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The Experience of Living with Congenital Heart Disease

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The Experience of Living with Congenital Heart Disease

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This thesis for honors recognition has been approved for the Department of Nursing.

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Abstract

Congenital heart disease (CHD) is seen in about 1,000,000 Americans, and each year there are approximately 35,000 infants born with a cardiac defect (American Heart Association [AHA], 2008a). The purpose of this thesis was to explore the experience of adults living with congenital heart disease and their quality of life. Data were collected from two female English-speaking adults from Montana. The phenomenological method was selected to get an understanding of the individuals' everyday experiences of living with CHD. The lived experience of CHD was described with the following themes: (a) seeking a diagnosis, (b) fear and uncertainty, (c) ongoing treatment, and (d) reclaiming health. The findings of this study can help nurses to understand the struggles that individuals with CHD go through on a daily basis.
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Chapter I

The Experience of Living with Congenital Heart Disease

Congenital heart disease (CHD) is seen in about 1,000,000 Americans, and each year there are approximately 35,000 babies born with a cardiac defect (American Heart Association [AHA], 2008a). In the first year of life, CHD causes more birth defects than any other disease (Zieve & Fogel, 2007). These defects range from being “holes” between chambers to completely missing chambers or valves of the heart. According to Hockenberry, “Although there are more than 35 well-recognized defects, the most common heart anomaly is ventricular septal defect (VSD)” (2005, p. 894). Congenital heart disease is a structural and functional defect of the heart resulting from abnormal development of the heart before birth (Zieve & Fogel, 2007). Congenital heart disease occurs in 8 out of every 1000 births (AHA, 2008a). In every 1000 infants, 2 or 3 will be symptomatic in their first year of life (Hockenberry, 2005).

Over the past few decades, medical technology has improved, quality of life of individuals with CHD has also improved, and mortality decreased (AHA, 2008a). Depending on the severity of the cardiac defect, surgeries can be used as a treatment. With minor defects, children are surviving to be adults with tolerable limitations such as decreased exercise capacity while more severe defects can lead to developmental delays or learning disabilities (AHA, 2008a). Adults are adjusting to the mental and physical limitations that occur with CHD by learning to live with the limitations through adjustment of their daily activities. In the United States, an estimated 20,000 people reach adulthood that have CHD (UCSF Medical Center, 2007). The purpose of this thesis is to
explore the experience of adults living with congenital heart disease and their quality of life.

*Etiology and Risk Factors*

The etiology of CHD in 90% of the cases is unknown. It is thought to be a combination of genetic and environmental factors (Hockenberry, 2005). Cardiac defects can be related to “various genetic and chromosomal syndromes such as Down syndrome, trisomy 13, Turner’s syndrome, Marfan syndrome, Noonan syndrome, and Ellis-van Creveld syndrome” (Zieve & Fogel, 2007, ¶6). There are several risk factors that increase the chance of congenital heart disease. According to Hockenberry, “Maternal factors include chronic illnesses such as diabetics or poorly controlled phenylketonuria (PKU), alcohol consumption, and exposure to environmental toxins and infections” (2005, p. 894). Some other intrauterine factors that are risk factors include congenital rubella and treatment with anticonvulsant drugs (Porth, 2007). If a first-degree relative, parent, or siblings have a cardiac defect, there is an increased risk for congenital heart disease. Left-sided obstruction lesions have a higher risk in families than if the lesion is right-sided (Hockenberry, 2005).

*Impact of Congenital Heart Disease*

Congenital heart disease causes many stressors and problems. Family, society, and medical staff are all affected when an adult has CHD. The individual has to cope with all the symptoms that occur with CHD and treatment needed to correct the defect or prevent arrhythmias or heart failure. The family and individual are affected financially and emotionally. They have to cope with the stress that comes with CHD due to the costs and many hours spent at doctor’s appointments. It is also very stressful for the individual
because of having to continually watch what kinds of activities he or she participates in. The society is affected because of the amount of money and time that is put into taking care of an adult with CHD.

**Impact on client.** The individual can be affected by congenital heart disease in many different ways depending on what kind of defect is present. The most common type of defect is ventricular septal defect (VSD) which can cause symptoms such as shortness of breath, fast, hard breathing, failure to gain weight, fast or pounding heart rate, and frequent respiratory infections (Zieve & Fogel, 2007). Individuals must take medications for the defects, and if the defect is bad enough, the individual can have the defect surgically repaired. Adults have also had to deal with living with CHD their entire life. From the moment they are born, they have CHD and learn to deal with all the complications and procedures that are a part of life as an individual with CHD.

**Impact on family.** Caregivers of individuals with congenital heart disease have many tasks that cause stress to occur in the family environment. Before adulthood, caregivers have to watch the child and limit the type of activities that the child participates in because of the limited exercise capacity. The caregiver also has to schedule and keep track of clinical appointments. Another stressor that occurs is making sure the child is getting the right medications at the right time (Davis, 2004). Families will also go through emotional and financial burdens that come at a vulnerable time. Education is very important for successful coping skills (AHA, 2008). Successful coping skills can include being able to utilize outside resources, being able to problem solve when a situation occurs, or even learning new ways that will help that person relax when times are getting stressful.
Economic impact. Congenital heart disease each year costs over 2.2 billion dollars. This cost only covers the inpatient surgeries that are associated with CHD (AHA, 2008). The costs that are associated with CHD are decreased after the individual has had surgery. Costs will include getting regular check-ups from his or her doctor. Also, there may be some medications that need to be taken with the different defects.
Chapter II

Review of Literature

With congenital heart disease, there are many different aspects of life that impact adults living with CHD. CHD has many different types of defects. The literature will be explored for pathophysiology, types of CHD, treatment, and health maintenance. Finally, how CHD affects all the aspects of an individual’s life will also be examined.

Pathophysiology

Congenital heart disease can be classified in many different ways. The first is by the anatomical defects. The second is the hemodynamic alterations. And the final classification is the amount of tissue oxygenation (Porth, 2007). The fetal heart develops between the fourth and seventh weeks of gestation which is when the defect occurs. Shunted blood can affect the amount of oxygen in the blood and can also affect the volume of blood that is delivered to the pulmonary circulation (Porth, 2007). When the blood is being shunted, left-to-right shunting means the blood is diverted from the arterial system to the venous system while right-to-left shunting happens when blood is diverted from the venous system to the arterial system. There are two different tests that can be used to find defects. The first is an ultrasound which allows the fetus to be examined for developmental and functional progress. Also used is an echocardiography of the fetus which allows for heart defects to be distinguished (Porth, 2007).

