

Jiawen Wang & Yang Zhang

PARENTS CARING FOR A CHILD WITH CONGENITAL HEART DISEASE

CENTRIA UNIVERSITY OF APPLIED SCIENCES

Bachelor of Health Care, Nursing

October 2017

ABSTRACT

Centria University of Applied Sciences	Date October 2017	Author Jiawen Wang & Yang Zhang
Degree programme Bachelor of Health Care, Nursing		
Name of thesis PARENTS CARING FOR A CHILD WITH CONGENITAL HEART DISEASE		
Instructor Hanna-Mari Pesonen	Pages 4+29	
Supervisor Maria Björkmark		
<p>With the evolution of family planning policy, fertility rates are increasing. Consequently, the number of infants born with congenital defects is also increasing across the globe. More specifically, the rate of infants born with congenital heart disease is on the rise. Unfortunately, there are not many solutions for this serious problem, and the general public remains virtually ignorant of possible treatments.</p> <p>The proposes of this thesis is to study the experience of taking care of the children with CHD. To make the public, especially the parents of CHD-afflicted children, more aware of congenital heart disease.</p> <p>Our thesis studied the parents' experience of taking care of the children with congenital heart disease. The research used the methodology which includes literature review, data collection and data analysis. According to the thesis theme and the research studies, we can have the following results: CHD can be prevented through the examination and we have to giving the CHD children supports form the society.</p>		

Key words Congenital Heart Disease, Children, Parents, Caring, Nursing problems, education.

LIST OF ABBREVIATIONS

CHD: Congenital heart disease.

NCBI: National Center for Biotechnology Information

AHA: American Heart Association

CONTENTS

ABSTRACT

LIST OF ABBREVIATIONS

CONTENTS

1 INTRODUCTION	1
2 THEORETICAL FRAMEWORK	2
2.1 Congenital Heart Disease	2
2.2 Nursing care of a child with CHD	2
2.2.1 Treatment	3
2.2.2 Prevention of CHD	4
2.3 Care needs.....	5
2.4 Health education	6
3 PURPOSE, AIM, AND RESEARCH QUESTION	8
4 METHODOLOGY	9
4.1 Literature review.....	9
4.2 Data collection	9
4.3 Data analysis.....	11
5 RESULTS	12
5.1 What parents can do for themselves	13
5.1.1 Emotional management	13
5.1.2 Prevention	14
5.2 What parents can do for their children	15
5.2.1 Maintain an optimistic attitude	15
5.2.2 Giving support	16
6 DISCUSSION	19
7 REFERENCES	21
8 APPENDIX 1:	25

1 INTRODUCTION

Nowadays, many diseases are well known. Unfortunately, very few are well understood. When it comes to many diseases, people might only know the name or have just a little basic information. However, they are just as likely to absorb erroneous information from the internet or through hearsay. Should the public encounter these diseases in their own lives, the incorrect information would be a bad influence. Therefore, this thesis believes that common diseases should be better understood. That is why we should promote public knowledge of the common diseases and correct their misperceptions.

Congenital heart disease (CHD) is one of the most common diseases in the world. Research has shown that there are about 100,000 infants born with congenital heart disease every year in China. In North America, there are 1,800,000 Americans living with congenital heart disease (Beckerman 2015). In Finland, about 500 children are born with congenital heart disease every year. The number is increasing annually. (Jalanko 2017).

Congenital heart disease is usually considered fatal. In fact, it is not necessarily untreatable and is certainly not always fatal. Most of the public think that congenital heart disease is a very serious disease that is untreatable, very dangerous and likely terminal. Actually, not all congenital heart diseases patients will die: Some patients' issues will clear up on their own; some with minor malformation will not need any therapy at all; some with moderate symptoms can be treated with drugs or corrected by surgery or other procedures. Only some patients with very serious situations, which are hard to cure, will perish from the disease. (Beckerman 2015.)

This thesis is for the public, especially for those who wish to become parents or who are already parents. We chose this topic because we want people to know about this congenital disease. It is necessary to make people know that congenital heart disease is not necessarily a fatal disease. As medical staff, it is our business to correct people's misunderstandings about congenital heart disease. We want people all over the world to know more about this disease and are thus giving it more attention.

2 THEORETICAL FRAMEWORK

This chapter explains what congenital heart disease is and also focuses on nursing care, prevention, healthcare needs and education.

2.1 Congenital Heart Disease

Congenital heart disease is often reduced to a “congenital heart defect”. Actually, word “defect” is more accurate than word “disease” (ASA 2015). Congenital heart disease is the most common type of congenital malformation in the children. “Congenital” means that the heart disease existed at birth. It is the heart and large blood vessels forming incorrectly during the embryonic period or dysplasia that often causes the anatomic abnormalities. Alternately, the abnormality can be caused by channels failing to close automatically before birth. The morbidity of congenital heart disease incidence is in 0.4% - 1% in newborns. This means that every year about 150,000 to 200,000 newborn will be diagnosed with congenital heart disease. (Beckerman 2015.)

The causes of congenital heart disease can be divided into two parts: One of the reasons is genetic inheritance; the second is environment. The genetic factor only contains 8% of the total. There are three aspects of genetic inheritance: Parents’ chromosomal abnormalities, monogenic inheritance, and polygenic inheritance. Most instances of congenital heart disease are the results of environment causes. This typically means that the pregnancy was affected by a hard environment: Air pollution, the stimulation of chemical or physical factors such as drinking alcohol or taking over-the-counter or illegal drugs over the counter or illegal drugs; infections during the first trimester; the gestational diabetes mellitus, etc. Any one of these factors can hurt the embryo and cause defects during pregnancy. The congenital heart disease that results merely manifests itself after birth. (Sullivan 2016.)

