjects according to the criteria and contacted primary caregivers to ask for their permission to allow their infants to participate in this study. The purposes of the study were explained, along with benefits, risks, length of time, and the right to refuse to participate in the study. The procedure for data collection was clearly described in both verbal and written explanations. Informed consent (Appendix) was obtained from each primary caregiver.

Procedures

The sequence of data collection was as follows:

1. A formal letter issued by the Faculty of Graduate Studies of Mahidol University was submitted to the Director of King Chulalongkorn Memorial Hospital, the Thai Red Cross Society asking for permission and for participation in carrying out the research and data collection.

2. The objectives and details of research procedures were explained to the head of the Pediatric Cardiology Department of Pediatrics and head of the Pediatric Out-Patient Department.

3. The research setting was prepared

4. The instruments and the equipment were prepared.

5. Screening for and recruiting of subjects based on the inclusion criteria took place at the Pediatric Cardiology Clinic, Department of Pediatrics, King Chulalongkorn Memorial Hospital, Thai Red Cross Society, on Wednesday and Friday from 1.00 to 4.00 p.m. Then, those selected subjects were invited to study by a letter from the researcher. The researcher collaborated to health officials for follow-up date when they were willing to participate in this study.

6. The objectives and details of the implementation of the supportive educative nursing system were explained by the researcher for the protection of the human subjects (Appendix). Before the subjects received medical care, they were interviewed for general information for 10-15 minutes.

7. The demographic data of children with cyanotic heart disease at risk of cyanotic spells and of primary caregivers were collected by the researcher from the medical history and interviews.

8. The researcher trained the primary caregivers on signs of cyanotic spells by teaching following the instruction plan. Afterward, the researcher showed the video tapes about the ocurrence of cyanotic spells. They also received the assessment form of cyanotic spells form 1 to 8 weeks and confirmed they would do the assessment. The researcher motivated the primary caregivers to record cyanotic spells at home by postcard and telephone.

9. Within eight weeks, the primary caregivers were interviewed based on the questionnaire about behaviors on caring for children with cyanotic heart disease at risk of cyanotic spells, and then they progressed to the supportive-educative nursing system plan.

Supportive-educative nursing system plan

Step 1: 8th Week Teaching the primary caregivers

1. Building a relationship: the researcher built up a relationship with the subjects. This was done by means of self-introduction, telling them about the purpose of the study and informing them of the duration and activities of the program. This included the assessment of the disease, medical care, caring for the children, agency of caregivers, and self-care requisites of children.

2. Instruction on knowledge about caring for children with cyanotic heart disease at risk of cyanotic spells. The researcher trained the individual caregiver based on the lesson plan about nursing care given to children with cyanotic heart disease at risk of cyanotic spells. They received a comprehension check by watching the video on cyanotic spells. The same time, they were given a pamphlet about cyanotic spells on how to take care of children with cyanotic heart disease at risk of cyanotic spells. Some additional clarification and demonstration were given to the primary caregivers who did not really understand, and the researcher made a strong effort in advising and encouraging the primary caregivers to be patient and to continue the child caring function by themselves. This activity lasted 20-30 minutes.

Step II: 9th Week Continuity of behavior by telephone

The primary caregivers were guided and encouraged by telephone to continue behaviors to care for the children with the following key concepts:

1. The problem about caring for children
2. Guidance and exchanging ideas about caring for children
3. Supporting and encouraging primary caregivers
3. Motivating caregivers to record cyanotic spells.

Step III: 10th Week Providing a supportive environment via postcards and reminding caregivers of the following key concepts:

1. Nursing appropriately and continuously using the information in the pamphlet about cyanotic spells
2. Recording the occurrence of cyanotic spells, following the assessment form

3. Inquiring via telephone about any questions
4. Following-up with doctors and participating in group activities.

Step IV: 12th Week Providing a supportive environment through group activities.

The researcher started the supportive-educative nursing system with this group, before they received medical care. The researcher assessed primary caregiver behavior in caring for the children, concerning the practice, guidance with support, and preparing an encouraging environment. The researcher and three to five caregivers discussed the following issues: preventing the occurrence of cyanotic spells, symtoms indicating cyanotic spells, assistance when cyanotic spells occur, and by taking about 20-30 minutes to complete this activity. All primary caregivers received group activities on one time. They could exchanged the experiences in caring for the children, and the researcher provided guidance for appropriate behaviors follow to a point of problem. While the researcher provided convenient help to the primary caregivers such as co-ordination with doctors and nurses or the other health officials. The researcher also followed the record of cyanotic spells.

Step V: 14th Week Providing a supportive environment via postcard and reminding caregivers of the following key concepts:

1. Nursing appropriately and continuously using the information in the pamphlet about cyanotic spells.
2. Recording the occurrence of cyanotic spells, following the assessment form.
3. Inquiring via telephone about any questions
4. Following-up with doctors

Step VI: 16th Week Completed questionnaire

The subjects were interviewed at the post-test by using the same questionnaire, and the assessment form of cyanotic spells were collected. The researcher summarized the problems arising from the actual practice. The questionnaire and the assessment form were completed by the researcher.

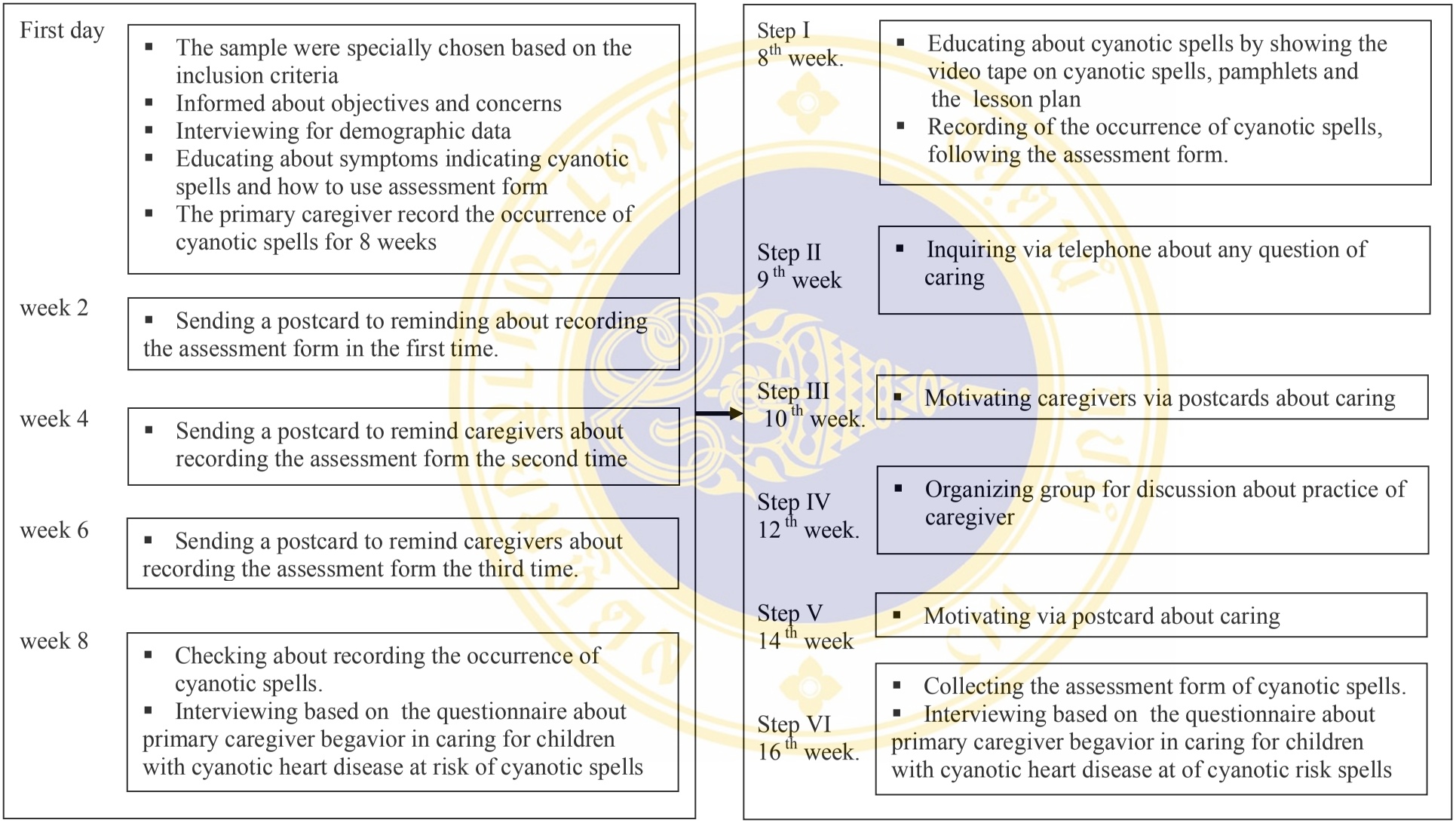

Diagram I The process of data collection

Data analysis

SPSS/FW (Statistical program for the Social Science For Windows) was used in analyzing the data. The level of significance was set at 0.05 to test the hypothesis. The statistics used in this study are as follows:

1. Frequency and percentage were used to decribe the characteristics of primary caregivers and children with cyanotic heart disease at risk of cyanotic spells.

2. Frequency, percentage, mean, and standard deviation were used to describe primary caregiver behavior and the occurrence of cyanotic spells.

3. Comparison between before and after the experiment regarding primary caregiver behavior was tested by paired t-test, since the data was in normal distribution.

4. Comparison between before and after the experiment regarding the occurrence of cyanotic spells was tested by paired t-test, since the data was in normal distribution.

CHAPTER IV
RESULTS

This study was a pre-experimental single group pre-test and post-test which intended to compare primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and the occurrence of cyanotic spells before and after the provision of a supportive-educative nursing system. In this chapter, the results of the data analysis are presented in two parts:

Part 1: Characteristics of subjects

1.1 Characteristics of children with cyanotic heart disease at risk of cyanotic spells

1.2 Characteristics of primary caregivers

Part 2: The results of hypotheses testing

2.1 The results of hypothesis 1

2.2 The results of hypothesis 2

Part 1 Characteristics of subjects

Table 1 Frequency and percentage of demographic characteristics of primary caregivers (n=30)

Characteristics	Frequency (n=30)	Percentage
Relationship with the patients		
Mother	24	80
Father	5	16.67
Maternal grandmother	1	3.33
Age (years)		
21 – 30	11	36.67
31 – 40	15	50.00
≥ 41	4	13.33
Marital status		
Married	28	93.33
Divorced/Separated	2	6.67
Educational level		
Primary education	12	40.00
Secondary education	11	36.67
Diploma	4	13.33
Bachelor's degree or equivalent	3	10.00

Table 1 Frequency and percentage of demographic characteristics of primary caregivers (n=30) (continued)

Characteristics	Frequency (n=30)	Percentage
Occupation		
No occupation	1	3.33
Agriculture	6	20.00
Laborer	17	56.67
Merchant	3	10.00
Government official	2	6.67
State enterprise	1	3.33
Family income (baht/month)		
Below 5,000	10	33.33
5,001 – 10,000	12	40.00
10,001 – 15,000	6	20.00
More than 15,000	2	6.66
Characteristics of family		
Nuclear family	11	36.67
Extended family	19	63.33
Child care assistance		
Having no child care assistance	10	33.33
Having child care assistance	20	66.67

Table 1 showed the demographic characteristics of the primary caregivers of children with cyanotic heart disease at risk of cyanotic spells. In this study, most of the primary caregivers were mothers (80%), 50% had an age range from 31 to 40 years. Almost all of them were married (93.33%). The largest group of the primary caregivers had a primary education (40%). The occupation of the majority of primary caregivers were laborers (56.67%), and 40% had a family income of 5,001-10,000 baht/month. Most lived in an extended family (63.33%), and had child care assistance (66.67%).