The types of CHD are as follows: ventricular septal defect, atrial septal defect, pulmonary stenosis, aortic coarctation, transposition of the great arteries, and tetralogy of fallot. Some other conditions that are prevalent with CHD include Eisenmenger’s syndrome and Ebstein anomaly (UCSF Medical Center, 2007).
**Ventricular septal defect.** A ventricular septal defect (VSD) is a hole between the right and left ventricles through the wall or septum of the heart. It is also called a “hole” in the heart (AHA, 2008c). This defect allows blood to flow from the left to right ventricle. The blood then does not go through the aorta into the body. Some of the signs and symptoms associated with VSD are shortness of breath, an enlarged heart, and pulmonary hypertension. To diagnose VSD, a heart murmur may be heard; a chest x-ray, echocardiogram, or electrocardiogram can be used. To treat VSD, drugs or open-heart surgery are used when the defect is discovered in childhood. As an adult, the individual needs to continually see a cardiologist for check-ups and may need to use antibiotics before any surgeries or dental procedures. He or she may also need to take continuous doses of blood pressure medication and diuretics which allows the heart to pump better (UCSF Medical Center, 2007).

**Atrial septal defect.** An atrial septal defect (ASD) is a hole in the wall of the heart between the left and right atria. The defect can be many different sizes and occur on many different areas of the septum between the atrias (Ritz, 2007). The blood flows from the left atrium to the right atrium causing more blood to be pumped into the lungs. This causes a murmur to occur. ASD can also cause the right side of the heart to enlarge and congestive heart failure to occur. To diagnose ASD in adulthood, a chest x-ray, echocardiogram, or electrocardiogram can be used. To treat ASD, cardiac catheterization can be done by placing a catheter through a blood vessel into the heart, and then a septal repair device is chosen to close up the hole (UCSF Medical Center, 2007).

**Pulmonary stenosis.** Pulmonary stenosis is a narrowing of the pulmonary valve or artery. It is most commonly caused from a malformation during fetal development and
accounts for ten percent of all congenital defects (Lee, 2006). This causes the heart to work harder to pump blood to the lungs. Most people with pulmonary stenosis do not have any signs and symptoms, but if it is severe they may present with rapid breathing, fainting, cyanosis, and low energy. Pulmonary stenosis can be diagnosed through a chest x-ray, echocardiogram, electrocardiogram, and exercise tests to measure the amount of oxygen in the muscles while exercising. Treatment includes surgical replacement of the valve or a valvuloplasty during which a catheter is put into a blood vessel through the leg. When it is at the valve, a balloon is inflated to stretch out the valve (UCSF Medical Center, 2007).

*Aortic coarctation.* A narrowing of the aorta occurs in aortic coarctation causing the heart to work harder to pump blood to the body. Signs and symptoms of aortic coarctation include hypertrophy, high blood pressure, epistaxis, exertional dyspnea, headaches, and leg fatigue and cramps, poor growth, and failure to thrive (Zieve & Fogel, 2007). Aortic coarctation can lead to stroke, congestive heart failure, or coronary artery disease if not treated. Aortic coarctation is diagnosed through blood pressure measurement, a chest x-ray, echocardiogram, electrocardiogram, and magnetic resonance imaging. It is treated through a heart catheterization (UCSF Medical Center, 2007).

*Transposition of the great arteries.* According to the UCSF Medical Center, “Transposition of the great arteries is when the two major arteries leaving the heart are connected to the wrong ventricles” (2007, ¶ 1). This results in the oxygenated blood being pumped back into the lungs and the blood without oxygen being pumped into the body. The signs and symptoms that occur with this are seen at birth. The baby is cyanotic and does not show improvement when given oxygen. There may also be a murmur that
can be heard. Some tests that are used to diagnose this condition are a chest x-ray, echocardiogram, electrocardiogram, and oxygen saturation. The treatment that needs to be done is a surgery that switches the arteries to the proper places. It is crucial that babies have this procedure so that they will survive to be adults. Some complications that can occur with this surgery include heart failure, leaks, and abnormal heart rhythms (UCSF Medical Center, 2007).

_Tetralogy of fallot._ Tetralogy of fallot is a combination of ventricular septal defect, pulmonary stenosis, right ventricular hypertrophy, and an overriding aorta (National Heart Lung and Blood Institute, 2007). Most of the adults with this condition have had surgical repair when they were children. If they have not, they will present with mild cyanosis and a murmur. To diagnose tetralogy of fallot, a chest x-ray, echocardiography, electrocardiogram, or looking at the oxygen level in arterial blood can be done. After having the surgery as treatment, antibiotics need to be taken when having any dental work or surgeries done. The individual also needs to continually get check-ups from a cardiologist (UCSF Medical Center, 2007).

_Eisenmenger’s syndrome._ Eisenmenger’s syndrome is a hole in the heart that allows oxygenated blood to flow back into the right ventricle and into the lungs. The hole can be a septal defect, atrial septal defect, or patent ductus arteriosus. Unless this defect is corrected, the blood flow will eventually reverse, and unoxygenated blood will be pumped to the body. Cyanosis, gallstones, gout, high red blood cell counts, swollen or clubbed finger tips, stroke, kidney problems, fainting, heart failure, iron deficiency, coughing up blood, arrhythmia, and bleeding disorders are all symptoms that occur with Eisenmenger’s syndrome (UCSF Medical Center, 2007). Echocardiograms and heart
catheterization are done to show the defect, the size of the hole, and to measure pressure in the heart. Blood can be removed several times a year as a form of treatment. Antibiotics need to be taken before surgeries or dental procedures, and a nutritious diet is very important. It is important to avoid alcohol, smoking, salt, and overexertion. Surgeries can also be done to repair the hole (UCSF Medical Center, 2007).

**Ebstein anomaly.** Ebstein anomaly occurs when the tricuspid valve is deformed and blood leaks back into the atrium. The tricuspid valve is located lower in the heart making the right ventricle too small and right atrium too big. Some other complications that can occur include an arrhythmia, pulmonary stenosis, pulmonary atresia, and atrial septal defect (Texas Heart Institute, 2008). In adults with Ebstein anomaly, difficulty breathing, fainting, problems with exercising, and chest pain can occur. If the defect becomes serious enough, cyanosis and heart failure can also occur. Exercise tests, electrophysiology studies, and a Holter monitor for arrhythmias can be used to detect Ebstein anomaly. Chest x-rays, echocardiography, and electrocardiograms can also be done. Surgery and medications are used to treat the defect. According to the UCSF Medical Center, “If arrhythmia is present, radiofrequency ablation, a procedure in which a burst of energy destroys an abnormal electrical pathway in the heart, may be necessary” (2007, ¶ 3).

**Comorbidities**

Individuals with congenital heart disease may have to prevent comorbidities such as bacterial endocarditis, congestive heart failure, and arrhythmias. One risk factor is those individuals with pacemakers. Pacemaker implantation puts those at risk for heart failure. Another risk factor that needs to be watched for is different levels of brain
natriuretic peptides. And finally, an infection called bacterial endocarditis needs to be watched for closely.