2.2 Nursing care of a child with CHD

The main focus here is to provide adequate nutritional and fluid intake to maintain the growth and developmental needs of the child. Regarding nursing care, it is crucial to tell patient’s parents to utilize the correct feeding position and to feed the child small amounts of high-level nutrition and high calorie foods to support their bodies. Nurses need to know the children’s dietary habits and tell patients they cannot simply eat what they like. They have to eat the foods

that are good for their bodies whether or not they like them. Encourage them to have a taste and encourage them when they try. It is also important to strictly control the daily input and output and measure the patient's weight daily. (Du 2015.)

Preventing infection is very important. Children who have congenital heart disease are more susceptible to infection than healthy children. So nurses should take care to prevent infectious diseases contact. Immunizations are necessary. We should encourage patients to be inoculated with the latest vaccine. Hand washing is always important for every person. We should remind our patient and their family members that before and after doing anything, especially before and after eating food, they need to wash their hands. Nurses must also consider that they have the greatest ability to spread bacteria and infection between patients. We must remember to wash hands before and after touching any patient, and certainly before moving onto another patient. Never allow patients to get infection through personal contact with nursing staff. Finally, make sure that patients have access to preventive medication for the treatment of endocarditis. (Du 2015.)

It is crucial to observe patients for symptoms of Congestive Heart Failure or the development of endocarditis infection. We must also watch for the development of thrombosis, which may occur as a complication of congenital heart disease. We need to prepare the child for diagnostic and treatment procedures and to be able to explain cardiac problems to the patient and the parents. (Schoormans, Mulder, Melle, Pieper, Dijk, Sieswerda, Hulsbergen, Plokker, Brunninkhuis, Vliegen & Sprangers 2014.)

2.2.1 Treatment

The treatments for congenital heart disease depend on the type and the severity of the defects.

For some patients with mild symptoms, the signs are not obvious. For example, the atrioventricular septal defect, —a malformation which leaves a hole between the chambers of the heart—is a significant congenital cardiovascular defect. However, it is a very simple cardiac issue and often has no serious effect on patients. So there may not be any treatments for them, other than the taking of medicine to promote the heart's self-healing mechanisms. (Gibbons 2013.)

The situation may be different for patients with moderate symptoms, such as ventricular septal defect, which leaves patients with a hole in the wall of the two lower chambers of the heart (Ramaswamy 2015). This does have a small effect on the heart. Some patients may need immediate surgery; others may postpone the surgery until they are 3-5 years old. However, there is the possibility of self-healing. Some patients may only take some drugs or any other procedures. (Gibbons 2013.)

If a child has a severe congenital heart disease, surgery is the only way to treat the disease, or the disease will be life-threatening (Gibbons 2013). In that instance, the type of surgery will depend on the scope and degree of congenital cardiac abnormality. In the case of the atrial septal defect, if the diameter of the hole in the valve is so small that has no influence, it is fine to have no treatment. The hole might be self-healing. If the defect is not so big and does not have a big influence on quality of life, surgery may be postponed until the patient is 3-5 years old. The defect may also close on its own. But in cases of serious congenital heart disease, patients will need the surgery as fast as possible, or they will not survive. (Beckerman 2015.)

2.2.2 Prevention of CHD

Complicated acquired factors also influence congenital heart disease. One of the most important reasons for the incidence of congenital heart disease is if the mother is exposed to some harmful environment during pregnancy. Second hand smoke, for instance, is very harmful to infants' and children's growth development. So even if the mother does not smoke, a father or other person smoking can be very harmful. In any case, the pregnant woman's living environment can significantly impact the health of her fetus. (Massin, Hövels-Gürich & Seghaye 2007.)

Chemical substances also have a big teratogenic impact on congenital heart disease. To promote healthy intake, the mother can take some folic acid during her pregnancy and also get in the habit of following a healthy diet. She should certainly avoid contact with toxic substances in order to prevent the development of congenital heart disease. Expectant fathers can choose to give up smoking for their baby's health. (Massin et al 2007.)

Congenital heart disease can be found during a pregnancy ultrasound. If the doctor hears any abnormal heartbeats, they will do some tests to confirm whether the baby has congenital heart

disease or not. But not all the symptoms can be discovered before birth. Some of the signs may not manifest before birth, so it is important to examine newborns to make sure they are healthy. Trouble in newborns can be detected by signs like: A blue tone in lips, skin, or extremities; any breathing trouble, or developing abnormality. Many of the newborns will not manifest the signs and symptoms until a few years later. They may have any abnormal heart rhythms, breathing trouble, and dizziness. (Sullivan 2016.)

In the prenatal stage, prevention is the most important focus. But for newborns with congenital heart disease, it is most important to prevent complications. Reducing the workload of the heart is one way to protect the patient. Reducing the workload can help the patient resume a stable condition. For congenital heart disease patients, they should have enough rest. Observing the patients' signs and symptoms should be done every day; for some serious conditions, they should be observed every few hours. We should educate the patients and their families about how to take care of their patients and to what matters they must pay close attention. (Schoormans et al 2014.)

2.3 Care needs

Healthcare needs are important for patients. When nurses take care of their patients, they will meet some care needs but perhaps not all. It is important for nurses to be proactive with the monitoring of their patients. If the problem occurs with a patient, nurses should discover and deal with the problem immediately.

With congenital heart disease, we still encounter some nursing problems. Some senior nurses want to research more deep issues relating to nursing care about congenital heart disease. They do a lot of hard work finding patients and families that are willing to take the survey in the hopes of getting some helpful information. Equipped with these results, they can use the information to think about what things they can do to solve ongoing problems. This is important because those of us who provide nursing services to not just care patient's physiological maladies, we also care about our patient's mental health and social relations. (Rozenblum 2015.)

Parents will naturally feel confused when they start caring for children with congenital heart disease. The simple reason is that there is a big difference between caring for a healthy child and caring for one with congenital heart disease. It is more difficult for parents to take care of the latter. Usually, this child's parents will share their experiences to let others know how they

can care for their own child better. This information is helpful to new parents who wish to better care for their child with CHD. Also, a little medical knowledge study can help tremendously. Such as some parents remind their children to keep quiet as far as possible, avoid excessive crying, make sure children will get high quality sleep. Some children need to have regular life. They are not allowed to run and jump and have strenuous exercise. But they can follow their physical condition to do some proper exercise. They may not lie in bed whole day. For these children, night sleep must be guaranteed, because this is in order to alleviate the burden of the heart. (Wilson, Chinyere & Queenette 2013.)