Table 2 Frequency and percentage of demographic characteristics of children with cyanotic heart disease at risk of cyanotic spells (n=30)

Characteristics	Frequency (n=30)	Percentage
Sex		
Male	21	70.00
Female	9	30.00
Age (years)		
≥ 2 - 3	6	20.00
> 3 - 4	4	13.33
> 4 - 5	3	10.00
> 5 - 6	17	56.67
Duration of attention (years)		
> 1 - 2	4	13.33
> 2 - 3	8	26.67
> 3 - 4	3	10.00
> 4 - 5	6	20.00
> 5 - 6	9	30.00
Type of disease		
Tetralogy of Fallot	30	100.00
Hospitalization (before this study)		
no	28	93.33
yes	2	6.67

Table 2 showed the demographic characteristics of children with cyanotic heart disease at risk of cyanotic spells. Most subjects were male (70%). More than a half of subjects were >5-6 years old (56.67%). Most subjects had > 5-6 years of duration of attention (30%). All of subjects were diagnosed Tetralogy of Fallot. In addition, 93.33% had no hospitalization before this study.

Part 2: Results of hypothesis testing

2.1 Hypothesis 1: The post-test scores of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells was higher than the pre-test scores.

The effects of a supportive-educative nursing system on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells are presented in Table 3.

Table 3 The comparison by paired t-test of means and standard deviation scores of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells at pre and post intervention classified by overall results and each category. (n=30)

Primary caregivers behaviors	Min	Max	$\bar{X}$	SD	t-value
Overall primary caregiver behavior					
Pre – test	26	46	37.20	5.18	-18.02**
Post – test	50	56	53.00	1.89	
Primary caregiver behaviors in response to universal self-care requisites					
Pre – test	5	12	7.73	1.76	-18.71**
Post – test	12	15	13.87	0.86	
Primary caregiver behaviors in response to developmental self-care requisites					
Pre – test	2	5	3.50	1.10	-7.87**
Post – test	5	6	5.50	0.51	
Primary caregiver behaviors in response to health deviation self-care requisites					
Pre – test	19	33	25.87	3.42	-14.17**
Post – test	31	36	33.63	1.48	

**p<.01

Table 3 showed that there was a statistically signigficant difference in the mean scores of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells between pre-test and post-test (t-value = -18.02, p<.01). The post-test mean score of 53.00 (SD=1.89) was higher than the pre-test mean score of 37.20 (SD=5.18). Moreover, the mean scores of primary caregiver behavior in each category between pre-test and post-test showed that there was a statistically significant difference.

The universal self-care requisites category showed that there was a statistically signigficant difference in the mean scores of primary caregiver behavior between the pre-test and post-test (t-test: t-value = -18.71, p<.01). The post-test mean scores of 13.87 (SD=0.86), was higher than the pre-test mean scores of 7.73 (SD=1.76). The developmental self-care requisites category showed that there was a statistically significant difference in the mean scores of primary caregiver behavior between the pre-test and post-test (t-value = -7.87, p<.05). The post-test mean scores of 5.50 (SD=0.51), was higher than the pre-test mean score of 3.50 (SD=1.10). The health deviation self-care requisites category also showed that there was a statistically significant difference in the mean scores of primary caregiver behavior between the pre-test and the post-test (t-test: t-value = -14.17, p<.05). The post-test mean score of 33.63 (SD=1.48), was higher than the pre-test mean score of 25.87 (SD=3.42).

This study indicated that after primary caregivers received the supportive-educative nursing system, they had significantly changed their behaviors in caring for children with cyanotic heart disease at risk of cyanotic spells. Therefore hypothesis 1. was supported.

Table 4 The comparison by paired t-test of mean and standard deviation scores of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells, at pre and post intervention related to Self-Care Requisites and classified by each item. (n=30)

Questions	Pre		Post		t-value
	$\bar{X}$	SD	$\bar{X}$	SD	
Primary caregiver behaviors in response to universal self-care requisites					
1. How do you feed your child each a day ?	1.97	0.76	3.00	0.00	-7.40**
5. When event do you feed water, milk, or fruit juice to your child ?	1.33	0.55	2.83	0.38	-11.24**
8. How do you care your child while sleeping ?	1.77	0.82	2.80	0.41	-7.00**
9. How do you prevent constipation to your child ?	1.30	0.53	2.40	0.62	-9.10**
11. How do you prevent a cold, a fever, a cough, and throat irritability to your child ?	1.37	0.49	2.83	0.38	-12.76**
Primary caregiver behaviors in response to developmental self-care requisites					
6. While your child is playing, what do you do?	1.50	0.51	2.53	0.51	-8.46**
7. While your child is crying, what do you do mostly ?	2.10	0.88	2.97	0.18	-5.52**
Primary caregiver behaviors in response to health deviation self-care requisites					
2. How do you care about child getting iron medicine ?	2.57	0.73	3.00	0.00	-3.26**
3. If a doctor ordered iron medicine for your child, then do you care for your child by getting iron medicine?	2.07	0.87	2.90	0.40	-5.47**

** $p<.01$

Table 4 The comparison by paired t-test of mean and standard deviation scores of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells, at pre and post intervention related to Self-Care Requisites and classified by each item. (n=30) (continue)

Statement	Pre		Post		
	$\bar{X}$	SD	$\bar{X}$	SD	t-value
4. If your child vomits or has diarrhea, what do you do ?	1.33	0.61	2.37	0.56	-7.88**
10. When your child has constipation in the first stage, what do you do first?	2.40	0.72	2.90	0.31	-4.01**
12. How do you give your child a correct dose of drugs for treatment of cyanotic heart disease at risk of cyanotic spells ?	2.57	0.50	2.93	0.25	-4.10**
13. If drugs for treatment cyanotic heart disease at risk of cyanotic spells were used up, what do you do ?	1.90	0.99	2.57	0.57	-5.14**
14. What is your method in caring for your child to get the drug ?	2.97	0.18	2.97	0.18	*
15. What are signs and symptoms of cyanotic spells ?	1.37	0.56	2.37	0.49	-7.88**
16. When your child had cyanotic spells, what did you observe ?	1.93	0.83	2.97	0.18	-7.00**
17. If your child had cyanotic spells, but you were not sure about signs and symptoms of cyanotic spells, what did you do ?	1.47	0.68	2.87	0.35	-9.96**
18. If your child had cyanotic spells, what did you do ?	2.53	0.63	3.00	0.00	-4.07**
19. How do you care your child for follow-up ?	2.77	0.43	2.80	0.41	-0.44^{NS}

* The correlation and t cannot be computed because the standard error of the difference is 0.00, ** p<.01, NS = not statistically significant at the level 0.05

Table 4, indicated the average scores of primary caregiver behavior in response to universal self-care requisites of children with cyanotic heart disease at risk of cyanotic spells of items no. 1, 5, 8, 9 and 11 of the subjects at the pre-intervention stage were between 1.30-1.97. At the post-intervention stage, the average scores were between 2.40-3.00, and all items were significantly higher than at the pre-intervention stage at a statisticaly significant level of 0.01. The average score on primary caregiver behavior in response to developmental self-care requisites of children with cyanotic heart disease at risk of cyanotic spells of items no. 6 and 7 of the subjects at the pre-intervention stage were between 1.50-2.10. At the post-intervention stage, the average scores were between 2.53-2.97, and all items were significantly higher than at the pre-intervention stage at a statisticaly significant level of 0.01. The average scores of primary caregiver behavior in response to health deviation self-care requisites of children with cyanotic heart disease at risk of cyanotic spells of items no. 2, 3, 4, 10, 12, 13, 14, 15, 16, 17, 18 and 19 of the subjects at the pre-intervention stage were between1.37-2.97. At the post-intervention stage, the average scores were between 2.37-3.00, and all items were significantly higher than at the pre-intervention stage at a statisticaly significant level of 0.01., but items no. 14 and 19 were also found not statistically significant at the level 0.05.

The 2.2 Hypothesis 2: The frequency of the occurrence of cyanotic spells after primary caregivers receive the supportive-educative nursing system was lower than or equal to the frequency of the occurrence of cyanotic spells before receiving the supportive-educative nursing system.

Table 5 Comparative analysis of the average frequency per month of the occurrence of cyanotic spells before and after receiving the supportive-educative nursing system (n=30)

Cyanotic spells (times/month)	Min	Max	Median	$\bar{X}$	SD	SEM	t-value	df
Before	0	30	3.75	8.63	10.52	1.92	2.41*	29
After	0	34	2.50	6.33	8.90	1.62		

*p<.05

Table 5 showed that some subjects had an average frequency per month of the occurrence of cyanotic spells equal to zero both before and after receiving the supportive-educative nursing system. Some subjects had a higher average frequency per month of the occurrence of cyanotic spells after compared with before receiving the supportive-educative nursing system. However, there was a significant difference in the mean of the occurrence of cyanotic spells among subjects before and after receiving the supportive-educative nursing system (t-value = 2.41, p<.05). The mean of the occurrence of cyanotic spells in subjects after receiving the supportive-educative nursing system was 6.33 (SEM= 1.62) times/month, which was lower than before receiving the supportive-educative nursing system at 8.63 (SEM=1.92) each/month. In addition, the median of the occurrence of cyanotic spells in subjects after receiving the supportive-educative nursing system was 2.50 times/month, which was lower than before receiving the supportive-educative nursing system at 3.75 each/month. This study indicated that after primary caregivers received the supportive-educative nursing system, children with cyanotic heart disease at risk of cyanotic spells had a significantly decreased occurrence of cyanotic spells. Therefore hypothesis 2. was supported.

Table 6 Frequency and percentage of the occurrence of cyanotic spells in individual cases after receiving the supportive-educative nursing system (n=30)

The occurrence of cyanotic spells (times/month)	Frequency (n=30)	Percentage %
Decrease	19	63.33
Increase	8	26.67
Similar	3	10.00

Table 6 shows frequency and percentage of the occurrence of cyanotic spells in individual cases after receiving the supportive-educative nursing system. 63.33% of the subjects had a decrease in the occurrence of cyanotic spells at post-test; 26.67% had an increase of the occurrence of cyanotic spells. In addition, 10% had similar frequency of occurrence of cyanotic spells.

Table 7 Comparison of the degree of severity of the occurrence of cyanotic spells before and after receiving the supportive-educative nursing system by frequency and percentage (n=30)

The degree of severity of the occurrence of cyanotic spells	Frequency (n=30)	Percentage %
Decrease	9	30.00
Increase	9	30.00
Similar	12	40.00

Table 7 shows the degree of severity of the occurrence of cyanotic spells in individual cases before and after receiving the supportive-educative nursing system. The degree of severity of the occurrence of cyanotic spells were analyzed from the assessment form of the occurrence of cyanotic spells that record by primary caregivers, and it moved toward severity. The largest group of the subjects had a similar degree of

severity of the occurrence of cyanotic spells both before and after receiving the supportive-educative nursing system (40%). 30% of subjects had an increased degree of severity of the occurrence of cyanotic spells in individual cases after receiving the supportive-educative nursing system, and 30% of subjects had a decreased degree of severity of the occurrence of cyanotic spells in individual cases after receiving the supportive-educative nursing system. However, subjects with an increased degree of severity, and subjects with a decreased degree of severity were equal in the degree of severity of the occurrence of cyanotic spells. However, in this study semi-unconsciousness was the highest degree of severity of the occurrence of cyanotic spells. Five subjects had a decreased degree of severity in the semi-unconsciousness degree. This study indicated that after primary caregivers received the supportive-educative nursing system, children with cyanotic heart disease at risk of cyanotic spells had a significantly decreased occurrence of cyanotic spells according to severity of the occurrence of cyanotic spells. Therefore hypothesis 2. was supported.

CHAPTER V
DISCUSSION

This study has identified several important issues. First, a comparison of 30 primary caregiver behavior before and after participation in the supportive-educative nursing system. Secondaly, a comparison of the occurrence of cyanotic spells of children with cyanotic heart disease at risk of cyanotic spells before and after receiving a supportive-educative nursing system.