**Bacterial endocarditis.** Bacterial endocarditis is an infection of the endocardium or the heart valves. It is common in individuals that have tetralogy of fallot, ventricular septal defect, mitral valve prolapse, transposition of the great arteries, patent ductus arteriosus, aortic coarctation, or aortic valve lesions (UCSF Medical Center, 2007). Some of the symptoms that occur with bacterial endocarditis include fever, joint pain, rash, poor appetite, weight loss, and fatigue. Blood tests and urine samples are used to detect the presence of bacteria and infection. Antibiotics are used as a treatment, and it can take anywhere from four to six weeks to recover (UCSF Medical Center, 2007).

**Pacemaker implantation.** Pacemaker implantations are seen in many individuals today, but those with congenital heart disease may be at risk for heart failure. Researchers have done a quantitative study to see if pacemaker implantation is a risk factor for heart failure in young adults with CHD. The results of the study show that out of the thirty-nine participants who had pacemaker implantation, twenty-five had an elevated BNP plasma level and decreased oxygen uptake which were the criteria for heart failure. Compared to those without the pacemaker implantation, the levels of oxygen uptake were not as low and the BNP plasma levels not as high as those with pacemakers. For those subjects with pacemaker implantation, heart failure was “associated with significantly prolonged paced QRS complex duration, lower heart rates at rest, lower maximum heart rates, and lower maximum systolic blood pressure” (Nothroff et al., 2006, p. 388). The study used 346 young adults with CHD. The participants were both male and female and were between the ages of fourteen and fifty. To look for heart failure in the participants, the oxygen
uptake and BNP plasma levels were watched. All of the participants underwent a physical examination, cardiopulmonary exercise testing, and had samples taken of peripheral venous blood.

*Natriuretic peptides.* Individuals with heart disease are watched for different levels of brain natriuretic peptides (BNP). A qualitative study with twenty individuals was done to look at the effect of hypoxia on the secretion of natriuretic peptides. Ten individuals had cyanotic congenital heart disease and the other ten were noncyanotic controls. In the study, the individuals fasted, and then the next morning measurements were taken of “N-terminal proatrial natriuretic peptide (proANP), N-terminal probrain natriuretic peptide (proBNP), blood urea nitrogen, serum creatinine, hemoglobin, arterial oxygen saturation, body mass index, resting metabolic rate, and body water” (Hopkins et al., 2004, p. 2873). The results showed that in cyanotic individuals, resting heart rate and hemoglobin were higher and resting arterial oxygen saturation was lower than in the control group. It also showed increased proANP and proBNP by many times in cyanotic individuals. In conclusion, the study showed that hypoxia had a direct effect on natriuretic peptide secretion. The nursing implications that came out of the study will allow nurses to pay more attention to natriuretic peptides and watch the levels in patients with hypoxic congenital heart disease (Hopkins et al., 2004).

*Treatment*

There are several different treatments that may be implemented with those individuals with CHD. Antibiotics were once thought to help prevent infection during or after dental work, but it is now thought that they do not help. Two forms of treatment that have shown to be effective with CHD are cardiac resynchronization therapy and bosentan
therapy. In the society, hospitals and community health care systems are being challenged every day to provide services to the populations at risk for congenital heart disease. According to Lowdermilk, “An interdisciplinary team approach is vital for providing holistic care” (2004, p. 1089). The team needs to help in every aspect including educating the individual and family, helping financially and psychosocially, and doing the surgery and rehabilitation treatment (Lowdermilk, 2004).

Antibiotics. Prophylactic antibiotics were once thought to help prevent infective endocarditis in individuals with CHD who were having dental work done. New guidelines have come out from the American Heart Association (2008b) identifying that the risks of taking prophylaxis antibiotics outweigh the benefits. Taking these antibiotics before going to the dentist is not necessary and can cause allergic reactions or antibiotic resistance to occur. According to the American Heart Association, “Only the people at greatest risk of bad outcomes from infective endocarditis — an infection of the heart's inner lining or the heart valves — should receive short-term preventive antibiotics before common, routine dental and medical procedures” (2008b, ¶ 4).

Cardiac resynchronization therapy. Cardiac resynchronization therapy (CRT) in one study showed improvement of haemodynamics in individuals with CHD. Researchers reported that more studies need to be done on CRT. Researchers found, “Cardiac resynchronization therapy attempts to improve inter- and intra-ventricular electromechanical co-ordination, hence its effects are critically dependent on the presence of baseline ventricular dyssynchrony” (Diller, Okonko, Uebing, Yen Ho, & Gatzoulis, 2006, p. 269). In this study, seventy-five individuals with surgically corrected transposition of the great arteries (TGA) were involved. Most of these individuals
reported they were asymptomatic and in sinus rhythm. Forty-nine individuals with congenitally corrected TGA were also included and reported they were symptomatic and in sinus rhythm. In both of these groups, the individuals that were symptomatic had conduction delay, right bundle branch block, a QRS duration equal to or greater than 200, and reduced systemic ventricular function. They also had cardiomegaly and decreased peak oxygen consumption while exercising. These symptoms were all looked at throughout the test to see if the individual would be eligible for CRT. Healthy individuals were used as controls to tell how individuals with CHD were affected.

*Bosentan therapy.* Bosentan is an endothelin receptor antagonist used to treat pulmonary arterial hypertension. According to the American Society of Health-System Pharmacists, “It works by stopping the action of endothelin, a natural substance that causes blood vessels to narrow and prevents normal blood flow” (2005, ¶2). A qualitative study was done with thirty-three patients between the ages of fifteen and sixty-four with congenital heart disease and pulmonary arterial hypertension to look at the results of how bosentan therapy affects exercise capacity, cardiopulmonary hemodynamics, and arterial oxygen saturation. At the beginning of the study, baseline data were collected for the individuals, and then they were put on Bosentan therapy for one year with checkups every three to six months. Throughout the study, the individuals did six-minute walks and had right-sided heart catheterizations. The results of the study show that the treatment was well tolerated. The individuals had an increase in exercise tolerance at the end of the study. The bosentan therapy also reduced right ventricular afterload and improved pulmonary blood flow allowing higher systemic oxygen delivery. The nursing implications that came out of this study allow nurses to be able to monitor individuals
that are on the bosentan therapy and to be able to follow their results to see if the
treatment is working. (Schulze-Neick et al., 2005).

Another study showed that bosentan therapy was safe and well tolerated in adults
with Eisenmenger’s syndrome. The ten individuals, between the ages of thirty-eight and
forty-six, participated in the study through informed consent. Baseline data were
collected, and the individuals had a three-month assessment that included oxygen
saturations at rest, a six-minute walk test, respiratory mass spectrometry, and
transthoracic echocardiography. Oxygen saturations and the distance traveled in the six-
minute walk both increased. The individuals did not have any major adverse effects. The
echocardiography after three months showed that there was an improvement in
pulmonary haemodynamics and right ventricular systolic function. Finally, it showed that
there was no elevation in liver enzymes. (Gatzoulisab et al., 2005).