2.4 Health education

Reducing the workload of the heart is critical since decreased activity and energy expenditure of energy will decrease oxygen requirements. We should tell patients to get sufficient, quality rest. They should also avoid some unnecessary activities, as these may overtax or fatigue the patient's heart. We must also do our best to control the patient's emotion, to avoid excessive crying because extreme emotion also affects the heart function. Our patient can do some exercise, however, to help their body become stronger. We can help them do some simple bedside activities, while observing the patient's situation. If the patient has any uncomfortable feeling, they should simply stop. Another issue is to prevent constipation, as subsequent bowel movements may overtax heart function. (Takken, Giardini, Reybrouck, Gewillig, Hövels-Gurich, Longmuir, McCrindle, Paridon & Hager 2011.)

As a nurse, there are many things to do for our patients. Centered care and patient satisfaction represent key dimensions of health care quality. Our idea is to observe nurse's attitudes and behavior when they take care of congenital heart disease patients. Since the population of children with congenital heart disease is growing, the role of nurse specialists is expanding. In order to advance congenital heart disease nursing, the establishment of an international nursing research agenda is recommended. We aimed to investigate research priorities as perceived by nurse specialists and researchers in congenital heart disease nursing. (Rozenblum 2015.)

The nurse should be given studies investigating the knowledge and education of patients, outcomes of advanced nursing practice, the quality of life, transfer and transition, and illness experiences and psycho-social issues regarding congenital heart disease. In this study, we could

carry out a nursing class for congenital heart disease. Nurses should focus on these areas of the highest priority, in order to expand and strengthen their professional knowledge in congenital heart disease nursing. (Rozenblum 2015.)

With the number of CHD-afflicted children increasing, surgical intervention is an increasingly popular treatment. Patients will have many questions after surgery. The most common problem is postoperative complications since infants are too small to stave off wound infection and combat bacteria. They are not, like adults, who have already developed strong resistance. They are more susceptible to inflammation and their bodies are more delicate. Bacteria and infection can produce other terrible complications. These complications can easily kill the patient. We don't have any surefire way to prevent them from taking the patient's life. So nurses need to pay attention when their patients come back to the intensive care unit after surgery. (Bryan 2015.)

Pain is another important issue. Children are very sensitive to feelings of pain. They will become very agitated and may cry or scream. You cannot control them immediately and it can become a problem if you need to do perform a treatment. It is hard to treat a patient in great pain. Fear itself can be a problem for young patients. The reason is that hospital is an unknown place for them. Everything is strange and unfamiliar so they will naturally feel scared and nervous. Often their parents cannot be present. They cannot talk or explain their feelings. And nurses cannot simply stay with their patients and let them cry or scream; neither is this good for their recovery. We also encounter other problems after surgery, and we should find a way to solve them: Talk to the doctor and to the parents; study more to improve our knowledge and expertise. We must do these things in order to help children return to health. (Bryan 2015.)

3 PURPOSE, AIM, AND RESEARCH QUESTION

The proposes of this thesis is to study the experience of taking care of the children with CHD. To make the public, especially the parents of CHD-afflicted children, more aware of congenital heart disease. It is also to influence opinions on this disease, to decrease the negative information about this disease, and to change the minds of the parents who may want to give up on their children suffering from it. Giving more advice and sharing the experiences of families currently dealing with congenital heart disease-afflicted children will help them have more confidence as they care for their children. Giving more advices and telling the experience to the current families with congenital heart disease children will help them have more confidence to take care of their own children.

The aim is helping the public to get more information about congenital heart disease, to correct misinformation about this disease. In so doing, we hope to assist the families of children who suffer from congenital heart disease.

Research Question:

1. How can parents take care of their congenital heart disease child?

4 METHODOLOGY

The methodology chapter includes three parts: literature review, data collection, and data analysis. In this section, we will explain the procedure how we searched for and analyzed the data.

4.1 Literature review

Literature review is a text written by someone to consider the critical points of current knowledge including substantive findings, as well as theoretical and methodological contributions to a particular topic. Literature reviews are secondary sources, and as such, do not report any new or original experimental work. (Shuttleworth 2012.)

The literature review needs to be done in five steps. The first step is the question formulation. The second one is finding the appropriate studies according to the keywords and the questions. The third one is analyzing and selecting the studies through inclusion and exclusion criteria. The fourth one is summarizing and synthesizing the selected studies. The last step is determining the results. (DeBolt 2017.)

4.2 Data collection

Data collection is often formalized through organized the relevant questions, establishing a data collection plan which contains the following activity. (Rouse 2016.)

Our thesis is based on children with Congenital Heart Disease. We collected the data from SAGE Premier, NCBI, Science Direct and Emerald. Our inclusion criteria were the following keywords: Congenital Heart Disease, Heart, Child, Caring, Parents and experience, to limit the databases; the year limit from 2010-2017; the children's age limit from 0-14. All the articles are reliable. The exclusion criteria were the articles that were public before 2010; the articles that include the adults, because we are talking about the children between 0-14; the websites. In this thesis, we talked about the patients with congenital heart disease and the parents taking care of the patients. We found thousands of studies that are talking about congenital heart disease in these databases. Because the number of articles, we have searched are in the thousands, it is so difficult to choose the articles to focus on. To confirm the accuracy, we limited the years to decrease the number of articles for our thesis since the age may decrease the reliability. So we adjusted the year limit from 2010 to 2017. We also used more keywords

to make the search more accurate. We typed out these keywords on the advance search. We used the keywords like “congenital heart disease”, “pediatric”, “parents”, and “experience”. The more keywords and the year limit made the data more compact and more specific. Then we found 24 sources in SAGE Premier; 15 sources of OVID; 28 sources in Science Direct; and 20 sources in Emerald. These articles are relevant to our thesis. We read the title of these found articles, we analyzed how closely these articles were related to our thesis. We eliminated the articles that only had a little information with the children who have congenital heart defects and the articles that are not very close to our topic. At last, we chose seven articles from the 24 sources in SAGE Premier; one article from the 15 sources of OVID; one article from 28 sources in Science Direct; and one article from the 20 sources in Emerald. So, in the end, we had a total of 10 articles.