The research design was a single-group pre-test/post-test design, which had internal validity. There was control of differential selection among subjects, but there was lack of control in external validity, because the thirty children with cyanotic heart disease at risk of cyanotic spells and primary caregivers were not randomly assigned in this study. In addition, the primary caregiver subjects had a significant difference in experience of care for children with cyanotic heart disease at risk of cyanotic spells, raising the possibility of experimenter effect. However, this research was conducted in a real world setting, not a laboratory, and such occurrences were unavoidable. The researcher has seperately discussed the characteristics of the sample groups and tested the results of the hypotheses as follows.

Characteristics of Sample Groups

Mostly primary caregivers of children with cyanotic heart disease at risk of cyanotic spells were mothers ranging in age from 31-40 years. Mostly primary caregivers had a primary education level. The marital status of the primary caregivers were couples. The type of family was extended with family members giving help in caring for children, and assisting the primary caregivers to learn and gain experience from other persons. The experience may have certain effects on their decision-making and operation in caring for children (Hanucharurnkul, 1995: 54) and preparation and adaptability in a better state than those without experience. And such experience may affect their capability in learning performance for their children's care and their motives in

thinking, decision-making and learning about playing a part in developing the dependent-care agency of the primary caregivers. Orem and Taylor (1986: 48) said that experience is a good motivation stimulating agency and the use of such dependent-care agency. However, the occupation of the majority of primary caregivers were laborers. They have to work outside their house, and they have household duties and high responsibility. Therefore, they have an increased role, and they can easily have self-care deficit because they are tense and tired. The study of Ozer (1993) discovered that mothers who had many roles suffered from effects on the roles of a mother, especially in families with ill children who needed more care than normal children. Moreover, 40% had a family income of 5,001-10,000 baht/month and 33.33% had a family income of below 5,000 baht/month. It showed that more than half of subjects had a very low family income. Family income is a resource which is related to dependent care agency (Orem, 1985: 175), because the persons who have high income would have more opportunity than the persons with low income to seek things that benefit health such as nutritional food and public health care (Pender,1987: 161-162). The characteristics data included basic factors already mentioned that may influence the dependent care agency of primary caregivers, as shown in Table 1.

All of the subjects were children with Tetralogy of Fallot. Most of the subjects were male and ranging in age from >5-6 years. It showed that they had high risk for the occurrence of cyanotic spells, because their developmental stage and sex were causes of high activity such as type of playing. In addition, mostly cyanotic spells occur in the Tetralogy of Fallot (Park, 2002: 115), and was called “tet spells”. Moreover, the subjects had underlying Tetralogy of Fallot from the duration of attention of more than 1 to 6 years. The characteristics data included basic factors already mentioned that may influence the children, as shown in Table 2.

Results of Hypothesis Testing

Hypothesis I

The post-test scores of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells was higher than the pre-test scores.

The finding of this study showed significant support for Hypothesis 1. The mean of post-test scores of primary caregiver behavior were higher than the mean of pre-test scores, which showed a statistically significant difference ($p<.01$). The mean scores of primary caregiver behavior in caring, in the pre and post intervention period were 37.20, and 53.00, respectively (see Table 3). This can be explained as follows:

Firstly, at the first time primary caregivers lacked knowledge and understanding in caring for children with cyanotic heart disease at risk of cyanotic spells, but the behavior which is acquired by learning, a supportive-educative nursing system, can help the primary caregivers to gain knowledge and skill in caring that led them to develop the capability to perform primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells. Wantanee Thongmee studied the effects of a supportive-educative nursing system on maternal behaviors in caring for infants with respiratory infections. The sample population were the mothers who had infants aged 0-12 months with respiratory infections. This study showed that the scores related to maternal behavior in caring for infants with respiratory infections of the group with a provision of a supportive-educative nursing system was higher than the group with normal nursing service from the health team.

Therefore, the researcher used a teaching approach to develop knowledge and ability in self-care requisites of primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells. It was expected that the information, knowledge, and skills that they learned would support the primary caregivers to be able to decide about desirable child caring.

According to Orem (2001: 16-19), teaching can help develop knowledge and practices. Thus, in the present study, a group process of interaction was applied. It was believed that this could result in a change of the subjects' behaviors. Moreover, a teaching vidio tape which modeled the steps of caring was also used to help primary

caregivers understand and become interested in cyanotic spells (Arnold, et al., 1988 cited by Pensirinapa, N. 1995; 39). An illustration for the primary caregiver was distributed to understanding of Tetralogy of Fallot and cyanotic spells. A pamphlet for the primary caregiver was distributed as well. In this study, it was found that the primary caregivers studied and used it as their guideline. The primary caregivers received the pamphlet about the content of the instruction of self-care practice of cyanotic spells. The content explained about the meaning of cyanotic spells, signs and symptoms, effects of cyanotic spells, and preventing and helping the children when cyanotic spells occur. Therefore, it was specific to cyanotic spells more than the handbook about Tetralogy of Fallot in the cardiology clinic. This would enable the primary caregivers to appreciate the appropriate behaviors in caring for the children who had risk of cyanotic spells. In addition it would help the primary caregivers to memorize it more easily. The cartoons in this pamphlet tried to make the data attractive and synchronous so that it would help the caregivers to understand the content easily by using, several colors and lovely cartoons. The results of this study might reflect that it could make the primary caregivers better recognize and use it and it was also more convenient for self-study at home. Some subjects stated that they had read the pamphlet at least twice. In general, the materials in the manuals or pamphlets could stimulate acquisition of new knowledge and learning (Clayton,1963: 43, cited by Nicha Wongwai, B.E. 1998: 58). According to Pounyathalang (1998: d) the group of mothers with primigravida cases under the supportive-educative nursing system were given a manual on self-care performance and infant care. The experimental group was found to achieve higher self-care agency and dependent care agency scores than the control group. Furthermore, after teaching including a demonstration was used with the primary caregivers to reinforce how to practice. The researcher conducted a teaching activity providing specific knowledge according to the primary caregivers' requirements, created a teaching environment on an individual background basis in a friendly atmosphere, which included discussion sessions for exchanging viewpoints and knowledge between the researcher and the primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells at home. It also included consideration in finding out the guidelines to solve the problems. Orem (1995: 15-19) states that the teaching process according to an individual's requirements will help

develop knowledge and practice. So far the contents of individual instruction will include only specific information to provide knowledge and guidance only for specific problems, the primary caregiver has encountered, since the primary caregivers can learn about the things they need and then they will be able to understand and cooperate with doctors in the treatment process. In addition to this, primary caregiver behavior in caring for the sick infants can be appropriately changed and also complications and dangers will be reduced (Noparat Rasanui, B.E. 2538: 44). Moreover, individual differences will be taken into consideration while the relationship is beneficial for effective treatment and is perceived as a kind of communication skill that should be applied with the patients or caregivers to ensure trust, ease, recognition of its usefulness, and willingness to give information. At the same time, in this study the researcher could understand the problem and knew the direction to give the guidance and consultation to the patients. Then, the patients or caregivers could take advantage as they could follow the medical treatment plan correctly, give better cooperation in various activities, and practice a continuous follow-up (Boonsri Prabsak and Siriporn Jirawatanakul, B.E. 2531: 87-88). Self-care is behavior, so it must be learned. Thus, the nurses need to consider completeness and ability of the person to develop self-care capability (Prakong Intarasombut, B.E. 2536: 150). Therefore, the researcher created an instructive plan for development behaviors of the primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells. Van Hoozer (Van Hoozer, et al., 1987: 80) said that efficient instructions must be set as the goal and good activities. Also, the studies of Duangkhae Ammarapitakn (B.E. 2537: i-ii) and Sunee Suntornmeesatien (B.E. 2537: i-ii) discovered that the sample group who were provided with systematic teaching and instruction had better self-care behavior when compared to the group without instruction provided. Moreover, guiding, supporting, and adjusting the environment can help to develop and maintain behaviors of primary caregivers.

Guiding is considered as a method to deliver help to the primary caregivers to help them make a decision about child care. Orem (1995: 15-49) found that guiding is valid in situations in which persons must make choices and a suitable decision by themselves under the nurse's instruction. Therefore, if the primary caregiver practice

was inappropriate, the researcher would provide suggestions and alternatives to guide them. The researcher encouraged the caregivers to do infant care practice and express their feelings about it. The researcher also praised the caregivers whenever they correctly practiced it in order to enhance their confidence and continuous learning (Beland & passos, 1981: 486). This research used the telephone as a method of guidance. Because this method was easy, quick and provided direct contact, between the primary caregiver and the researcher, it was chosen by the primary caregivers to receive information to make decisions themselves about specific problems. In this research, three primary caregivers used the telephone with the researcher for guidance. The first consulted about food for the children, the second case consulted about follow up, and the third case consulted about appropriate activity for the children. Moreover, the researcher gave them a pamphlet which consisted of contents related to caring for children with cyanotic heart disease at risk of cyanotic spells, and the telephone number of the researcher, which the primary caregivers could repeatedly read or use as a guideline for practice at home. The pamphlet helped the primary caregivers to memorize and correctly practice child care.

The primary caregivers' abilities helped sustain their effort and prevented them from missing participation in the supportive-educative nursing system. The researcher established a relationship with the primary caregivers and children with cyanotic heart disease at risk of cyanotic spells on an individual basis by informing them of the duration and activities of the program and ensured the responsibility to help them in order to foster trust. This good relationship between the nurse and the primary caregiver could help to increase the quality of teaching and learning. Furthermore, having trust could increase the quality of communication (Somjit Hanucharurnkul, 1997: 47). Moreover, the researcher made follow-up visits by means of telephone calls to answer their problems and clarify doubts, and the researcher would cheer them when they had appropriate practice during every contact. As for the follow-up by telephone by the researcher, it was found that the primary caregivers were happy, and they felt good with continued interest from the nurse. They had a warm and secure feeling, and also confidence and pride in themselves. This was consistent with the idea of Beland and Passos (1981: 480) who claimed that supporting and giving moral support has an influence on pushing for a better

behavior potentiality in a person, helping a person to be of strong mind, reducing internal stress, fostering confidence and building up confidence to cope with problems and enabling them to be patient with what happened. Temduang Choyhirun (B.E.2545: 86) studied the effects of computer-assisted instruction in a supportive-educative nursing system on self-care practice in school-age children with nephrotic syndrome(NS) and found that the effects of support by telephone calls once a week could answer their problem and clarify doubts. It was effective in increasing self-care practices in school-aged children with NS.

The researcher arranged the environmental conditions to facilitate learning by the primary caregivers by complete rooming-in and by providing them with instructions on changing and improving themselves, by demonstrating how to take care of children, by teaching, by demonstrating how to assess understanding sufficient for building up their confidence and reducing anxiety. Apart from telephone contacts, the primary caregivers would received a postcard, and its main contents were about caring for the children. The postcard was sent to the primary caregivers every four weeks. It helped motivate the primary caregivers to practice care continuously. Moreover, the researcher created a group discussion of the primary caregivers in caring for the children after they had instructions for about one month, and the group included two to three cases for discussion about caring for the children. The primary caregivers were allowed to meet the researcher and other primary caregivers in the same category, to share and exchange their experiences. Moreover, the researcher provided support with encouragement to promote motive-creation and questions on caring problems including guidance by the researcher. Orem (1995: 18) points out that environment creation by arranging a session to allow the primary caregivers to share their experience among their peer group will help them understand the instructions, and receive support and other help. The group helped the members to realize their behaviors from information provided by other members, and the members supported each other, so they had more self-confidence and less loneliness (Marram, 1978 : 141-142). So, the mothers who have accessibility with logistical support, environmental adaptability or contact with important persons, have items which help them develop the self-care agency (Orem, 1995: 215) by adjusting thoughts and behaviors to achieve the set target (Somjit Hanucharurnkul, B.E.2538: 47). In this

research, most primary caregivers were pleased to participate in and satisfied with this nursing care.