Living with Congenital Heart Disease

Many different aspects are affected when an individual is living with congenital
heart disease. This section looks at the different areas of life that are changed. Quality of
life, disease knowledge, and changing healthcare systems are the most important aspects
of life that are affected. Other areas of an individual’s life that are affected include
psychopathology, exercise, pregnancy, and heartbeat sensitivity.

Quality of life. Nurses play a role in identifying and assessing how adults with
congenital heart disease perceive their quality of life. A quantitative study was done to
examine whether the quality of life differed with different anomalies. Quality of life in
this study was described as the individual’s “behavioral and cognitive capacities,
emotional well-being, and abilities required for the performance of domestic, vocational,
and social roles” (Simko & McGinnis, 2005, p. 207). The study took place in an outpatient cardiology clinic and used 124 English-speaking adults over the age of eighteen. The tool used was called a Sickness Impact Profile (SIP), which uses 136 items that are associated with activities of daily living. The scores ranged from 0 to 100 where 0 was no dysfunction and 100 was maximal dysfunction. The scores on the classification showed from “0 to 3.99 as having no disability, 4.00 to 9.99 as having mild disability, 10.00 to 19.99 as having moderate disability, and more than or equal to 20.00 as having severe disability” (Simko & McGinnis, 2005, p. 208). The tool had a reliability ranging from 0.81 to 0.95. The tool also used content and criteria validity. The results showed that most adults with CHD perceived no disability. The areas most affected were work, sleep, and rest. Also, results of the study showed that different anomalies resulted in different levels of disability. Through this study, nurses will be able to help set up support groups for adults with CHD for their psychosocial needs. It will also help nurses to assess the individual’s needs by knowing that the quality of life is different for everyone.

Another study with 629 individuals showed “that the severity of congenital heart disease is marginally associated with patients’ quality of life. Patients’ assessment of their quality of life relates more to functional status than to the initial diagnosis or the course of the illness” (Moons, Van Deyk, De Geest, Gewillig, & Budts, 2005, p. 1198). Three different aspects were looked at in the study. The initial diagnosis was evaluated. The second was the illness course which was split into three different categories, mild, moderate, or severe defects, based on the disease severity index. Finally, current functional status was based on three classification methods. The methods are the ability index, CHD functional index, and NYHA functional class. Quality of life was defined in
this study as "the degree of overall life satisfaction that is positively or negatively influenced by people's perception of certain aspects of life important to them, including matters both related and unrelated to health" (Moons et al., 2005, p. 1196). There were several ways that the study measured quality of life. The first was the linear analogue scale where patients rate their overall perceived quality of life. The second was the satisfaction with life scale which has five statements and seven responses that have to be answered ranging from “strongly agree” to “strongly disagree.” The third was the schedule for the evaluation of individual quality of life-direct weighting. Moons et al. stated, “It consists of three successive steps: firstly, the respondent nominates the five areas that are most important for his or her quality of life; secondly, the actual status of each specified area is rated from 0 to 100 on a visual analogue scale; and, thirdly, the relative importance of each selected area is quantified relative to each other area with the use of a five segment disk” (2005, p. 1196). And finally, they looked at the individuals' self-perceived health.

*Disease knowledge.* Out of the sixty-two individuals that took part in this study, sixty were satisfied with the amount and type of information that were given to them by their cardiologist. Information that was well understood included need for regular follow-up and outpatient visits, past treatment, diet, drug regimens and side effects, pregnancy risks, occupational choices, dental practices, and oral contraceptive use. Some information that needed to be further talked about was physical activity, the heart defect's name and anatomy, and endocarditis. The reason for follow-up was not well known by the individuals. The individuals also needed help with information regarding smoking and alcohol use and symptoms of deterioration related to the heart disease. The
individuals chosen for the study were Dutch-speaking and over the age of eighteen. A questionnaire was developed to measure the individuals’ responses. It was called “the ‘Leuven Knowledge Questionnaire for Congenital Heart Diseases,’ which measures knowledge in all four domains: (1) the disease and its treatment; (2) the prevention of complications, including endocarditis; (3) physical activities; and (4) reproductive issues” (Moons et al., 2001, p. 75).

Transferring from pediatric to adult health care. The transition of health care from pediatric to adult cardiologists is an important area for people with congenital heart disease. A quantitative study was done to determine how successful transfers were for individuals with CHD (Graham et al., 2004). The study also looked at successful transfer correlates. In the study, 360 eligible participants were used that were between the ages of nineteen and twenty-one. Data were collected through standardized questionnaires, interviews, and the participants’ demographic information. The results of the study showed that out of the 360 participants, 170 had success in transferring from pediatric to adult care. According to the correlate findings of the study, “successful transfer was related to reported frequency of adolescent cardiac appointments, patients’ beliefs about where and when adult follow-up should take place, and health status” (Graham et al., 2004, p. 200-201). The participants’ independence in attending appointments, dental antibiotic prophylaxis use, and substance abuse all made a difference in how a person transferred from pediatric to adult care.

There are several recommendations that make transitioning from pediatric to adult health care occur smoothly: a) during adolescence, the doctors should begin to inform the individual and family about transitioning to adult healthcare; b) the transition should then
take place anywhere from the ages of fourteen to eighteen; c) the transition should include a pediatric cardiologist and a nurse specialist, who has experience in counseling and transferring arrangements; d) one of the most important parts of transitioning is education. The individual and family need to be informed about the plan for transitioning and also “understand their cardiac condition, healthcare needs, and prognosis” (Deanfield et al., 2003, ¶ 4). Education also needs to be provided for medications, exercise and future complications. Knowing how to function in the adult healthcare system so that the individual can get appropriate medical advice is also an aspect of transitioning. Another important part is the parents’ letting go and allowing the adolescent to have individual sessions with the cardiologist and nurse specialist. One final recommendation is that the transitioning process needs to be a gradual one that allows for communication to happen between the healthcare team, family, and individual.

Coping with congenital heart disease. Emotional and behavioral problems can occur in individuals with CHD. The results of one study showed that predictors for behavioral and emotional problems were being female, having early hospitalizations, restrictions imposed by physicians, low exercise capacity, personal experience, and certain anomalies. Some nursing interventions that came out of the study showed that nurses should pay attention to the individual’s experience and should offer psychological counseling if it is needed (Van Rijen et al., 2004). In the study, psychopathology was tested in 362 young adults ranging from twenty to forty-six years old. The quantitative study used a self-report questionnaire, a Young Adult Self-Report (YASR), and a Young Adult Behavioral Checklist (YABCL). Through these tools, behavioral and emotional problems were assessed. The YASR had a reliability of 0.84 to 0.89 and had good
construct validity. The YASR has 110 problem items and "response format is 0 = 'not true,' 1 = 'somewhat or sometimes true,' and 2 = 'very true or often true'" (Van Rijen et al., 2004, p. 1606). The YABCL also used the same format but had 105 problem items. The YABCL reliability was 0.81 and had good validity.