Table 1: searches of articles

NAME	1st	2st	End
SAGE Premier	6945	24	7
OVID	1325	15	1
Science Direct	3106	28	1
Emerald	127	20	1
TOTAL	11503	87	10

4.3 Data analysis

The process of evaluating data using analytical and logical reasoning to examine each component of the data provided. We made the collected data more accurate and made the data look clearer (Galetto 2017). The data analysis should start by article arrangement.

We found 10 articles in total. From these 10 articles, we wished to know how the parents were taking care of their congenital heart disease child.

The Summary of Article is in Appendix 1

5 RESULTS

Our thesis studied the parents' experiences on taking care of the children with congenital heart disease. The research used the methodology which includes literature review, data collection and data analysis.

According to the thesis theme and the research studies, we can have the following results: CHD can be prevented through the examination and we have to give the CHD children support form the society. We divided them into 2 parts: one is in the side of parents and the other is the side of child patients.

Table 3. Results of the thesis

WHAT PARENTS CAN DO FOR THEMSELVES?	WHAT PARENTS CAN DO FOR THEIR CHILDREN
Emotional management	Maintain an optimistic attitude
CHD can be prevented: <ol style="list-style-type: none"> 1) Pre-pregnancy preparation 2) Prenatal preparation 3) Antenatal examination 4) Environmental preparation 	Giving support: <ol style="list-style-type: none"> 1) Physical support 2) Psychological support 3) Nutritional support

5.1 What parents can do for themselves

Parents are very important for their children. They have a big influence on children's activity and emotions. As the parents, they have rights to make decisions for children because the children don't have the sense of judgement to decide between right or wrong.

5.1.1 Emotional management

Physical illnesses usually have a serious effect on the psychological well-being of any individual. An illness of early origin, with necessary diagnostic and treatment intervention, can affect the emotional balance and behavioral adaptation of children and adolescents. This is applicable to congenital heart disease, especially if it is serious and life-threatening. Psychological implications are a significant part of chronic illnesses and they can affect the prognosis and outcome. Congenital heart diseases that are diagnosed early can influence mother-infant interactions from the beginning. It is a crucial period of the infant's psychological development, and thus may adversely affect the mental health of children and adolescents. Children and juveniles who have congenital heart diseases can have anxiety, depressive reactions, low self-esteem or impulsiveness. The behavioral and emotional problems of children and adolescents, if not diagnosed and managed early, can lead on to significant psychological morbidity in later life. (McKechnie 2016.)

Studies of families coping with children with special health care needs indicate high levels of parenting stress, with families with children with special health care needs at risk of major psychological and social disturbances and financial strain. Despite increased knowledge of the factors affecting children with special health care needs themselves, evidence for the effectiveness of preventative and treatment interventions in the form of parent education programs remains limited. At the moment the parents discover that the baby has congenital heart disease they will feel resistant and incredulous. Then they will be terrified, concerned, anxious and worried about the future. They will have great distress as they cannot accept the image for the future of their child, and for the family. It may incite the breakup of the family. (Marokakis, Kasparian & Kennedy 2017.)

Children who have congenital heart disease will have more medical fears and more physiological anxiety than other healthy children. These children could show an increased feeling of inferiority and anxiety and more impetuous behavior. They will lack confidence, experience

depression, and also have some potential risk for poor performance in school. Extreme, aggressive behavior, depression and anxiety are common in congenital heart disease-afflicted children. They might be crying every day. That will influence both the parents' and the children's emotions. So the first priority is adjusting psychologically, accepting the truth and considering the future. There are a great number of things that they can do: Getting information about congenital heart disease; figuring out the etiology, what caused the disease; making a plan about the future; talking with the doctors and nurses about the treatment and nursing care; and ascertaining the multipara's psychological state, preventing the onset of postpartum depression. The suggestion is to be optimistic, to believe that everything will be fine and sunny days will eventually arrive. (McKechnie 2016.)

5.1.2 Prevention

Congenital heart disease can be prevented. This is for people who don't have a child, for people who are preparing to have a child, and for the parents during the pregnancy. The cause of congenital heart disease is: 1) Heredity. 2) The high age of the mother during pregnancy. 3) Taking medicine without the doctor's advice. 4) Infection during pregnancy. Prospective parents should have enough preparation before assuming the burdens of having a baby. The preparation for the mother should include: Quitting smoking and abstaining from alcohol; staying away from the radiation-emitting appliances; never taking medicine without a doctor's advice; and considering the family's history of disease. (Yang, Chen, Wang, Gau, Chen & Moons, 2012.)

The prenatal examination is one examination that parents must do. It is very important. Prenatal examination can help by medical machines to find out if there are any deformities or congenital diseases during the embryonic development. The main cause of neonatal and infant death is congenital heart disease. Right now, with the continuous improvement and updating of ultrasound equipment, ultrasonic inspection has been widely used in prenatal care. Almost all types of congenital heart disease can be diagnosed by ultrasound in prenatal care. Therefore, prenatal use of ultrasound on the fetus, for the purpose of congenital heart disease screening and diagnosis, can reduce the incidence of congenital heart disease in newborns. (McKechnie & Pridham 2012.) Hospitals use fetal echocardiography to observe the fetal heart function and then provide counseling and education opportunities for the parents. Palliative care is not common but it may be offered following prenatal diagnosis. Palliative care is a new

choice for family at prenatal diagnosis. (Rychik 2013) Although the method for screening needs to be improved and more established, every pregnant mother should be advised to do the screening. It can decrease congenital heart disease morbidity. (Pinto, Sheng, Keenan, Byrne, Stanton & Kinney 2016.)