It was evident that the supportive-educative nursing system is an inseparable activity when it is conducted effectively as planned in fostering the development of the self-care agency and the dependent-care agency. The findings of this research support Orem's theory, proving that the nursing system is a key factor in developing the dependent-care agency.

Moreover, the average scores of primary caregiver behavior after intervention was statistically significantly higher than average scores at the period before intervention. When considering the content of each item, it discovered that of average scores of 19 items. 17 items were statistically significantly higher than average scores at the period before intervention at the level 0.01, while item no.14 had the same average score. Only one item no.19 was not statistically significant at the level 0.05. Accordingly, it can be seen that the subjects had changed as follow;

Self-care requisites for primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells were changed as in the following details;

Universal self-care requisites: it was found that the subjects could gain a very high average score in all items. It indicated the difference of scores regarding primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells at pre-intervention and post-intervention period. As a result, that difference was statistically significant at the level 0.01. Those were the practice in caring for children to receiving appropriate food and water, sleeping, preventing constipation, and respiratory tract infection. At the post-intervention period, mostly the appropriate behavior was feeding. However, all of the items helped in reducing the factors of cyanotic spells, and they had a high average score in all items.

Developmental self-care requisites: it was found that the subjects could gain a very high average score in all items. It indicated the difference of scores regarding primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells at pre-intervention and post-intervention period. As a result, the difference

was statistically significant at the level 0.01, which was the practice in caring for children when children were crying and playing. Crying and playing are factors to stimulate cyanotic spells. They had high average score in these items, so the children should decrease the factors to stimulate cyanotic spells.

Health-deviation self-care requisites: it was found that the subjects could gain a very high average score in nearly all items. It indicated the difference of scores regarding primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells at pre-intervention and post-intervention period. As a result, the difference was statistically significant at the level 0.01. That was the practice in caring for children when children had health-deviation, and it related to cyanotic spells. At the post-intervention period, the most appropriate behavior was caring when cyanotic spells occured in the children. Therefore, severity of the occurrence of cyanotic spells was decreased, as shown in Table 7. Even if average scores in item no.14 were not statistically significant, the average scores in pre and post test had similar average scores. Primary caregivers had appropriate behaviors about giving drugs for the children. Moreover, their were a high average score in this item. However, item no. 19 was not statistically significant at the level 0.05. This item has content about follow-up. It will be a problem to correct in future, but it did not affect the occurrence of cyanotic spells in this study because all subjects had participated in the supportive-educative nursing system plan.

Hypothesis II

The frequency of the occurrence of cyanotic spells after primary caregivers received the supportive-educative nursing system was lower than or equal to the frequency of the occurrence of cyanotic spells before receiving the supportive-educative nursing system.

The research results found that the mean of the occurrence of cyanotic spells after primary caregivers received the supportive-educative nursing system was lower than the frequency of the occurrence of cyanotic spells before receiving the supportive-educative nursing system with statistical significance ($p<.05$) (Table 5) which can be explained as follows.

This research studied the effects of the supportive-educative nursing system on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells. The hypothesis testing was an assessment of the result of the behavior of primary caregivers, and the dependent-care agency of the primary caregivers, with the primary caregivers having the potential of developing the ability to put into performance their child care. The results showed Hypothesis 1 was supported because the subjects had more appropriate behaviors in the post-intervention period. The results might be because the frequency of the occurrence of cyanotic spells was decreased by appropriate behaviors of the primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells, because the appropriate behaviors of primary caregivers covered therapeutic self-care demand of children with cyanotic heart disease at risk of cyanotic spells.

However, when considering the occurrence of cyanotic spells, it was found that most of the subjects had a frequency of occurrence of cyanotic spells at post intervention lower than at pre intervention. One explanation may be because primary caregivers received the supportive-educative nursing system and could learn from the useful information and suggestions provided. Therefore, they could have more appropriate behaviors. According to the study of Ratanachadawan Munkunnan (B.E.2541: 69) it was found that the mean score of self-care deficit of older children with thalassemia was decreased statistically after receiving nursing care according to the program ($p<.001$). Frequency of blood tranfusion in the 3 mounths after the program started was statistically significantly lower than during the 3 months before entering the program ($P<.01$), but frequency of infection and hematocrit were not different ($p>.05$). Moreover, Sasichol Kamproh (2001: iv) who studied the effectiveness of health education programs upon maternal behaviors in caring for children with ventricular septal defect found that after the experiment the mothers in the experimental group gained a significantly higher level of: perceived severity, perceived vulnerability of getting complications, perceived response efficacy, perceived self-efficacy, behavior intention and behaviors on caring for children with VSD ($p<.001$) than before the experiment. It was also found that after the experiment the average frequency of respiration infection of children decreased significantly ($p<.001$) among the children whose mothers were in the experimental group.

The occurrence of cyanotic spells was evaluated at pre-intervention at 2 months and post-intervention at 2 months by the assessment form of the occurrence of cyanotic spells. As for the continuity of assessment, caregivers received telephone follow-ups, with joint participation at every 4 weeks. Postcards were also sent for motivation to record data. As for the follow up by telephone by the researcher, it was found that primary caregivers were attentive in raising their questions, and telling stories of their children with cyanotic spells. When the researcher analyzed the results of the occurrence of cyanotic spells in individual cases, it was found that 63.33% (19 cases) had decreased occurrence of cyanotic spells, while 26.67% (8 cases) had increased occurrence of cyanotic spells, and 10% (3 cases) had a similar occurrence between pre and post intervention (Table 6). In addition, degree of severity of the occurrence of cyanotic spells were analyzed from the assessment form of the occurrence of cyanotic spells, and degree of severity in individual cases was analysed. It was found that the degree of severity of the occurrence of cyanotic spells in individual cases before and after receiving the supportive-educative nursing system was as follow. Most of the subjects had asimilar degree of severity of the occurrence of cyanotic spells among before and after receiving the supportive-educative nursing system (40.00%). 30.00% of subjects had an increased degree of severity of the occurrence of cyanotic spells in individual cases after receiving the supportive-educative nursing system, and 30.00% of subjects had a decreased degree of severity of the occurrence of cyanotic spells in individual cases after receiving the supportive-educative nursing system. However, subjects with an increased degree of severity and subjects with a decreased degree of severity were equal in degree of severity of the occurrence of cyanotic spells. However, semi-unconsciousness was the highest degree of severity of the occurrence of cyanotic spells. Five subjects had decreased degree of severity in semi-unconsciousness degree. These results supported the concept that supportive educative nursing system had effects on the occurrence of cyanotic spells on frequency and severity of cyanotic spells.

However, some subjects had higher frequency of occurrence of cyanotic spells in post intervention than pre intervention. It could be explained that they had a serious condition of disease, and some cases commented about recording data that they could not completely record it because the children went to school (4 cases). Also, in this

research, two subjects received an operation after completion of the project. Moreover, the researcher could not control the primary caregivers to observe and record every occurrence of cyanotic spells. The researcher could only motivate them to do so continualy and verify a correct recording in the first day of participation. However, most primary caregivers said that "I try to record each of the occurrences of cyanotic spells" and "I feel satisfied with recording cyanotic spells because it helps my child to have a cyanotic spells data report for the doctor when we have follow ups, and the doctor asks me about cyanosis or cyanotic spells of my child." This showed that the relationship and follow up guidance and support by the researcher with the primary caregivers under the supportive educative nursing system plan had been successful, making the primary caregivers able to practice by decreasing their children' rate and severity level of occurrence of cyanotic spells.

CHAPTER VI

CONCLUSIONS AND RECOMMENDATIONS

In this chapter, the conclusions of the study will be presented first. The section will be closed with the recommendations from the results for nursing practice, nursing education, nursing administration and nursing research.

Conclusion

The aim of this study was to determine the effects of a supportive-educative nursing system on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and the occurrence of cyanotic spells, in order to ascertain caregiver's performance in a pediatric cardiology clinic, department of pediatrics using a pre-experimental design.

There was one group of subjects selected by purposive sampling. The sample in this study was 30 cases. These consisted of children with cyanotic heart disease at risk of cyanotic spells and primary caregivers who had children with cyanotic heart disease at risk of cyanotic spells who attended at the Pediatric Cardiology Clinic, Department of Pediatrics, King Chulalongkorn Memorial Hospital, Thai Red Cross Society. The children were 2-6 years old, and had never undergone any palliative operation or total correction. They were free from the following conditions: febrile convulsions, epilepsy, cerebrovascular accidents, brain abscess, breath holding spells, and heart failure. The caregivers were the primary caregivers, able to read or listen in the Thai Language, who were willing to participate in this study, and able to communicate with the researcher by telephone. The exclusion criteria were any subject who undergone any palliative operation or total correction during of the experimental period.

The research was undertaken in the Pediatric Cardiology Clinic, Department of Pediatrics, King Chulalongkorn Memorial Hospital, Thai Red Cross Society, Thailand. The period of data collection was from January to June 2003. The study used a pre-experimental single-group pre-test-post-test design to evaluate primary caregiver behavior

in caring for children with cyanotic heart disease at risk of cyanotic spells and the occurrence of cyanotic spells using a supportive-educative nursing system.

The instruments used in this study consisted of two parts as follows:

1. Instruments for data collection comprised of:

1.1 The questionnaire of children's and caregivers' background information

1.2 The questionnaire of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells

1.3 The assessment form of cyanotic spells in assessing for the occurrence of cyanotic spells of children with cyanotic heart disease at risk of cyanotic spells

2. Instruments for intervention

2.1 The instruction plan about cyanotic spells for primary caregivers which explained about cyanotic spells and signs and symptoms for the occurrence of cyanotic spells.

2.2 The supportive-educative nursing system for primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells

2.2.1 An illustration of cyanotic heart disease

2.2.2 The instruction plan about primary caregiver behavior self-practice in caring for children with cyanotic heart disease at risk of cyanotic spells. It explained about cyanotic spells, covering causes, prevention of cyanotic spells, and assistance during occurrence of cyanotic spells.

2.2.3 A Video tape about the ocurrence and assistance during occurrence of cyanotic spells for the primary caregiver

2.2.4 A pamphlet about cyanotic spells

2.2.5 Postcards about assessing and recording the occurrence of cyanotic spells

Five relevant experts tested the content validity of the questionnaire of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells. The assessment form of cyanotic spells in assessing for the occurrence of cyanotic spells in children with cyanotic heart disease at risk of cyanotic spells. An instruction plan about cyanotic spells for primary caregivers, a pamphlet about

cyanotic spells, an illustration of cyanotic heart disease, a video tape about the occurrence and assistance during occurrence of cyanotic spells for primary caregivers and a postcard about assessing for and recording the occurrence of cyanotic spells. The questionnaire of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells was tested for reliability among 10 primary caregivers who had similar characteristics to the subjects in this study. Data was analyzed by Cronbach's Alpha Coefficiency reliability. The reliability of this questionnaire was 0.88.

Before commencing research and data collection, permission was sought from the Faculty of Graduate Studies, Mahidol University and the Director of King Chulalongkorn Memorial Hospital, Thai Red Cross Society. The institutional ethics review board approved the materials used in conducting the supportive-educative nursing plans, the means of collecting data and the consent forms. Permission was also sought from the pediatricians, who had the responsibility for the patients in the Pediatric Cardiology Clinic and the Head nurse of the out-patient pediatric department and the parents or caregivers of the pediatric patients. The researcher outlined the procedures and the complications to them through the consent form, and if they wanted to participate in this study, they signed the form.