Exercise. Exercise intolerance is very prevalent in individuals with congenital heart disease. Studies have been done to see how exercise capacity is affected in individuals with CHD. The results of one study showed that adults with CHD and non-congenital heart failure had decreased exercise capacities that were similar. This decrease in exercise capacity in CHD subjects was an increased risk for hospitalization and death. Also in the results, reduced oxygen consumption was seen in CHD subjects compared to the healthy subjects. Participants with more complex CHD lesions had a worse exercise capacity than those with simple CHD lesions (Gerhard-Paul et al., 2005). A quantitative study done on exercise intolerance compared how exercise affected 335 adults with congenital heart disease, twenty-three healthy subjects, and forty non-congenital heart failure subjects. All the participants were between the ages of twenty and sixty-eight and consented to take part in the study. The study was carried out by having the participants perform cardiopulmonary exercise tests on a treadmill. Throughout the test, measurements were taken of carbon dioxide production, oxygen uptake, ventilation, heart rate, and arterial blood pressure. Through this study, the researchers found that exercise intolerance is affected by congenital heart disease and the different lesions that occur with CHD (Gerhard-Paul et al., 2005).

Pregnancy. A study done to examine the outcomes of pregnancy in fifty-three women between the ages of twelve and fifty showed that individuals with severe
pulmonary regurgitation or impaired subpulmonary ventricular systolic function are at a greater risk for adverse cardiac outcomes. Therapy was helpful for those whose symptoms were recognized early and who were watched closely. Researchers discovered, “A multidisciplinary approach that includes availability of high-risk obstetric care, specialized cardiology assessment and follow-up, and genetic counseling is recommended for women with congenital heart disease contemplating pregnancy” (Khairy, Ouyang, Fernandes, Lee-Parritz, & Landzberg, 2006, p. 523). The most common cardiac complication that occurred was congestive heart failure with arrhythmias. With each participant, baseline data were collected before pregnancy or on the first visit and then data were collected throughout the pregnancy. Definitions about cardiac, neonatal, and obstetric events were determined by Siu and colleagues. Out of all the pregnancies, eighteen were aborted, two intrauterine fetal demises occurred, seventeen cesarean sections, and fifty-five vaginal births occurred (Khairy et al., 2006).

Heartbeat sensitivity. Sensitivity to heartbeat is thought to be affected by congenital heart disease, so researchers conducted a study to see if people with CHD had a sensitivity to heartbeat. At the end of the study, the results showed the participants with CHD “were more distracted by audible heartbeat during a concentration task than healthy controls” (Rietveld, Karsdorp, & Mulder, 2004, p. 208). The results also showed that the healthy controls were better at estimating their own heart rate than the participants with CHD. And finally, the CHD participants and healthy controls had the same amount of anxiety when listening to audible heartbeats. The study used twenty participants with CHD and twenty healthy control participants. The participants of the study took part in three different tests. The first was “used to test attention for heartbeat” (Rietveld et al.,
by having the participants perform a concentration task while listening to no heartbeat, a heartbeat of 70 bpm, or a heartbeat of 150 bpm. The second test “was used to test estimation of own heart rate” (Rietveld et al., 2004, p. 205). This was done by having the participants listen to two buzzing sounds and then estimating how many times their heart beats in between the sounds. The last test was to “test vulnerability to become anxious from audible heartbeat” (Rietveld et al., 2004, p. 206) by listening to no heartbeat, a heartbeat of 70 bpm, and a heartbeat of 150 bpm. During the tests, recent physical symptoms, state and trait anxiety, quality of life, heartbeat, and concentration were all assessed.

Educational Resources

Using the internet is a common way to find quick information. The only problem is whether or not the information being looked at is valid. A tool is available that allows anyone to be able to tell if a website is accredited and valid or not. The tool is called HONcode and can be downloaded at http://www.hon.ch/HONcode/Plugin/Plugins.html. This tool looks at authority, complementarity, privacy, attribution, justifiability, transparency, financial disclosure, and advertising policy information on a website to tell if it is valid.

Now some websites that are valid and a good source of information about congenital heart disease will be looked at. The first is Medline Plus which can be found at http://www.nlm.nih.gov/medlineplus/congenitalheartdefects.html. This website gives general information about CHD and includes anything from diagnosis and treatment to the different types of CHD. Another good website is WebMD which also gives basic information about CHD. WebMD can be found at http://www.webmd.com/heart-
disease/guide/congenital-heart-disease. Finally, another good website is the American Heart Association. The website is http://www.americanheart.org/presenter.jhtml?identifier=1200000. The American Heart Association gives general information about CHD while also providing studies that have been completed on issues related to CHD.
Chapter III
Methodology

The purpose of this research paper was to learn, through individuals’ experiences, how to live with congenital heart disease. Phenomenology was the method that was chosen to complete this research paper. The phenomenological method is “a system of interpreting and studying the world of everyday life” (Russell, 2004, p. 220). Throughout this section, phenomenology will be described along with Giorgi’s Method of data analysis. The sample, setting, confidentiality, bracketing, and the researcher’s biases will also be evaluated.

Phenomenology Method

Phenomenology is a research approach that describes an individual’s experience. According to Russell, “Phenomenology is both a philosophy and a research method that explore and describe everyday experiences in order to generate and enhance the understanding of what it means to be human” (2004, p. 220). The phenomenological method can be used for individuals with congenital heart disease by gaining the individual’s experience of living with CHD and what it means to him or her. Along with a holistic approach, an in-depth understanding of how CHD affects an individual’s life can be gained.

Bracketing. Bracketing is a process that must occur for a phenomenological method to work. According to Russell, “Bracketing requires the researcher to identify any previous knowledge, ideas, or beliefs about the phenomenon under investigation” (2004, p. 222). Then the researcher must remove any biases that occur. The interview and
questions were given so that the researcher’s bias did not appear in any way. At the time, the researcher did not have any biases towards congenital heart disease.

Sample and Setting

Data were collected from two English-speaking adults with congenital heart disease. Both participants were female between the ages of 18 – 55. The data collection took place in a convenient location for the participants. It occurred at a time that was suitable for the participants. The participants took part in the interviews on a voluntary basis and had the option to refuse any questions.

Data Collection

Data were collected through in-depth interviews. As previously stated, the interviews took place in a convenient private location and at a suitable time for the participant. The same interview questions were asked for both participants. Each interview was audio-taped and transcribed into a document.