We want to ask all prospective parents and all parents-to-be to please be responsive to your future child. Don't let this disease encumber you and affect your child's entire life.

5.2 What parents can do for their children

Children with congenital heart disease experience double suffering—both physically and psychologically.

5.2.1 Maintain an optimistic attitude

The most important thing for the patient is to maintain a good mood and avoid upset or anger. When your child makes some mistakes, do not just criticize them, it will make him feel upset. Consider some special way to educate him. (López, Frangini, Ramírez, Valenzuela, Terrazas, Pérez, Borchert & Trachsel 2016.)

Children are very fragile, but they can also grow up to become strong individuals. This process begins with education by the parents. As the parents, they should keep the child company; They should teach the child to be tough. They should tell him how to face difficulties and how to respond to challenges. The patients not only need the company of their parents, but also the company of the surrounding society. They need family, friends, peers, schoolmates, teachers, even strangers to interact with. Help these children make more friends. They can be fellow patients in the hospital, children in school, their teachers, or other family members. With company, children can develop more mature emotions and access more information from the outside world. (Pridham, Harrison, McKechnie & Brown 2017.)

Parents should ensure the child's good mood and maintain a stable emotional environment. Sometimes, the child will feel uncomfortable; they will be irritable or anxious. During this time, parents shouldn't leave the children alone. They can help the child to make connections with

other children, to make new friends. Care should be taken to ensure that the child's physical movement is excessive when they play with other children, however. Tell jokes, stories and express other joyful things to the child, so that the child will retain a sense of optimism; this could have a rehabilitating effect. (Marokakis et al 2017.)

5.2.2 Giving support

Support is one of the important things that children need in their process of growing. They need support from parents, from the medical staff, from peers, from friends and from school environments.

School is a public place where children will stay for a long time. There are classmates and teachers in class. For school-age children, most of the day time that children spend is in school. Having company within the school environment will help their psychological wellbeing. It is the same as having company from their parents. The first 20 years, we will be spending with our parents. When we feel upset or get into trouble, parents always accompany us and encourage us, giving advice and lifting us up. Psychological support is very important in children's life. Physical support is also important for children. A hug, a kind touch, even direct eye contact to indicate interest in the child's activity, these are all forms of physical support. (Pridham et al 2017.)

Children who suffer from cardiac dysfunction usually sweat more. They need to take extra steps to keep the skin clean. In summer their parents should let them take more frequent showers. During winter, they will use hot towels to wipe their children's body. During this time, it is important to remember to keep the body warm! (Magalhães, Queiroz & Chaves 2016.)

Parents must also ensure that their child has enough water to drink in order to avoid dehydration. This also helps keep bowel movements unobstructed. If the child's stool is dry, defecation will be difficult for the child; it can increase abdominal pressure and overtax the heart, which could have serious consequences. (Marokakis et al 2017.)

Parents should also keep the air circulating inside the child's bedroom, and reduce the likelihood of respiratory tract infection by preventing the child from staying in more crowded public

places. They should also be pay attention to changes in the weather—temperature increases or decreases—adjusting clothing in time so as to prevent colds. (Marokakis et al 2017.)

Most children with serious congenital heart disease need surgery to fix their heart problem. Before the surgery, their parents will become nervous as they try to prepare their child for a successful surgery. Before the surgery, they will take great care with their child. During this time, they must also attend to their emotions to maintain a sense of calm. (Marokakis et al 2017.)

The postoperative period is more important because after surgery, children are very weak, and their bodies are more susceptible to disease and post-op complications. During this time, everything for them is dangerous. They are in a high-risk environment. At this time, diet is a big concern. Parents should encourage their child to eat fresh fruits and vegetables and other healthy, easily digested foods. (Gower, Higgins, Doherty & McCormack 2016.)

Some parents blindly believe that after surgery, they should let their children eat more fish and meat because after surgery it is necessary to increase proteins in order to spur growth and development. In fact, they should also give children to eat some tomatoes, cabbage, bitter gourds, spinach, apples, bananas and other fresh foods to supplement vitamin intake. These are things that new parents can learn from the parents of older CHD-afflicted children who have already gone through the experience. (Gower et al 2016.)

They will know how to cook healthy food for their child, how to promote their child's healthy diet. This starts with controlling their child's salt and monosodium glutamate intake, which should be no more than about 3 grams. Since too much salt intake can cause hypertension and increase the burden on the heart, excessive salt intake can lead to heart failure. (Gower et al 2016.)

After surgery, children must not be overeating. Parents can let them eat normally but excessive eating also increases the burden on the heart. Parents should prevent children from eating especially before going to bed and never let the children get too full. Reducing sweets is also helpful. Some children do not want to eat after surgery, and their parents may be tempted to offer them cake, chocolate and other sweets to whet their child's appetite. This is wrong! Because these sweets contain an unhealthy proportion of protein and fat. If the dessert intake is

too heavy, it may cause pediatric indigestion, dry stool, loss of appetite, lack of protein and malnutrition, all of which will retard rehabilitation. (Gower et al 2016.)

While administering postoperative care, parents must pay attention to avoid more intense activities in the first month. Violent activities are not conducive to the recovery of cardiac function, while rapid breathing during postoperative healing could easily lead to thoracic deformity. Usually, after three months, children can return to normal life. They may return to more vigorous activities after a major event, but still need to gradually increase the amount of activity according to the particular child's physical conditions. (Marokakis et al 2017.)

After surgery, children will feel the wound very uncomfortable, even painful. Parents should be careful. They must not allow children free use of their hands lest they irritate the wound. After stitches, remember the wound should not be soaked in water. During the recovery period, a scab will naturally cover the wound. Tell the children not to forcibly pick the scab; let the scab fall off naturally after the skin underneath has healed. The edge of the cut and the surrounding area may be uncomfortable or itchy. There may even be shoulder joint ache. These are normal postoperative responses. As the time passes, these things should recover gradually. Shower can be taken after three weeks, but showers should be limited to a short period of time. Always avoid hard rubbing around the wound. And after showering, wipe dry the wound area immediately. (Marokakis et al 2017.)