The supportive-educative nursing system plans were designed for primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells. The thirty primary caregivers who had the necessary characteristics for inclusion were interviewed using the questionnaire of the child's and caregivers' background information and then tested by the questionnaire of primary caregivers' behaviors in caring for children with cyanotic heart disease at risk of cyanotic spells. The researcher interviewed the primary caregivers about their behaviors in caring, and the researcher showed a video about the occurrence of cyanotic spells and explained the assessment form for recording the occurrence of cyanotic spells of the children to primary caregivers which was to be used every day for eight weeks. The primary caregivers received motivation by telephone and postcards. At eight weeks, the primary caregivers received the supportive-educative nursing system and they continuously recorded the assessment form of the occurrence of cyanotic spells to complete the intervention at 16 weeks. The intervention commenced on 15 January 2003. As of 13 June 2003, the intervention were completed for a total of thirty primary caregivers. The primary caregivers were

then appointed to post-test at 16 weeks by using the questionnaire of primary caregiver behavior for children with cyanotic heart disease at risk of cyanotic spells in a similar procedure to the pre-test.

The data consisted of the characteristics of the sample, the primary caregiver behavior scores, the occurrence of cyanotic spells, and hypothesis testing, all of which were analyzed by using SPSS/FW Version 10.0. The differences of means between pre-post interventions were compaired by paired t-test.

The research results are as follows:

1. The post-test scores of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells was higher than the pre-test scores.

2. The frequency of the occurrence of cyanotic spells after primary caregivers receive the supportive-educative nursing system was lower than the frequency of the occurrence of cyanotic spells before they received the supportive-educative nursing system.

Research Limitations

1. The subjects were not selected by means of a randomized sampling technique but by purposive sampling. Thus, the results of the study could be generalized only to a population similar to the sample.

2. The suggestions from the other staff providing their own nursing care could not be controlled by the researcher.

3. The researcher could not control the primary caregivers in observing the occurrence of cyanotic spells at home environment in some cases because the children had to go to school.

Recommendations

The findings of this study provided several important implications for nursing practice, nursing education, nursing research, and nursing administration.

Nursing practice

1. Academic raising for staff in nursing care for the primary caregivers should be organized to develop knowledge and conceptual thoughts in a uniform pattern in nursing practice.

2. There should be a uniform, consistent pattern of primary nursing care using the supportive-educative nursing system.

3. Pamphlets, video tape about the occurrence of cyanotic spells and assistance, an illustration, and postcards about caring for cyanotic spells should be provided and placed in Pediatric Cardiology Wards and Pediatric Cardiology Clinics to disseminate knowledge and understanding.

4. Research results should be transformed into a guideline for a nursing care plan, nursing practice, and follow-ups. Such information should be given to personnel who will follow-up with those who have problems and who will perform close evaluation.

5. The research results will assist primary caregivers and pediatric staff to be aware of the cyanotic spells of children with cyanotic heart disease at risk of cyanotic spells and help prevent problems while waiting for operation.

6. The result of this research can be used as a guideline for management to raise awareness of the importance of nursing care for primary caregivers of the children. The management should be urged to support the use of specific areas of this nursing system. Moreover, the results showed that nursing care should be developed from theories and research utilization for appropriate care. Advanced practice nurses can be the best leaders in role development including the collaboration from others in the profession i.e. doctors , nutritionists,etc..

Nursing education

The results can be used as a guideline in implementing theoretical teaching and practical teaching for nursing students on the significance of holistic care, coping and implementation of Orem's Nursing Theory with the aim of developing the behaviors of the primary caregivers. It can be used as a guideline in education programs and to plan a supportive-educative nursing system to help the primary caregivers and their families effectively and continuously. In addition, it is advisable to have a training session for related personnel in this service field to inform them of steps involved in relationship

creation, and instructing primary caregivers to teach them about caring for children with cyanotic heart disease at risk of cyanotic spells.

Nursing research

For nursing research, it is obvious that future studies are based on the findings about different behaviors of primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells between follow-up. The study results provide nurses with baseline information of primary caregiver behavior and for further study of factors influencing primary caregivers' behaviors in caring for children with cyanotic heart disease.

Nursing Administration

The supplementary teaching on the topic of a supportive-educative nursing system on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells should be provided to clinical nurses. Because the occurrence of cyanotic spells is considered a major problem for children, particularly in children with cyanotic heart disease at risk of cyanotic spells. The research has shown that it lowers the rate of the occurrence of cyanotic spells. This strategy certainly enables the nurses to realize what the extent of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells is as well as recognizing all important problems encountered by the primary caregivers. As a result, nurses will be capable of adjusting the primary caregiver behavior about children's care to be more suitable and effective. Moreover, the instructions on primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells should be distributed to all of the primary caregivers who bring their children with cyanotic heart disease to the hospitals for treatment. They should also receive advise on the usefulness of these instructions. This is helpful to encourage the primary caregivers to practice children care activity appropriately when they go back their home; also rate of the occurrence of cyanotic spells will be obviously reduced.

Suggestions for further studies

1. The effects of the supportive-educative nursing system on the primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells and the occurrence of cyanotic spells in the long-term should be thoroughly investigated.

2. A study of the effects of a supportive-educative nursing system on the primary caregiver behavior in caring for children with acyanotic heart disease at risk of congestive heart failure and the occurrence of congestive heart failure should also be carried out.

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APPENDIX

List of experts consulted on validation of questionnaire.

The following experts assisted the researcher in developing all instrument used in this study

1. Professor Jul Tisayakorn. M.D.
   Expert of Paediatric Cardiology
   Chulalongkorn hospital, Chulalongkorn University

2. Associate Professor Porntape Leardsapcharearn M.D.
   Expert of Paediatric Cardiology
   Chulalongkorn hospital, Chulalongkorn University

3. Associate Professor Wilai Leesuwan
   Nursing Department, Faculty of Medicine,
   Ramathibodi hospital, Mahidol University

4. Assistant Professor Dr.Jariya Wittayasooporn
   Nursing Department, Faculty of Medicine,
   Ramathibodi hospital, Mahidol University

5. Associate Professor Julai Arpaichirarachakit
   Nursing Department, Thai Red Cross College of Nursing

Research consent form

การพิทักษ์สิทธิ์ของผู้เข้าร่วมวิจัย

ดิฉันนางสาวอรจิรา เทียนน้ำเงิน เป็นนักศึกษาพยาบาลปริญญาโท สาขาการพยาบาลเด็ก ภาควิชาพยาบาลศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล มีความประสงค์ที่จะศึกษา

เรื่อง ผลของการพยาบาลระบบสนับสนุนและให้ความรู้ต่อพฤติกรรมผู้ดูแลในการดูแลเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหันและการเกิดภาวะเขียวกะทันหัน

รายละเอียดการวิจัยโดยย่อ การวิจัยนี้เป็นการศึกษาถึงผลของการพยาบาลระบบสนับสนุนและให้ความรู้ต่อพฤติกรรมผู้ดูแลในการดูแลบุตรโรคหัวใจพิการแต่กำเนิดชนิดเขียว ที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหันและการเกิดภาวะเขียวกะทันหันในผู้ป่วยเด็กที่มารับการตรวจที่แผนกผู้ป่วยนอกเด็กโรคหัวใจของโรงพยาบาลจุฬาลงกรณ์ สภากาชาดไทย จึงใคร่ขอความร่วมมือจากผู้ดูแลและผู้ป่วยเด็กเพื่อเข้าร่วมในการศึกษาครั้งนี้ โดยการตอบแบบสัมภาษณ์ข้อมูลทั่วไป แบบสอบถามพฤติกรรมผู้ดูแลในการดูแลบุตรโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน แบบบันทึกภาวะเขียวกะทันหัน การเข้ากลุ่มแลกเปลี่ยนประสบการณ์การดูแลเด็ก และการติดตามการดูแลเด็กทางโทรศัพท์และไปรษณีย์บัตรจากผู้วิจัย เพื่อนำผลการศึกษาไปใช้เป็นแนวทางในการให้การพยาบาลและพัฒนาคุณภาพการพยาบาลสำหรับผู้ดูแลที่มีบุตรป่วยโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหันต่อไป

ผู้วิจัยรับรองว่าจะเก็บข้อมูลที่เกี่ยวกับผู้เข้าร่วมวิจัยเป็นความลับและจะนำเสนอผล การวิจัยในภาพรวม หากท่านมีข้อสงสัยดิฉันยินดีอธิบายให้ท่านเข้าใจได้ตลอดเวลา ท่านมีสิทธิที่จะตอบรับหรือปฏิเสธหรือยกเลิกการเข้าร่วมการศึกษาได้ทุกเวลา โดยจะไม่มีผลต่อการรักษาหรือบริการที่ท่านและบุตรจะได้รับจากโรงพยาบาล

ขอขอบคุณทุกท่านที่ให้ความร่วมมือ

(นางสาว อรจิรา เทียนน้ำเงิน)
ผู้วิจัย

ข้าพเจ้าได้รับทราบรายละเอียดของการวิจัยดังที่ได้อธิบายไว้ข้างต้น มีความเข้าใจและยินดีเข้าร่วมการศึกษาครั้งนี้ด้วยความเต็มใจ

ลงนาม.....

(.....)

No. 123/2003

Documentary Proof of Ethical Clearance
The Committee on Human Rights Related to Human Experimentation
Mahidol University, Bangkok

.....

Title of Project : The Effects of Supportive-Educative Nursing System on Primary Caregiver Behaviors in Caring for Cyanotic Cardiac Children with the Risk of Cyanotic Spells and the Occurrence of Cyanotic Spells

Principal Investigator : Miss Onchira Theannamngian

Name of Institution : Faculty of Medicine Ramathibodi Hospital

Approved by the Committee on Human Rights Related to Human Experimentation

Signature of Chairman : _____

(Professor Dr. Srisin Khusmith)

Signature of Head of Institute : _____

for (Professor Dr. Pornchai Matangkasombut)

Date of Approval : 25 JUN 2003

ที่ จพ.ล.๒๗๘ /2546

โรงพยาบาลจุฬาลงกรณ์
1873 ถนนพระรามที่ 4
แขวงปทุมวัน เขตปทุมวัน
กรุงเทพฯ 10330

๒๙ มีนาคม 2546

เรื่อง ยินดีให้เก็บข้อมูลเพื่อประกอบการทำวิทยานิพนธ์
เรียน คณบดีบัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล
อ้างถึง หนังสือที่ ทม 0802.01(ศย)/279 ลงวันที่ 10 มีนาคม 2546

ตามหนังสือที่อ้างถึง บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล แจ้งความประสงค์ขอความอนุเคราะห์ให้ นางสาวอรจิรา เทียนน้ำเงิน นักศึกษาบัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล หลักสูตรปริญญาโท สาขาวิชาการพยาบาลเด็กฯ เข้าเก็บข้อมูลจากผู้ดูแลผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียว ที่แผนกผู้ป่วยนอก เด็กโรคหัวใจ ภปร ชั้น 9 โดยใช้แบบสัมภาษณ์และแบบประเมินภาวะเขียวกระทันหันเป็นเครื่องมือในการวิจัย ตั้งแต่วันที่ 10 มีนาคม 2546 ถึงวันที่ 31 พฤษภาคม 2546 นั้น

โรงพยาบาลจุฬาลงกรณ์พิจารณาแล้ว ไม่ขัดข้อง ยินดีให้ดำเนินการตามที่แจ้ง กรุณาติดต่อขอพบหัวหน้าพยาบาล ตึกจักรพงษ์ชั้น 2 ในวันที่เก็บข้อมูล อนึ่ง ก่อนพบบุคคลดังกล่าว ขอให้นักศึกษานำบัตรนักศึกษาหรือบัตรประจำตัวประชาชนพร้อมจดหมายฉบับนี้มาติดต่อรับบัตรประจำตัวผู้เก็บข้อมูล ณ ตึกอำนวยการ ชั้นล่าง ห้องหมายเลข 4

จึงเรียนมาเพื่อทราบ

ขอแสดงความนับถือ

(รองศาสตราจารย์นายแพทย์คเณศร์ แวววิจิต)
รองผู้อำนวยการฯฝ่ายวิชาการ
ปฏิบัติการแทน ผู้อำนวยการโรงพยาบาลจุฬาลงกรณ์

ฝ่ายการพยาบาล โทรศัพท์ 0-2256-4360
ฝ่ายกุมารเวชศาสตร์ โทรศัพท์ 0-2256-4951

Questionnaire

Part : 1 The questionnaire of child's and primary caregiver's background Information

แบบสัมภาษณ์ข้อมูลทั่วไป

ผู้ป่วยเด็กชื่อ.....