Confidentiality

Throughout the research process, confidentiality was maintained. The participants were voluntary, and each signed an informed consent. Confidentiality was kept by not using any names of participants. Pseudonyms were used for any data collection. Data collected was not given out to any other sources for any reason. Audiocassette tapes were kept in a locked cabinet and destroyed after data analysis was completed. All records were kept confidential in a locked file, and identifiable information was not included in the study. Confidentiality was also kept through the researcher having an NIH certification and IRB approval.
Data Analysis

Data were analyzed through Giorgi’s method. With this method, an interview took place with two or three individuals that have lived with CHD. This method allowed the researcher to gain an understanding of the experiences of the individuals with CHD. Giorgi’s method, as described by Russell (2004), includes the following steps:

1. Read the entire disclosure of the lived experience straight through to obtain a sense of the whole.

2. Reread the disclosure to discover the essences of the lived experience under study. Look for each time a transition in meaning occurs. Abstract these meaning units or themes.

3. Examine meaning units for redundancies, clarification, or elaboration. Relate meaning units to each other and to a sense of the whole.

4. Reflect on the meaning units, and extrapolate the essence of the experience for each participant. Transform each meaning unit into the language of science when relevant.

5. Formulate a consistent description of the meaning structures of the lived experience for all participants (p. 230).
Chapter IV

Results

The purpose of this study was to gain an understanding of the experience of living with congenital heart disease. The two women that were interviewed are between the ages of 18-55. They both live in the rural northwest United States. For confidentiality reasons, these women will be called Tina and Beth. Tina has a patent foramen ovale while Beth has a complete heart block with a pacemaker. Both of these women have had a long journey with CHD. They both described their experiences of living with CHD through these themes: seeking a diagnosis, fear and uncertainty, ongoing treatment, and reclaiming health.

Seeking a Diagnosis

Both Tina and Beth lived with CHD for many years before they finally understood their diagnosis. As Tina was trying to find out about her diagnosis, she had to spend a great deal of time in the hospital and went through many hardships. Tina shared her story:

The only thing that I knew that was wrong with me medically speaking was I had migraines . . . I do not have any symptoms of having this disease and so actually the symptoms that appeared that led to this discovery was a stroke . . . We were eating dinner and I just went numb . . . So that night, everything just changed; it involved a couple weeks of being in the hospital and actually resulting in being medically airlifted to Salt Lake City, Utah. And at that time, they did a procedure called an angiogram and when they did the angiogram they found a blood clot in my brain and they said, “where did that come from” . . . The opening in my heart
is so small they couldn’t find where the blood clot came from. And they even did a test, I am going to call it the bubble test, and I passed it. The opening is so small that the bubbles went the correct direction in my heart. So I was still in kind of a recovery from this trouble and they were trying to figure out what was wrong with me and that summer they sent me to the Mayo Clinic in Rochester Minnesota. So that would have been the summer of 1989. They did a transesophageal echo, you might hear it referred to as a TEE, and that discovered it... So no [real] effects other than what happened they think was somehow a clot had snuck through it and into my brain. And obviously small, very small. But it’s amazing how something so teeny tiny, they said, they showed me a pencil. And they said see the lead of a pencil, that’s how small it is. And it’s amazing how it shut me down. I couldn’t walk, I couldn’t talk.

As the years went on, Tina lived knowing that she had a small hole in her heart but that was all that was said. No one had any major concerns about it, so she continued to go on with her life. It was not until years later that she found out exactly what she had when she shared:

So, I had a bone, a foot that needed surgery and when I told the orthopedic specialist about it, actually who I went to was a bone, a foot specialist, he said, “I don’t like your history at all.” He said, “I won’t do surgery on your foot until your heart gets reevaluated.” And if you can believe it, that was in 2005. At that point, I had never had a heart person look at me. So all this trouble happened to me in 1989, and in 1989 they knew I had a PFO [patent foramen ovale], I had a opening. Never, ever, did I have a need for a heart person to look at me.
Beth also took many years to find out her diagnosis. When she was very young, she was in the hospital and went through many different tests. Beth stated, “The earliest I remember was when I was about five and I had to get a new pacemaker. I didn’t really know what it was, what it was for or anything.” As Beth grew older, she continued to learn more about her disease. She said that she found out more about her condition at the age of nine or ten when she commented:

The only thing I knew was that I was born with something, something was wrong with my heart. Well, when I was nine, I got another pacemaker because the battery ran out. So I kind of understood more about it, just that I needed it to help my heart beat fast enough.

As Beth was growing up, one of the symptoms that she experienced she shared through a story. She stated:

When I run hard enough and my heart beat gets above 150 or 160, the pacemaker cuts the heartbeats in half. So if I was running at 160, my heart would be pumping at 80, but I would still be running hard and I would get nauseous. And a couple times I would throw up in gym class and it was really embarrassing.

Beth also shared information about her pacemaker when she stated, “I can’t really tell when the battery wears out except that I get tired so hopefully if I start to get tired, really tired, I will be able to realize that something is wrong.”

Fear and Uncertainty

The theme of fear and uncertainty emerged with both Tina and Beth. Several situations occurred that caused fear to arise. Beth shared her experience when she commented:
I guess when I was twelve, when I found out I had cardiomyopathy, that kind of scared me because they didn’t really know how to fix it. But now it’s ok because it’s under control . . . Right now, I am just worried that the battery’s going to wear out and I am not going to know about it until I get really tired.

Tina also had a situation of fear when she stated:

After the angiogram, we were in Utah. It is not uncommon to . . . have trouble after because they can blow another clot. Because the process of them injecting fluid in through your body like that can move another clot and it did. So the next clot . . . was the worst clot. And I was in the process of having an EEG, and I was laying down with all those electrodes and all of a sudden the entire room just started to close. And I couldn’t speak again. I couldn’t move. I could hear everything all around me and it was just all of the sudden. And so now they tell me what really happened was that one went to my eye. And I have left eye permanent damage . . . So that one was much bigger than anything else I have ever experienced. And I will tell you, I didn’t ever want to go through that again. That was the one that was the scariest. And I think that was the one that I was thinking, if this can happen, what else can happen.

Both Beth and Tina also shared stories talking about how they were uncertain about their conditions. Beth showed uncertainty when she said:

Well, my mom has lupus and when she was pregnant, I think, I am not entirely sure, but she found out she had lupus when she was pregnant with me because she got sick. And so, I am not sure if that is what caused it. All I know is that she was sick when she had me . . . When I was born, I had complete heart block. And I
still don’t really know what it is. I guess it just made my heart not beat fast enough. So they put the pacemaker in . . . Well, when I was younger, they just kind of explained it really basic. And I didn’t know exactly what was going on. But now that I am getting older, I am probably not going to be seeing my pediatric doctor any more. He is trying to inform me more to get me ready to go to the doctor by myself and a different doctor. So that I can be more independent, like when I go off to college and stuff, if I ever got sick or was in the hospital, I would be able to tell the doctors that I had a pacemaker. Cause I can’t get MRIs because of the magnets and if anything ever happened that they were going to do that, they would want to know.