Also pay attention to weight control. From one month to three months after surgery, parents should be closely observing the child's physical condition, following doctor's orders by taking medication on time, and making certain that the amount drinking and urinating is balanced. Weight must not be allowed to increase too fast. And if the children have any uncomfortable feelings, go to the hospital! (Gower et al 2016.)

6 DISCUSSION

The literature reviews researched parents experience with congenital heart disease child. The research studies talked about the nursing care, surgeries, treatment, prevention and parents' experience of taking care of a congenital heart disease child.

After consulting a lot of information, we have a lot of new knowledge about congenital heart disease. We all know that congenital heart disease is very harmful for every child. In the past, we learned about treatment and care, which is important as even people who are very concerned about the disease and its complications, do not generally have any experience with treatment and nursing.

Because they don't know what is congenital heart disease, there is only one thing they can do. That is going to the health center or see the doctor to find some help. People always think that only doctors and nurses can help them. We wrote this paper to let more people know and understand what is congenital heart disease. To let parents know how to take care of their sick children, and to minimize morbidity as much as possible.

After writing this article, we know that exposure to drugs, viral infection, environmental pollution or radiation and other factors during pregnancy will result in more fetal heart abnormalities. This will lead to a dramatic increase in children suffering from congenital heart disease.

Preventing congenital heart disease is more important than the treatment. Therefore, parents should prepare themselves before they decide to have a baby.

Also, if their child already has some problem with the heart, it may manifest a variety of symptoms. Noting this information and important signs of congenital heart disease for the doctor is very useful to ascertain that this child has some heart problem. The sooner congenital heart disease is found, the easier it is to treat and to cure. Early detection is most conducive to the child's physical recovery.

There is one thing that parents need to remember: do not think that after treatment, one can relax their sense vigilance for their child's wellbeing. After leaving the hospital and returning home, without nurses and doctors, where there are no nurses and doctors on call to monitor the patient, the parents must pay great attention to their child's situation. Remember to give

enough nutrition, balance intake, enough water and proper exercise. We hope that this thesis will allow more people to learn more about congenital heart disease.

7 REFERENCES

- AHA. 2015. About Congenital Heart Defect. American Heart Association. http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/About-Congenital-Heart-Defects_UCM_001217_Article.jsp#.WawP7K1b68U Accessed: October 21, 2016.
- Beckerman, J. 2015. Congenital Heart Disease Explained. WebMD Medical Reference. <http://www.webmd.com/heart-disease/congenital-heart-disease#2-5> Accessed: October 18, 2016.
- Bertaud, S. 2016. The importance of early involvement of pediatric palliative care for patients with severe congenital heart disease. Archives of disease in childhood. http://d.scholar.cnki.net/detail/refdetail?tablename=SJPDTEMP_U&filename=SJPDB900CE3EB0784BA55959F2BEB184C8D6 Accessed: March 17, 2017.
- Bryan, M. 2015. Postoperative Care of the Adult with Congenital Heart Disease, Seminars in Cardiothoracic and Vascular Anesthesia. http://d.scholar.cnki.net/detail/refdetail?tablename=SJRS_U&filename=SJRS15052700019226 Accessed: October31, 2016.
- Connor, J. 2009. The Meaning of Cost for Families of Children with Congenital Heart Disease. Journal of Pediatric Health Care. [http://www.jpeds.org/article/S0891-5245\(09\)00276-4/fulltext](http://www.jpeds.org/article/S0891-5245(09)00276-4/fulltext) Accessed: April 5, 2017.
- DeBolt, D. 2017. Literature Review: Conducting & Writing: Steps for Conducting a Lit Review. UWF Libraries. <http://libguides.uwf.edu/c.php?g=215199&p=1420520> Accessed: September 8, 2017.
- Du, EY. 2015. Nursing experience in 62 cases of children with congenital heart disease. Cardiovascular Disease Journal of Integrated Traditional Chinese & Western Medicine. http://xueshu.baidu.com/s?wd=pa-peruri%3A%28dad24ca5e688e4fb828ccae3b5c60c2%29&filter=sc_long_sign&ks_para=q%3DNursing%20experience%20in%2062%20cases%20of%20children%20with%20congenital%20heart%20disease&us=4456947540431206910&tn=SE_baiduxueshu_c1gjeupa&ie=utf-8 Accessed: October22, 2016.
- Galetto, M. 2017. What is data analysis? NGDATA. <https://www.ngdata.com/what-is-data-analysis/> Accessed: June 8, 2017.
- Gibbons, G. 2013. How are Congenital Heart Defects Treated? National Institutes of Health. <http://www.nhlbi.nih.gov/health/health-topics/topics/chd/treatment> Accessed: October18, 2016.