H.N.....วันที่บันทึก.....

ที่อยู่.....

โทรศัพท์.....

ส่วนที่ 1 ข้อมูลส่วนบุคคลของผู้ดูแล

1. มีความสัมพันธ์เกี่ยวข้องกับเด็กป่วย โดยเป็น.....
2. อายุ.....ปี
3. สถานภาพสมรส
   - ( ) คู่
   - ( ) ม่าย หย่า หรือ แยกกันอยู่
4. ระดับการศึกษา
   - ( ) ไม่ได้เรียน
   - ( ) ประถมศึกษา
   - ( ) มัธยมศึกษา
   - ( ) ประกาศนียบัตร หรือ อนุปริญญา
   - ( ) ปริญญาตรี หรือ สูงกว่า
5. อาชีพ
   - ( ) ไม่ได้ประกอบอาชีพ
   - ( ) รับราชการ หรือ รัฐวิสาหกิจ
   - ( ) ค้าขาย
   - ( ) เกษตรกรรม
   - ( ) รับจ้าง
   - ( ) อื่น ๆ

6. รายได้ของครอบครัวโดยเฉลี่ยต่อเดือน

( ) น้อยกว่า หรือ เท่ากับ 5,000 บาท

( ) 5,000 - 10,000 บาท

( ) 10,001 - 15,000 บาท

( ) 15,001 - 20,000 บาท

( ) 20,001 - 25,000 บาท

( ) มากกว่า 25,000 บาท

7. วิธีจ่ายค่ารักษาพยาบาล

( ) เบิกค่ารักษาพยาบาลได้ทั้งหมด

( ) เบิกค่ารักษาพยาบาลได้บางส่วน

( ) จ่ายค่ารักษาเองทั้งหมด

( ) ใช้สิทธิบัตรต่าง ๆ

8. ครอบครัวของท่านมีปัญหาการเงินหรือไม่

( ) ไม่มี ( ) มี (ถ้ามีตอบข้อ 9)

9. ถ้ามีปัญหาการเงินอยู่ในระดับใด

( ) เล็กน้อย ( ) ปานกลาง ( ) มาก

10. ลักษณะครอบครัว

( ) ครอบครัวเดี่ยว (ผู้ที่อยู่ในบ้านเดียวกันประกอบด้วย พ่อ แม่ ลูก)

( ) ครอบครัวขยาย (มีญาติพี่น้องอื่น ๆ อาศัยอยู่ในบ้านด้วย)

11. ในขณะดูแลเด็กป่วยที่บ้าน ท่านมีผู้ช่วยเหลือร่วมรับผิดชอบดูแลด้วยหรือไม่

( ) ไม่มี

( ) มี คือ.....(โปรดระบุความสัมพันธ์กับเด็ก)

ส่วนที่ 2 ข้อมูลส่วนบุคคลของเด็กป่วย

1. อายุ.....ปี.....เดือน

2. เพศ

( ) ชาย

( ) หญิง

3. เป็นบุตรคนที่.....

ส่วนที่ 3 สำหรับผู้วิจัย

1. การวินิจฉัยของแพทย์.....

2. ระยะเวลาการเจ็บป่วยด้วยโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน จำนวน.....ปี.....เดือน

3. การเข้าพักรักษาในโรงพยาบาลด้วยภาวะเขียวกะทันหัน

( ) เคย ระบุ.....ครั้ง ( ) ไม่เคย

Part 11: The questionnaire of primary caregiver behavior in caring for children with cyanotic heart disease at risk of cyanotic spells

แบบสัมภาษณ์พฤติกรรมผู้แลในการดูแลเด็กป่วยโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน

คำชี้แจง

1) แบบสอบถามฉบับนี้มีวัตถุประสงค์เพื่อประเมินพฤติกรรมของผู้ดูแลในการดูแลเด็กป่วยโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน

2) ผู้วิจัยจะสัมภาษณ์โดยถามคำถามทีละข้อ และให้ผู้ดูแลเลือกตอบว่าคำตอบใดตรงกับพฤติกรรมที่ปฏิบัติหรือคิดว่าจะปฏิบัติหากมีเหตุการณ์นั้นเกิดขึ้น

3) โปรดทำเครื่องหมาย ✓ ในช่องคำตอบที่เลือก

ตัวอย่าง

1. อาหารที่ท่านดูแลให้เด็กได้รับในแต่ละวัน คือข้อใด **(เลือกตอบ 1 ข้อ)**

(✓) 1. ข้าวหรือแป้งอื่น ๆ เนื้อสัตว์ ตับ ไข่แดง นม ขนมต่าง ๆ

( ) 2. ข้าวหรือแป้งอื่น ๆ ไข่แดง ตับ เนื้อสัตว์ ผัก ผลไม้ ขนมต่าง ๆ

( ) 3. ข้าวหรือแป้งอื่น ๆ ไข่แดง แป้ง นม ขนมต่าง ๆ

2. ท่านป้องกันไม่ให้เด็กท้องผูกอย่างไร **(ตอบได้มากกว่า 1 ข้อ)**

(✓) 1. สังเกตการถ่ายอุจจาระของเด็กทุกวัน

(✓) 2. ดูแลให้เด็กรับประทานผัก ผลไม้ หรือน้ำผลไม้ทุกวัน

( ) 3. ดูแลให้เด็กดื่มน้ำวันละประมาณ 6-8 แก้ว

1. อาหารที่ท่านดูแลให้เด็กได้รับในแต่ละวัน คือข้อใด **(เลือกตอบ 1 ข้อ)**

( ) 1. ข้าวหรือแป้งอื่น ๆ เนื้อสัตว์ ตับ ไข่แดง นม ขนมต่าง ๆ

( ) 2. ข้าวหรือแป้งอื่น ๆ ไข่แดง ตับ เนื้อสัตว์ ผัก ผลไม้ ขนมต่าง ๆ

( ) 3. ข้าวหรือแป้งอื่น ๆ ไข่แดง แป้ง นม ขนมต่าง ๆ

2. ท่านดูแลให้เด็กได้รับวิตามินเสริมธาตุเหล็กอย่างไร**(เลือกตอบ 1 ข้อ)**

( ) 1. หลังอาหาร ½ ชั่วโมง

( ) 2. หลังอาหารทันที

( ) 3. หลังอาหารมากกว่า 1 ชั่วโมง

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19. ท่านพาเด็กมารับการตรวจอย่างไร **(เลือกตอบ 1 ข้อ)**

( ) 1. ตามวันและเวลาที่แพทย์นัดทุกครั้ง

( ) 2. ตามวันและเวลาที่แพทย์นัดทุกครั้ง ถ้าสามารถมาได้

( ) 3. เฉพาะเมื่อเด็กไม่สบายจึงพามาตรวจ

Part 111: The assessment form to record the occurrence of cyanotic spells

แบบประเมินการเกิดภาวะเขียวกะทันหันที่เกิดขึ้นในผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียว สำหรับผู้ดูแลเด็ก

คำชี้แจง

แบบประเมินนี้มีวัตถุประสงค์เพื่อช่วยผู้ดูแลในการบันทึกการเกิดภาวะเขียวกะทันหันที่เกิดขึ้นกับเด็กป่วย โดยให้ท่านพิจารณาข้อความในแต่ละข้อความที่ท่านได้สังเกตเห็นว่าเด็กมีอาการดังกล่าวในแต่ละครั้งที่มีภาวะเขียวกะทันหัน แล้วทำเครื่องหมาย ✓ ลงในช่องคำตอบ

วันที่/ครั้งที่ / อาการ																				
	ครั้งที่			ครั้งที่			ครั้งที่			ครั้งที่			ครั้งที่			ครั้งที่			ครั้งที่		
	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3
1. กระวนกระวาย หรือกระสับกระส่าย และหรือร้องไห้																					
2. มีลักษณะเขียวบริเวณริมฝีปาก ปลายมือ ปลายเท้า มากขึ้นกว่าเดิมทันทีทันใด																					
3. มีอาการหายใจหอบลึก																					
4. นั่งยอง ๆ เป็นพัก ๆ																					
5.มีอาการตัวอ่อนแล้วหลับไป																					

หมายเหตุ

* ถ้ามีอาการอื่น ๆ โปรดระบุ

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The script of vedio tape about cyanotic spells

บทบรรยายประกอบภาพวิดิทัศน์

เรื่อง อาการแสดงภาวะเขียวกะทันหันและการช่วยเหลือเมื่อผู้ป่วยเกิดภาวะเขียวกะทันหัน

เวลา	ภาพ	ข้อความ	หมายเหตุ
30วินาที	ภาพผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียว	ภาวะเขียวกะทันหันเป็นภาวะแทรกซ้อนที่มักเกิดขึ้นในเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวโดยเฉพาะชนิดที่มีเลือดไปปอดน้อย เช่น TOF และถ้าหากว่าเด็กมีภาวะเขียวกะทันหันเกิดขึ้นบ่อย ๆ หรือ ปล่อยให้เกิดภาวะนี้นาน ๆ ก็อาจจะทำให้สมองพิการหรือเสียชีวิตได้	
2 นาที	ภาพผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียว	อาการที่แสดงว่าเด็กมีภาวะเขียวกะทันหัน สามารถสังเกตได้ว่าเด็กจะกระวนกระวายหรือกระสับกระส่ายหรือร้องไห้และมีอาการเขียวมากขึ้นบริเวณริมฝีปาก ปลายมือ ปลายเท้า ร่วมกับหายใจหอบลึก ต่อมาจะมีตัวอ่อนแล้วหลับไป	ภาพเน้น * ริมฝีปาก * ปลายมือ-ปลายเท้า * หน้าอก
30 วินาที	ภาพมารดากำลังช่วยบุตรเมื่อเกิดภาวะเขียวกะทันหันขึ้น	สิ่งที่ผู้ดูแลจะช่วยเด็กได้คือ ถ้าเด็กร้องไห้ปลอบให้สงบ แล้วจัดให้อยู่ในท่างอเข่าชิดหน้าอกมากที่สุด ในที่ที่มีอากาศถ่ายเทสะดวก	
10 วินาที	ภาพผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวหลังได้รับการช่วยเหลือจากผู้ดูแล	หลังจากที่ได้ให้การช่วยเหลือเด็กแล้ว เด็กจะมีอาการดีขึ้น จะสังเกตเห็นว่าเด็กเขียวน้อยลง หายใจหอบน้อยลง	
15 วินาที	ภาพผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่มีอาการเขียวกะทันหัน	แต่ถ้าเด็กเกิดภาวะเขียวกะทันหันขึ้นและไม่ได้รับการช่วยเหลือ อาการจะรุนแรงมากขึ้น จะมีตัวแข็ง ตาเหลือก ไม่รู้สึกตัว หรือชักได้	
10 วินาที	ภาพผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวในภาวะปกติ	ดังนั้นผู้ดูแลเด็กคือผู้ที่มีบทบาทสำคัญมากที่สุดที่จะช่วยให้เด็กปลอดภัยจากภาวะเขียวกะทันหัน	

Instruction plan about primary caregiver behavior in caring for children at risk of cyanotic spells