Tina also spent a lot of time being uncertain. She shared her story:

Actually, they found it and I didn’t even know I had it. It was like, we’ll find it but we’ll tell your doctors back in Helena . . . Didn’t really even know what they were talking about until I got back here and then it was kind of like, well, you have it but it’s no big deal. And basically they felt good about it because it was a possible path that that clot could have come. And honestly, I was thinking well, if they’re not worried about it, I guess I better not be too. Cause they’re not even having me see a cardiac doctor. And the first time I got scared about it was when the foot surgeon said, “I don’t like your history.”

*Ongoing Treatment*

Both participants explained that the ongoing treatment process is a very long period. It is very expensive to get all the procedures done and can be a financial burden. Also because they both live in Montana, they have to travel to many different locations to
receive treatment. There are many check-ups and procedures that occur when an individual has CHD. And finally, there are many different medications that are used throughout the course of treatment.

*Financial burden.* Medical expenses are very expensive and both participants expressed that insurance is a very important aspect for someone with a major medical problem. Tina expressed how insurance has helped her by stating:

> Insurance has been very very helpful. You really can’t do this without insurance.

The stroke [cost me] 40 thousand dollars. In 1989, 40 thousand dollars, that was a long time ago. We’ve for the last two years maxed our medical bills and then we’ve paid more . . . It takes ten thousand dollars every year to max that. We have been ok because we’re frugal people and because having health insurance, quality health insurance has been a priority.

Tina also said that the device used for the PFO closure in 2005 was “ten thousand dollars, at that time it was ten thousand dollars.”

Beth similarly talked about insurance and how it has helped her family. She commented, “The pacemakers, I think they cost around twenty thousand each.” She also mentioned that the medicine she takes only costs three dollars a month. Beth said that her family has “a pretty good insurance plan” which helped to pay for her medical expenses.

*Travel.* Living in the rural northwest brings up many problems when it comes to getting the medical care or procedures done that need to be done. There are many times when an individual has to travel out of the state to bigger medical facilities. Tina had to travel to several different states to receive treatment as well as staying in the state. She had to be “medically airlifted to Salt Lake City, Utah.” She received treatment at St.
Peter’s Hospital. Tina also had to travel to the Mayo Clinic in Rochester, Minnesota to go through many procedures. The last place Tina has had to travel was to Missoula for the PFO closure.

Beth showed similarities in having to travel out of state to receive treatment. Beth said to get new pacemakers put in, she has to go to “Salt Lake at the pediatric doctor.” She also has to “go to the doctor in Great Falls every six months and he is a pediatric cardiologist.”

*Check-ups and procedures.* After being diagnosed, Tina and Beth both had to attend regular check-ups with their doctors and went through many procedures. Tina shared:

> So in 2005, the foot just got way too sore and [the foot surgeon] said, “Definitely there is no question, it has to be surgery so you have to go see a heart specialist” . . . [The heart specialist] couldn’t have been more thorough. I finally understood what I really had, why it needed to be closed. So then they sent me over to Missoula. But the gentleman over in Missoula, he wasn’t quit sure . . . So my doctors over here had to work a little bit to say no, absolutely not. Then he sat down with me again and he said, “I’m telling you right now, I have some reservations about whether or not you are a candidate for a PFO closure and then I will turn around and tell you that I have a patient in the hospital right now that had an opening, had foot surgery, and he stroked.” So I was like, close it. I’ve already had too much . . . And they did, he did. And then, it is a very expensive device. It’s ten thousand dollars, at that time it was ten thousand dollars, and it failed inside of me. So he gets it up inside of me and they just go into your artery
in your hip area. It’s just like the arteriogram . . . This device is, they go up inside of you, and it’s a two part umbrella. So one part opens up like this [top part] and they give it a little tug and the other part opens up [bottom part] and then your body builds cells and closes it up. This part [bottom part] didn’t open. So they had to pull this part [top part] closed and bring the whole thing back through. And something really hurt during the procedure. And that’s unusual. Because as a patient, I never ever hurt during any of these procedures before. And I really bruised. So the gentlemen, the doctor had to come to my family and say, “I’ve done 35 of these and I’ve never had the device fail. And because it failed, we actually made the opening bigger because we had to close what we had already opened and then we had to bring it back in through her heart” . . . [They did the procedure again] right then and there. They did it right all at the same time. Fortunately they had another device and fortunately it was bigger because the small one that they originally started with wouldn’t have worked anymore.

After the completion of Tina’s surgery, she had to have regular check-ups with her cardiologist. She stated, “At first, it was like a year check. And that’s when they’ve done two. They’ve done a TEE and they’ve done a bubble test. No more. They’re like, we know it’s sealed. We’ve tested it. You’re done.”

When Beth was born, she had to be hospitalized for her treatment and to get the pacemaker put in. Beth explained the hospitalization by stating:

I think it was two months, two or three, and they didn’t put a pacemaker in right away but I had one outside of my body helping me and then when they did, I was
really small when I was born so it was in my tummy, but it was really bulging out, but now you can’t even tell.

Beth also has to get check-ups. The pacemaker has to be monitored “every six months and then now they have expected battery life for it.” The batteries are expected to last “eight to ten years” and once that battery life is about up, the pacemaker has to be monitored “every three months.” Beth stated that she “[didn’t] know how exactly they do it, but they attach . . . an electrocardiogram. They attach these little electrodes all over and then they put a magnet over it and the computer reads it.” Also with her six month check-ups, Beth has to have any x-ray.

*Medications.* With having CHD, Tina had to take many different medications throughout the treatment that she received. Tina stated that as the doctors were figuring out what she had, “they were trying so many medicines on me when I got back to Montana . . . And the medicines, I didn’t need them. And fortunately I was on coumadin.” Tina also stated that later on in her treatment “they [had] me on a drug called Verapamil, which is a vascular drug. People a lot of times say, do you have a heart problem?” Tina also stated that while having the PFO closure, she was put on verced and after the closure, they put her on plavix.

Beth also has medications that she needs to take. She takes vasotech for the cardiomyopathy. She takes her medications twice a day usually at breakfast and dinner. Beth stated that “for now I think [I will have to take medications for life], but I don’t know if I will grow out of it. They said maybe, but I guess it is working right now so they are just going to stick with the medicine.”
Reclaiming Health

After many years, Tina and Beth were able to get on with their lives. Tina told her story stating:

So fortunately that summer, it was like I got to reclaim my health. And then began the process of, you know, do I have this time bomb ticking inside of me and I can’t let that, I can’t feel like that. Previous to that, I was this strong healthy energetic jogger. I had to let myself return to that. By profession, I am a health and physical education teacher. So I just had to say, what can I do to just regain that and just go on. And it is quite a process. I still think that medical health is more accepted than the mental health. But when something like this happens, they are tied. They are just tied together. There is as much mental, wow, this isn’t at all what I planned, as there is medical. And what does this mean. Basically at that time, it meant, we don’t know, we think you are going to be fine, go on. So I did.