- Gower, C & Higgins, A & Doherty, N & McCormack, D. 2017. Understanding the experiences of fathers of children with congenital heart disease: An interpretative phenomenological analysis. *Journal of Health Psychology*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/1359105316628757> Accessed: June 8, 2017.
- Jalanko, H. 2017. Sydämen rakenneviat lapsella. *TERVEYSKIRJASTO*. http://www.terveyskirjasto.fi/terveyskirjasto/tk.koti?p_artikkeli=dlk00502 Accessed: September3, 2017.
- Limbers, C. 2013. Factors Associated with Perceived Cognitive Problems in Children and Adolescents with Congenital Heart Disease. *Journal of Clinical Psychology in Medical Settings*. http://d.scholar.cnki.net/detail/refdetail?tablename=SSJD_U&filename=SSJD13062800013755 Accessed: October 14, 2016.
- Lo'pez, R & Frangini, P & Ram'irez, M & Valenzuela, P & Terrazas, C & Pe'rez, C & Borchert, E & Trachsel, M. 2016. Well-Being and Agency in Parents of Children with Congenital Heart Disease: A Survey in Chile. *World Journal for Pediatric and Congenital Heart Surgery*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/2150135115623284> Accessed: September3, 2017.
- Magalhães, S & Queiroz, M & Chaves, E. 2016. Neonatal nursing care of the infant with congenital heart disease: an integrative review. *European Journal of Preventive Cardiology*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1097/01.hjr.0000224483.72726.1a> Accessed: June 8, 2017.
- Marokakis, S & Kasparian, NA & Kennedy, SE. 2017. Caring for infants with posterior urethral valves: A qualitative study of parents' experiences. *Journal of Child Health Care*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/1367493517725833> Accessed: June 29, 2017.
- Massin, MM & Hövels-Gürich, H & Seghaye, MC. 2007. Atherosclerosis lifestyle risk factors in children with congenital heart disease. *European Journal of Preventive Cardiology*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1097/01.hjr.0000224483.72726.1a> Accessed: March 36, 2017.
- Matthias, G. 2013. Facilitators of and Barriers to Advance Care Planning in Adult Congenital Heart Disease. *Congenit Heart Dis*. http://d.scholar.cnki.net/detail/refdetail?tablename=SJWDTEMP_U&filename=SJWD13072900004304 Accessed: April 1, 2017.
- McKechnie, A. 2016. Walking the "Emotional Tightrope" From Pregnancy to Parenthood: Understanding Parental Motivation to Manage Health Care and Distress After a Fetal Diagnosis of Complex Congenital Heart Disease. *Journal of Family Nursing*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/1074840715616603> Accessed: August 14, 2017.

- McKechnie, AC & Pridham, K. 2012. Preparing Heart and Mind Following Prenatal Diagnosis of Complex Congenital Heart Defect. *Qualitative Health Research*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/1049732312458371> Accessed: June 2, 2017.
- Pinto, N & Sheng, XM & Keenan, HT & Byrne, JLB & Stanton, B & Kinney, AY. 2016. Sonographer-Identified Barriers and Facilitators to Prenatal Screening for Congenital Heart Disease. *Journal of Diagnostic Medical Sonography*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/8756479316677019> Accessed: June 1, 2017
- Pridham, K & Harrison, TM & McKechnie, AC & Brown, R. 2017. Motivations and Features of Co-Parenting an Infant with Complex Congenital Heart Disease. *Western Journal of Nursing Research*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/0193945917712693> Accessed: July 12, 2017
- Ramaswamy, P. 2015. Ventricular Septal Defect. *Medscape*. <http://emedicine.medscape.com/article/892980-overview> Accessed: October 9, 2016.
- Rouse, M. 2016. Data collection. *TechTarget*. <http://searchcio.techtarget.com/definition/data-collection> Accessed: April 10, 2017.
- Rychik, J. 2013. What Does Palliative Care Mean in Prenatal Diagnosis of Congenital Heart Disease? *World Journal for Pediatric and Congenital Heart Surgery*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/2150135112456405> Accessed: May 5, 2017.
- Rozenblum, R. 2015. Clinicians' Perspectives on Patient Satisfaction in Adult Congenital Heart Disease Clinics—A Dimension of Health Care Quality Whose Time Has Come. *Congenital Heart Dis*. http://d.scholar.cnki.net/detail/refdetail?tablename=SJWDTEMP_U&filename=SJWD15042100000229 Accessed: October 10, 2016.
- Sadoh, WE, Uzodimma C.C, Daniels Q, 2013. Congenital Heart Disease in Nigerian Children. A Multicenter Echocardiographic Study. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/2150135112474026> Accessed: October 10, 2016.
- Schoormans, D & Mulder, BJ & Melle, JP & Pieper, PG & Dijk, AP & Sieswerda, GT & Hulsbergen-Zwarts, MS & Plokker, TH & Brunninkhuis, LG & Vliegen, HW & Sprangers, MA. 2014. Illness perceptions of adults with congenital heart disease and their predictive value for quality of life two years later. *European Journal of Cardiovascular Nursing Journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology* Page 86-94. Accessed: May 1, 2017.
- Shuttleworth, M. 2012. What is a Literature Review? *Explorable*. <https://explorable.com/what-is-a-literature-review> Accessed: April 6, 2017.
- Sullivan, D. 2016. Congenital Heart Disease. *Healthline*. <http://www.healthline.com/health/congenital-heart-disease#Overview1> Accessed: October 18, 2016.

Takken, T & Giardini, A & Reybrouck, T & Gewillig, M & Hövels-Gürich, HH & Longmuir, PE & McCrindle, BW & Paridon, SM & Hager, A. 2011. Recommendations for physical activity, recreation sport, and exercise training in paediatric patients with congenital heart disease: a report from the Exercise, Basic & Translational Research Section of the European Association of Cardiovascular Prevention and Rehabilitation, the European Congenital Heart and Lung Exercise Group, and the Association for European Paediatric Cardiology. *European Journal of Preventive Cardiology*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/1741826711420000> Accessed: September 9, 2017.

Wiley, J. 2016. Parent education programmes for special health care needs children: a systematic review. US National Library of Medicine Institutes of Health. <https://www.ncbi.nlm.nih.gov/pubmed/27080366> Accessed: November 18, 2016.

Wong, JJM & Cheifetz, IM & Ong, C & Nakao, M & Lee, JH. 2015. Nutrition Support for Children Undergoing Congenital Heart Surgeries. *World Journal for Pediatric and Congenital Heart Surgery*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/2150135115576929> Accessed: October 18, 2016.