แผนการสอน เรื่องการดูแลเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน

วัตถุประสงค์	เนื้อหาการสอน	กิจกรรม	อุปกรณ์	ประเมินผล
เมื่อจบบทเรียนแล้ว ผู้ดูแลสามารถ 1. บอกความหมายของภาวะเขียวกะทันหันได้ 2. บอกผลกระทบของภาวะเขียวกะทันหันต่อเด็กป่วยได้	ภาวะเขียวกะทันหัน คือ กลุ่มอาการที่เกิดในผู้ป่วยเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่มีเลือดไปปอดน้อย เช่น TOF ภาวะเขียวกะทันหันเป็นภาวะที่เกิดจากการลดลงทันทีทันใดของปริมาณเลือดที่ไปปอด ทำให้ปริมาณเลือดจากหัวใจด้านขวาถูกบีบไปด้านซ้ายมากขึ้นโดยผ่านรูรั่วของผนังกั้นห้องหัวใจ เกิดภาวะออกซิเจนในกระแสเลือดลดลง ส่งผลให้สมองขาดออกซิเจนอย่างฉับพลัน ถ้าเกิดขึ้นบ่อย ๆ หรือปล่อยให้เป็นนาน ๆ จะทำให้สมองพิการและอาจตายได้	- สร้างสัมพันธภาพ กับผู้ดูแลและเด็กป่วย โดยแนะนำตัว บอกวัตถุประสงค์ - สอบถามความรู้เดิมของผู้ดูแลเด็กป่วยเกี่ยวกับภาวะเขียวกะทันหันแล้วนำเข้าสู่เนื้อหา - ผู้สอนบรรยายถึงความหมายและผลกระทบของภาวะเขียวกะทันหัน (เวลา 5 นาที)	ภาพแสดงลักษณะของความผิดปกติของหัวใจชนิดต่าง ๆ ที่มักจะเกิดภาวะเขียวกะทันหัน	- สังเกตความสนใจของผู้ดูแลและการซักถาม - ผู้ดูแลบอกความหมายและผลกระทบของภาวะเขียวกะทันหันได้ถูกต้อง ครบถ้วน

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2. ผู้ดูแลบอกได้ถึงอาการที่แสดงถึงภาวะเขียวกะทันหัน	เด็กจะเริ่มมีอาการเขียวมากขึ้นทันทีทันใด โดยเริ่มจากเด็กจะกระวนกระวาย กระสับกระส่าย หรือร้องไห้ หายใจหอบลึก ริมฝีปากและปลายมือปลายเท้าเขียวมากกว่าปกติ หลังจากนั้นจะมีตัวอ่อนแล้วก็หลับไป ถ้าอาการมากขึ้น เด็กจะตัวแข็ง ตาเหลือก ไม่รู้สึกตัว ชัก โดยมากเด็กมักมีอาการตอนเช้าหลังตื่นนอน ภาวะขาดน้ำ ขณะหรือภายหลังออกกำลังกายมากเกินไป ร้องไห้นาน เบ่งถ่ายอุจจาระ	- ผู้สอนบรรยายอาการที่แสดงถึงภาวะเขียวกะทันหัน - ฉายภาพวิดีทัศน์แสดงภาวะเขียวกะทันหัน - ซักถามถึงประสบการณ์ของผู้ดูแลเกี่ยวกับการเกิดภาวะเขียวกะทันหันที่เกิดขึ้นกับผู้ป่วย (เวลา 5 นาที)	โทรทัศน์ เครื่องเล่นวีดีโอ ภาพวิดีทัศน์แสดงภาวะเขียวกะทันหัน	สังเกตความสนใจและการซักถามอาการแสดงภาวะเขียวกะทันหัน รวมทั้งการตอบคำถามถึงอาการที่แสดงถึงภาวะเขียวกะทันหันของผู้ดูแลเด็กป่วย

วัตถุประสงค์	เนื้อหาการสอน	กิจกรรม	อุปกรณ์	ประเมินผล
3. ผู้ดูแลบอกได้ถึงการป้องกันการเกิดภาวะเขียวกะทันหันด้วยการลดปัจจัยสนับสนุนการเกิดภาวะเขียวกะทันหัน	การป้องกันการเกิดภาวะเขียวกะทันหัน มีแนวทางดังนี้ คือ 1. รับประทานอาหารที่มีธาตุเหล็กมากทุกวัน เช่น เนื้อสัตว์ต่าง ๆ ไข่แดง นม ถั่ว และรับประทานอาหารที่มีวิตามินซีมากทุกวันจากผักผลไม้ต่าง ๆ หรือน้ำผลไม้ เช่น ส้ม สับปะรด มะเขือเทศ เพื่อที่จะช่วยให้ร่างกายสร้างเม็ดเลือดที่มีคุณภาพในการรับออกซิเจน โดยแบ่งอาหารหรือนมออกเป็นหลายมื้อในแต่ละวัน 2. เมื่อเด็กอาเจียนหรือท้องเสีย ต้องให้ได้รับน้ำชดเชยอย่างเพียงพอ ถ้าไม่ดีขึ้นควรนำส่งโรงพยาบาลทันที เนื่องจากการเสียน้ำออกจากร่างกายทำให้มีภาวะเลือดหนืดขึ้นได้ ทำให้การไหลเวียนเลือดของร่างกายผิดปกติ 3. ให้เด็กได้พักผ่อนอย่างเพียงพอ ในเด็กเล็กวันละ10-15 ชั่วโมงหรือเด็กโตวันละ 8-12 ชั่วโมง และส่งเสริมการนอนด้วยการให้นอนในที่มีอากาศถ่ายเทดี ไม่มีเสียง แสง กลิ่นรบกวน 4. ไม่ปล่อยให้ลูกร้องไห้นาน ควรหาสาเหตุ	- ผู้บรรยายซักถามกิจกรรมที่ผู้ดูแลปฏิบัติ พูดคุยในพฤติกรรมการดูแลเด็กที่ยังไม่เหมาะสม ร่วมกันหาแนวทางการดูแลที่เหมาะสม และชมเชยในพฤติกรรมการดูแลที่เหมาะสมของผู้ดูแล - ผู้สอนบรรยายประกอบเอกสารให้ความรู้	เอกสารให้ความรู้เรื่องภาวะเขียวกะทันหัน	- สังเกตความสนใจการซักถามข้อสงสัยของผู้ดูแลและการร่วมหาแนวทางการดูแลที่เหมาะสม - ผู้ดูแลบอกถึงการป้องกันการเกิดภาวะเขียวกะทันหันได้ครบถ้วน

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	ที่ทำให้ลูกร้องไห้ สนองตอบความต้องการหรือเบี่ยงเบนความสนใจด้วยการเล่น หรือของเล่นที่เด็กชอบ 5. จัดกิจกรรมการเล่นที่ใช้แรงน้อย ไม่หลอกหรือเล่นด้วยการเล่นที่ทำให้เด็กตกใจ และสังเกตอาการเขียวกะทันหันขณะเล่น ถ้ามีให้หยุดเล่นและให้การช่วยเหลือทันที 6. สังเกตการขับถ่ายของเด็กทุกวัน และป้องกันไม่ให้ท้องผูกโดยให้เด็กรับประทานผัก ผลไม้ หรือน้ำผลไม้ทุกวัน 7. ป้องกันการติดเชื้อโดย 7.1 ทำความสะอาดปาก-ฟันทุกครั้งหลังอาหาร - เด็กเล็ก : เช็ดทำความสะอาดปากด้วยผ้าชุบน้ำ เช้าและเย็น - เด็กโต : แปรงฟันเช้าและก่อนอน และบ้วนปากหลังอาหารทุกครั้ง 7.2 พาเด็กไปพบทันตแพทย์ปีละ 1-2 ครั้ง และเมื่อมีฟันผุ แจ้งแพทย์ทุกครั้งว่าเป็นโรคหัวใจเพื่อให้ได้รับยาป้องกันการติดเชื้อก่อนทำฟัน			

วัตถุประสงค์	เนื้อหาการสอน	กิจกรรม	อุปกรณ์	ประเมินผล
	หรือในเด็กเล็กเมื่อพบเชื้อราในช่องปากจะต้องพาไปพบแพทย์ด้วยเช่นกัน 7.3 อาบน้ำวันละ 2 ครั้ง เช้า-เย็น ด้วยน้ำที่ไม่ร้อนหรือเย็นจนเกินไป 7.4 ให้เด็กล้างมือให้สะอาดก่อนรับประทานอาหาร ผู้ดูแลต้องล้างมือก่อนประกอบอาหารและป้อนอาหาร 7.5 จัดให้เด็กรับประทานอาหารที่ปรุงสุกใน ภาชนะที่สะอาด 7.6 ไม่ให้เด็กอยู่ใกล้ผู้ป่วยโรคติดเชื้อต่างๆ เช่น เป็นหวัด มีไข้ ไอ หรือเจ็บคอ ไม่พาลูกไปในที่มีคนหนาแน่น เช่น ห้างสรรพสินค้า โรงภาพยนตร์ ตลาด 7.7 พาลูกไปรับวัคซีนตามกำหนด 8. เมื่อลูกไม่สบาย เป็นไข้ เช็ดตัวลดไข้ และพาไปพบแพทย์ทุกครั้ง 9. ให้เด็กได้รับประทานยาอย่างถูกต้องตามที่แพทย์สั่ง และไปพบแพทย์ตามนัดทุกครั้ง 10. บันทึกการเกิดอาการเขียวกะทันหันของเด็กและแจ้งแก่แพทย์เมื่อไปพบแพทย์			

วัตถุประสงค์	เนื้อหาการสอน	กิจกรรม	อุปกรณ์	ประเมินผล
4. บอกได้ถึงการช่วยเหลือเมื่อเด็กป่วยมีภาวะเขียวกะทันหัน	เมื่อเด็กมีภาวะเขียวกะทันหันผู้ดูแลสามารถให้การช่วยเหลือได้โดย 1. จัดให้เด็กอยู่ในท่างอเข่าขึ้นมาชิดหน้าอกมากที่สุด - เด็กเล็ก : อุ้มแล้วงอเข่าเด็กให้มากขึ้นกว่าปกติหรือจัดให้นอนงอเข่าขึ้นมาชิดหน้าอก - เด็กโต : จัดให้นอนงอเข่าขึ้นมาชิดหน้าอกหรือนั่งยอง ๆ 2. ปลอบให้สงบถ้าร้อง การทำให้เด็กหยุดร้องจะช่วยลดภาวะเขียวกะทันหันได้ 3. จัดให้อยู่ในที่ที่อากาศถ่ายเทสะดวก 4. ถ้าอาการเขียวกะทันหันยังคงมีอยู่ และมีอาการหายใจเร็วหอบ ควรรีบพาเด็กมาพบแพทย์เพื่อทำการรักษาต่อไป	- ผู้สอนบรรยายการช่วยเหลือเมื่อเด็กป่วยมีภาวะเขียวกะทันหันพร้อมสาธิตการจัดท่าที่ถูกต้อง - ให้ผู้ดูแลฝึกปฏิบัติการช่วยเหลือเมื่อเด็กมีภาวะเขียวกะทันหันตามขั้นตอน - ร่วมอภิปรายหาแนวทางการช่วยเหลือที่เหมาะสมกับเด็ก	โทรทัศน์ เครื่องเล่นวีดีโอ ภาพวิดีทัศน์แสดงการช่วยเหลือเด็กเมื่อภาวะเขียวกะทันหัน	ผู้ดูแลบอกแนวทางการช่วยเหลือและแสดงขั้นตอนการช่วยเหลือเมื่อเด็กป่วยมีภาวะเขียวกะทันหันได้ถูกต้องครบถ้วน

Guideline for group discussion of primary caregivers in caring for children with cyanotic heart disease at risk of cyanotic spells

แนวทางการทำกิจกรรมกลุ่ม

เรื่อง การดูแลเด็กป่วยโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน

วัตถุประสงค์

1. เพื่อให้ผู้ดูแลทราบวัตถุประสงค์ของการเข้ากิจกรรมกลุ่ม
2. เพื่อให้ผู้ดูแลรู้จักและมีสัมพันธภาพที่ดีต่อกัน
3. เพื่อให้ผู้ดูแลแสดงความคิดเห็นและแลกเปลี่ยนประสบการณ์ซึ่งกันและกัน อภิปรายเกี่ยวกับปัญหาและข้อสงสัยของตนเองเกี่ยวกับการดูแลเด็กที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน และให้สมาชิกในกลุ่มหาแนวทางในการแก้ไขร่วมกัน