Tina also commented: “But as you see, I don’t look like someone who has a congenital heart disease . . . I have had such a heart workup, I don’t have a problem. And it’s so nice to know I don’t. I really know, I can just go on.”

Even though Tina was able to go on with her life, she stated that there were a couple of restrictions that she had. She shared:

I would have to say alcohol is the one thing. I don’t have to not drink, but when you are taking this much brain chemical, I think it would be really foolish to drink too much. So that’s my one. You know like a glass of wine at night, maybe two at the most. But I am really cautious about that.
Tina also mentioned, “And the one thing that I can never remember to do because I do feel so good, I don’t feel like someone who has anything wrong with their heart, is I have to be premedicated when I go to have dental cleaning.”

Tina had a very good support system. Throughout her treatment and recovery, Tina’s “family and friends have been right along.” Tina commented:

All the help that we had, just the most amazing things. Everybody did something. My mom and dad were older but it didn’t matter; they were taking care of the kids . . . Having your walk shoveled, I can’t tell you how much that meant to us. It was like who did this. Grandma, grandma hired it done. It was just amazing . . . There’s always this whole group of people behind those people and it’s so neat to be able to be one of them. It’s like that old pay it forward story. That is the way it should be.

Beth was also able to go on with her life. She stated, “I can pretty much do anything . . . I did gymnastics . . . I still cross country ski . . . The only things I can’t do are welding and things like that that deal with magnets.” Beth had a very good support system while she was being diagnosed and treated. She commented: “My family is really supportive. My extended family is pretty big and I remember my uncles and my great uncle would always be telling me they were praying for me.” Beth will also have to have a pacemaker for the rest of her life, but she stated that it is “not really [a burden] just because I don’t know what it would be like to not have one. So I guess it is pretty much like normal. Which is good.”
Conclusion

Both Beth and Tina went through many hardships and good times while living with CHD. It took many years for both of them to find out what their diagnosis was. They both had times in their treatment when they were scared and uncertain about what was going on. But as time went on, both Tina and Beth went to check-ups, took many different medications, traveled out of state to get treatment, and had to deal with the financial aspect of having a heart disease. Even through all of this, they were both able to go on with life and reclaim their health in the end.
Chapter V

Discussion

According to Thompson, “Congenital heart disease is a lifelong illness that requires a dedicated, consistent approach to healthcare delivery in order to guarantee quality care throughout the lifespan” (2007, p. 3). How the participants were affected physically and mentally is seen through the themes of seeking a diagnosis, fear and uncertainty, ongoing treatment, and reclaiming health. According to Ninivaggi, “The delivery of appropriate care for adult congenital heart disease (ACHD) is a largely unmet challenge in the U.S. and elsewhere” (2005, p. 59). The findings of Ninivaggi were similar to the experiences of the individuals living with CHD in this study.

Seeking a Diagnosis

Finding out the diagnosis can be a long process and take many years. According to one article, “Many live a normal life for years before their abnormality is discovered” (Cardiology Explained, 2004, ¶ 1). This article correlated with one of the two participants; she had a hole in her heart for many years before they actually found it and diagnosed her. The Cleveland Clinic states, “Congenital heart defects may be diagnosed before birth, right after birth, during childhood or not until adulthood. It is possible to have a defect and no symptoms at all” (2009, ¶ 3). Both participants in this study had no or very few symptoms. One of the participants was not diagnosed until she was an adult while the other individual was diagnosed right after birth. Even though the individuals were diagnosed at different times of their lives, the common theme that emerged was that it took many years for both of them to finally understand their diagnosis.
According to the Cleveland Clinic, "Congenital heart disease is diagnosed by a murmur on a physical exam and several diagnostic tests: Echocardiogram, Transesophageal echocardiogram, Intravascular ultrasound (IVUS), Cardiac catheterization, Chest x-ray, Electrocardiogram (ECG or EKG), Magnetic resonance imaging (MRI), or Positron emission tomography (PET) scan" (2009, ¶4). Both participants in the study had to go through at least one of these tests to be diagnosed.

Fear and Uncertainty

Fear and uncertainty was present with both participants and both of the participants went for years not knowing exactly what their diagnosis was. According to an article, "Only one half to three fourths of adults with CHD can correctly state or describe their diagnosis. Given complex anatomies and surgical repairs, it may not be possible for all patients with CHD to have precise anatomic knowledge" (Foster et al., 2001, p. 1181). In both of the participants that took part in this study, they both went for years not knowing exactly what their diagnosis was. This study and the article show that there is a need for healthcare to be better in the area of explaining to the patient what his or her diagnosis is. Nurses need to take more time with those individuals diagnosed with CHD to make sure that those individuals understand their diagnosis and how it is going to affect their lives.

Ongoing Treatment

In the area of ongoing treatment, some of the similarities that came up between the participants were traveling, medications, check-ups and procedures, and financial burden. They both expressed how important health insurance is to pay for all the costs of having CHD. According to Ninivaggi, "Health insurance for the adult with CHD may be
difficult to obtain or continue after reaching independence in adulthood. Life insurance is often not available to these patients” (2005, p. 62). Even though Ninivaggi reports that it is hard to get health insurance, both of the participants stated that they had good health insurance that helped pay for many of the medical costs. Nurses need to understand that it is important to remember that for an individual with CHD to pay for all the treatments and care that are needed, insurance is a vital part.

Reclaiming Health

Reclaiming health was a major theme for both participants. According to researchers, “Psychosocial needs, such as employment, contraception, pregnancy and physical exercise, are very important to enable a 'normal' life, complying with the postoperative hemodynamic situation of the patients” (Colonna, Manfrin, Cecconi, Perna, & Picchio, 2007, p. 83). Both participants in this study, reclaimed their health and lived their lives as any other person does. They both are active in exercising in different forms. Both of the participants have gone through multiple surgeries for their heart defects. After the surgeries, they both were able to reclaim their health and go on with their lives.

Recommendations for Future Research

More research needs to be conducted to validate the findings of this study. The size of this sample was very small and only represented those individuals that have CHD living in the rural northwest. More research should be conducted with a larger sample of individuals of varying ages, sociocultural, and economic subgroups to further investigate the relationship of the common themes.
Conclusion

The experience of living with CHD is a life-long process. It takes time to get a diagnosis and understand what it all means. Fear and uncertainty occur throughout the process and nurses need to be aware that this is going to occur. As the individual has to receive treatment, nurses can be there to help those individuals through all the tough times that come with it. And once the individuals are able to reclaim their health, they may never need to be seen again by doctors whereas others may have to have regular check-ups for the rest of their lives. After many years of being diagnosed and treated, both individuals were able to go on with their lives.
References