Yang, HL & Chen, YC & Wang, JK & Gau, BS & Chen, CW & Moons, P. 2012. Measuring knowledge of patients with congenital heart disease and their parents: validity of the 'Leuven Knowledge Questionnaire for Congenital Heart Disease'. *European Journal of Cardiovascular Nursing*. <http://journals.sagepub.com.ezproxy.centria.fi/doi/full/10.1177/1474515111429662> Accessed: August 18, 20

8 APPENDIX 1:

		ARTICLE NAME & JOURNALS	AUTHORS & YEARS	CONTENT & RESULTS OF ARTICLES
CARING A CHILD WITH CHD	KNOWLEDGES OF PARENTS	<p>Measuring knowledge of patients with congenital heart disease and their parents: validity of the ‘Leuven Knowledge Questionnaire for Congenital Heart Disease’.</p> <p>Europen Journal of Cardiovascular Nursing.</p>	<p>Yang, HL & Chen, YC & Wang, JK & Gau, BS & Chen, CW & Moons, P.</p> <p>2012.</p>	<p>The article told us the importance for the parents and the patients to have the knowledge of the CHD. Children with CHD and their parents need to have a good knowledge of their condition, treatment, medication and precautions. To develop a comprehensive assessment of the level of knowledge of CHD patients. In many cases, congenital heart disease is considered a chronic disease. Patients with coronary heart disease and their parents are expected to have a proper knowledge of CHD in order to take care of themselves and care for their children.</p>
		<p>What Does Palliative Care Mean in Prenatal Diagnosis of Congenital Heart Disease?</p>	<p>Rychik, J.</p> <p>2013</p>	<p>This article told us the prenatal diagnosis now is the most common means in CHD first detected. Hospital use fetal echocardiography to observe the fetal heart function and provides counseling and education op-</p>

		World Journal for Pediatric and Congenital Heart Surgery.		portunities for child's parent. Palliative care is not common, but it is useful for prenatal diagnosis. Palliative care is new choice for family at prenatal diagnosis.
		Preparing Heart and Mind Following Prenatal Diagnosis of Complex Congenital Heart Defect. Qualitative Health Research.	McKechnie, AC & Pridham, K. 2012	This article told us the importance of congenital heart disease prevention and prenatal examination. The preparing of their mind is the primary nursing care for their child with CHD. The knowledge of care-giving that parents consume will effect on their caring for children with congenital heart disease.
		Sonographer-Identified Barriers and Facilitators to Prenatal Screening for Congenital Heart Disease. Journal of Diagnostic Medical Sonography.	Pinto, N & Sheng, XM & Keenan, HT & Byrne, JLB & Stanton, B & Kinney, AY. 2016.	This article shows the importance of prenatal Screening for CHD. Many of the prenatal screening for CHD are very effective, they can find out fetus' health condition. We need to increase more establish screening place, let every prenatal mother do the screening, it can decrease CHD morbidity.

	WELLIGNBEING OF PARENTS & PATIENTS	<p>Walking the “Emotional Tightrope” From Pregnancy to Parenthood: Understanding Parental Motivation to Manage Health Care and Distress After a Fetal Diagnosis of Complex Congenital Heart Disease.</p> <p>Journal of Family Nursing.</p>	<p>McKechnie, A.</p> <p>2016.</p>	<p>The article pointed out that the distress of the families with CHD child. It is necessary to build on existing evidence of family-centered interventions to promote early childcare transitions and to support parental mental health when detecting fetal abnormalities such as congenital heart disease is detected.</p>
		<p>Well-Being and Agency in Parents of Children with Congenital Heart Disease: A Survey in Chile.</p> <p>World Journal for Pediatric and Congenital Heart Surgery.</p>	<p>Lo´pez, R & Frangini, P & Ram´irez, M & Valenzuela, P & Terrazas, C & Pe´rez, C & Borchert, E & Trachsel, M.</p> <p>2016.</p>	<p>The article pointed out that the well-being of the families with CHD child will improve the children’s health care. Congenital heart disease refers to the birth of a wide range of heart defects, from innocent murmurs to severe structural abnormalities. It is estimated that about 1% of children are born with CHD, many of whom have died in the first year of their lives. However, due to improved health care, the mortality rate in the past two decades has been greatly reduced, with an estimated 85% of</p>

				these children have come to adulthood. In addition to the impact on children's health, the uncertainties associated with the diagnosis of coronary heart disease and the high level of care for CHD children may lead to more frequent development of depression, depression, anxiety and despair in parents than parents More often than other chronic cases such as cystic fibrosis.
	NURSING CARE	Caring for infants with posterior urethral valves: A qualitative study of parents' experiences. Journal of Child Health Care.	Marokakis, S & Kasparian, NA & Kennedy, SE. 2017.	In this article, it talked about how the experience that the parents taking care of the congenital disease child. The diagnosis of child's congenital abnormal will make parents really disturbed. Parents need to learn how they try to face the challenges, and they need to learn to cope the trouble.
		Motivations and Features of Co-Parenting an Infant with Complex Congenital Heart Disease. Western Journal of Nursing Research.	Pridham, K & Harrison, TM & McKechnie, AC & Brown, R. 2017.	In this article, it talked about the method that the parents taking care of their CHD child together. Co-parenting is especially important for the children with a chronic condition. The quality of co-parenting and their relationship will effect on their care-giving to the child patients.

		<p>Understanding the experiences of fathers of children with congenital heart disease: An interpretative phenomenological analysis.</p> <p>Journal of Health Psychology.</p>	<p>Gower, C & Higgins, A & Doherty, N & McCormack, D.</p> <p>2017.</p>	<p>In the article, it confirms the advances in medical technology. More and more couples receive fetal diagnosis of complex congenital heart disease. After the diagnosis of fetal coronary heart disease, parents described many of their management problems. Parents who are diagnosed with fetal coronary heart disease are psychologically fragile and needed targeted assessments and effective interventions to support multiple and changing needs during a crisis that may span parental identity.</p>
		<p>Neonatal nursing care of the infant with congenital heart disease: an integrative review.</p> <p>European Journal of Preventive Cardiology.</p>	<p>Magalhães, S & Queiroz, M & Chaves, E.</p> <p>2016.</p>	<p>In this article, it talked about how is the nursing care in the current time and what is the insufficient for now. The home care from parents and the nursing knowledges still have a big disparity from nurses. The children patients need more professional nursing care, so the nurses and parents need more training about nursing patients.</p>