สมาชิกกลุ่ม

ผู้ดูแลและเด็กป่วยโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน จำนวน 2-5 ราย

สถานที่

ห้องตรวจโรคแผนกผู้ป่วยนอกเด็ก

ระยะเวลา

ประมาณ 20-30 นาที

หัวข้อที่สนทนา

1. การแนะนำตนเองของสมาชิกในกลุ่ม ใช้เวลาประมาณ 1- 3 นาที
2. จุดประสงค์การเข้ากลุ่ม ใช้เวลาประมาณ 3-5 นาที
3. การดูแลเด็กป่วยโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน ในด้านการสังเกตอาการ การป้องกันและการช่วยเหลือเมื่อเกิดภาวะเขียวกะทันหันขึ้น รวมทั้งการบันทึกการเกิดภาวะเขียวกะทันหันใช้เวลาประมาณ 10-15 นาที

กิจกรรม

1. ผู้วิจัยแนะนำตนเอง และให้สมาชิกแต่ละคนแนะนำตนเองและเด็กป่วย
2. ผู้วิจัยบอกวัตถุประสงค์ของการเข้ากลุ่ม
3. ผู้วิจัยกล่าวนำเรื่อง การดูแลเด็กโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่เสี่ยงต่อการเกิดภาวะเขียวกะทันหัน ซึ่งได้แก่ การสังเกตอาการ การป้องกันและการช่วยเหลือเมื่อเกิดภาวะเขียวกะทันหันขึ้น
4. กระตุ้นให้สมาชิกในกลุ่มได้พูดคุยบอกเล่าถึงการดูแลเด็กที่ช่วยป้องกันการเกิดภาวะเขียวกะทันหัน และการเกิดภาวะเขียวกะทันหันที่เกิดขึ้นกับเด็กป่วยและการช่วยเหลือ เพื่อให้สมาชิกกลุ่มได้แลกเปลี่ยนประสบการณ์และการแก้ไขปัญหาร่วมกัน รวมทั้งการบันทึกการเกิดภาวะเขียวกะทันหันตามแบบประเมินที่ได้รับ
5. ผู้วิจัยสรุปปัญหาและแนวทางแก้ไข
6. ผู้วิจัยนัดหมายการพบกันครั้งต่อไป

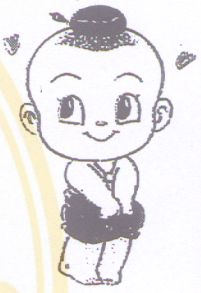
การประเมินผล

ผู้ดูแลเด็กป่วยทุกรายเข้าร่วมกิจกรรมกลุ่มรายละ 1 ครั้ง และมีส่วนร่วมในกิจกรรมกลุ่ม

Postcards about caring for cyanotic spells

ไปรษณียบัตรกระตุ้นเตือน

ถึง.....คุณแม่คนเก่งของหนู



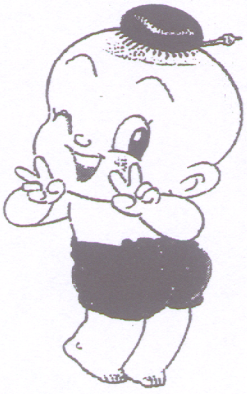
ที่พยาบาลบอกว่าคุณแม่ช่วยหนูให้ปลอดภัยจากภาวะเขียวกะทันหันได้นี่แต่คุณแม่ต้องทำตามนี้นะจ๊ะ

- อ่านแผ่นพับ "ภาวะเขียวกะทันหัน" แล้วดูแลหนูอย่างถูกต้อง
- เมื่อหนูมีภาวะเขียวกะทันหันคุณแม่ช่วยบันทึกให้หนูทุกครั้ง
- ถ้าคุณแม่สงสัยในการดูแลหนู โทรศัพท์ถามที่พยาบาลนะจ๊ะ (☎ 0-2993-9379 กด 4)
- พาหนูไปหาคุณลุงหมอตามนัดนะจ๊ะ

หนูรักคุณแม่มากที่สุด

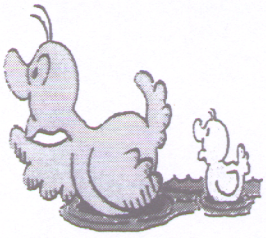
ปล. ถ้าคุณแม่รักหนูต้องช่วยดูแลให้หนูปลอดภัยจากภาวะเขียวกะทันหันนะจ๊ะ

ถึง.....คุณแม่คนเก่งของหนู



คุณแม่รักหนูหรือเปล่า ถ้าคุณแม่รักหนู คุณแม่อย่าลืมนะจ๊ะ

- บันทึกการเกิดภาวะเขียวกะทันหันที่หนูเป็นทุกครั้งตามแบบประเมินที่ที่พยาบาลให้นะจ๊ะ
- ถ้าคุณแม่สงสัยเกี่ยวกับการบันทึก ที่พยาบาลบอกว่าให้โทรศัพท์ถามได้ที่
- ถ้าคุณแม่สงสัยในการดูแลหนู โทรศัพท์ถามที่พยาบาลนะจ๊ะ (☎ 0-2993-9379 กด 4)



หนูรักคุณแม่มากที่สุดในโลก

A Pamphet about caring for children with cyanotic heart disease at risk of cyanotic spells

- ล้างมือให้สะอาดก่อนรับประทานอาหาร
- รับประทานอาหารปรุงสุกในภาชนะสะอาด
- ไม่เข้าใกล้ผู้ป่วยโรคติดเชื้อ
- รับวัคซีนตามกำหนด
- เมื่อเด็กมีไข้ ไอ เจ็บคอ พาไปพบแพทย์

8. เช็คตัวลดไข้ทุกครั้งที่มีไข้
9. รับประทานยาถูกต้องตามที่แพทย์สั่ง และไปพบแพทย์ตามนัดทุกครั้ง
10. บันทึกการเกิดภาวะเขียวกะทันหันทุกครั้ง และแจ้งแพทย์เมื่อมารับการตรวจ

การช่วยเหลือ เมื่อมีภาวะเขียวกะทันหัน

1. จัดให้ลูกนอนในท่าเข่าชิดอกมากที่สุด โดย
   - เด็กเล็ก : อุ้มแล้วงอเข่าเด็กให้มากขึ้นกว่าปกติหรือจัดให้นอนงอเข่าขึ้นมาชิดหน้าอก
   - เด็กโต : จัดให้นอนงอเข่าขึ้นมาชิดหน้าอก หรือนั่งยอง ๆ
2. ปลอบเด็กให้สงบถ้าร้อง การทำให้เด็กหยุดร้องจะลดภาวะเขียวกะทันหันได้
3. จัดให้อยู่ในที่อากาศถ่ายเทสะดวก

4. ถ้าอาการเขียวกะทันหันยังคงเป็นอยู่หรือมากขึ้นจนมีอาการหายใจเร็วหอบควรรีบพามาพบแพทย์เพื่อรับการรักษาต่อไป

หากมีข้อสงสัยติดต่อ
อรจิรา เทียนน้ำเงิน
โทร. 0-2993-9379 กด 4

ภาวะเขียวกะทันหัน
Cyanotic Spells

ที่ปรึกษา
ศาสตราจารย์นายแพทย์ จุล ทิสยากร
รองศาสตราจารย์นายแพทย์ ไพโรจน์ โชติวิทยธารากร
รองศาสตราจารย์นายแพทย์ พรเทพ เลิศทรัพย์เจริญ

อาจารย์ผู้ควบคุมวิทยานิพนธ์
อาจารย์ ดร. เรณู พุกบุญมี
รองศาสตราจารย์นายแพทย์ ไพโรจน์ โชติวิทยธารากร

จัดทำโดย
อรจิรา เทียนน้ำเงิน

เอกสารฉบับนี้เป็นเอกสารประกอบการศึกษา
ปริญญานิพนธ์พยาบาลศาสตรมหาบัณฑิต
สาขาการพยาบาลเด็ก
คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี
มหาวิทยาลัยมหิดล

ภาวะเขียวกะทันหัน

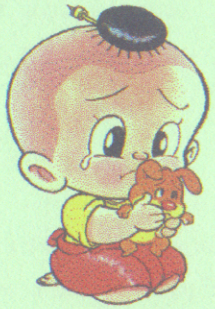
ภาวะเขียวกะทันหันเป็นกลุ่มอาการที่เกิดขึ้นในผู้ป่วยโรคหัวใจพิการแต่กำเนิดชนิดเขียวที่มีเลือดไปปอดน้อย

อาการ

เด็กจะมีอาการเขียวมากขึ้นทันทีทันใด โดยเริ่มจากเด็กจะกระวนกระวาย หายใจหอบลึก ร้องมาก ตัวและปากเขียวมากกว่าปกติ หลังจากนั้นจะมีตัวอ่อนแล้วก็หลับไป

ถ้าอาการมากขึ้นเด็กจะตัวแข็ง ตาเหลือก และไม่รู้สึกตัว ชัก

***** โดยมากเด็กมักมีอาการตอนเช้าหลังตื่นนอน ขาดน้ำ ออกกำลังกายมากเกินไป ร้องนาน ถ่ายอุจจาระไม่ออก**



อันตราย

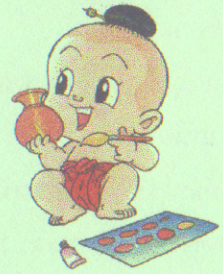
ถ้าเกิดขึ้นบ่อย ๆ หรือปล่อยให้เป็นนาน ๆ จะทำให้สมองพิการและอาจตายได้

การป้องกัน

1. รับประทานอาหารที่มีธาตุเหล็กมากทุกวัน เช่น เนื้อสัตว์ต่าง ๆ ตับ ไข่แดง นม ถั่ว และควรรับประทานอาหารที่มีวิตามินซีมากทุกวันจาก ผัก ผลไม้หรือน้ำผลไม้ต่าง ๆ และให้เด็กรับประทานอาหาร โดยแบ่งอาหารออกเป็นหลายมื้อ

2. เมื่อเด็กอาเจียนหรือท้องเสียให้ได้รับน้ำชดเชยอย่างเพียงพอ ถ้าอาการไม่ดีขึ้น ยังมีอาเจียนหรือท้องเสียและไม่สามารถดื่มน้ำชดเชยได้ ควรนำส่งโรงพยาบาล

3. ส่งเสริมการนอนให้นอนในที่ที่มีอากาศถ่ายเทดี ไม่มีเสียง แสง กลิ่นรบกวน
4. ไม่ปล่อยให้เด็กร้องนาน ควรปลอบให้หยุดร้องหรือเบี่ยงเบนความสนใจด้วยการเล่น
5. จัดกิจกรรมการเล่นที่เหมาะสมใช้แรงน้อย เช่น ต่อบล็อกไม้ ต่อภาพ วาดรูประบายสี เป็นต้น ถ้ามีอาการเขียวกะทันหันให้หยุดเล่นและให้การช่วยเหลือทันที



6. สังเกตการขับถ่ายทุกวัน ป้องกันไม่ให้ท้องผูก โดยการรับประทานผัก ผลไม้ หรือน้ำผลไม้ทุกวัน
7. ป้องกันการติดเชื้อ โดยการ
   - แปรงฟันเช้าและก่อนนอน และบ้วนปากทุกครั้งหลังอาหาร
   - อาบน้ำวันละ 2 ครั้ง เช้า-เย็น ด้วยน้ำที่ไม่ร้อนหรือเย็นเกินไป

BIOGRAPHY

NAME Miss Onchira Theannamngian

DATE OF BIRTH 26 February 1976

PLACE OF BIRTH Nakhon Ratchasima, Thailand

INSTITUTIONS ATTENEDE Thai Red Cross College of Nursing, 1993-1996
Bachelor of Nursing
Mahidol University, 2001-2003
Master of Nursing Science
(Pediatric Nursing)

POSITION & OFFICE Pediatric Cardiology Ward,
Chulalongkorn Memorial Hospital,
Thai Red Cross
Position: Register Nurse 5