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# Relationship between self-care and knowledge levels among adults with congenital heart disease

Valerie Ann Miller Bosco

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The University of San Francisco

RELATIONSHIP BETWEEN SELF-CARE AND KNOWLEDGE LEVELS  
AMONG ADULTS WITH CONGENITAL HEART DISEASE

A Dissertation Presented  
to  
The Faculty of the School of Education  
Learning and Instruction Department

In Partial Fulfillment  
of the Requirement for the Degree  
Doctor of Education

by  
Valerie Miller Bosco  
San Francisco  
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UNIVERSITY OF SAN FRANCISCO  
Dissertation Abstract

RELATIONSHIP BETWEEN SELF-CARE AND KNOWLEDGE LEVELS  
AMONG ADULTS WITH CONGENITAL HEART DISEASE

This descriptive study assessed the relationship between self-care and knowledge in adults with congenital heart disease in the four domains about their heart defect, treatments, and the preventive measures necessary to avoid complications. Thirty young adults with congenial heart disease (18 females; 12 males), ages ranged from 18 to 45 years were the participants from the adult congenital heart disease clinics in one tertiary medical center in Northern California. Patients' self-care and knowledge was assessed during an initial outpatient visit using the Exercise in Self-care Agency and the Leuven knowledge questionnaire for congenital heart diseases developed for this population.

Self-care scores ranged from 85 to 120 (mean 99.60) out of a possible total score of 140. The majority of patients (77%) had moderate knowledge (50% to 80% correct answers) about their treatment, frequency of follow up, dental practices, occupational choices, appropriateness of oral contraceptives, and the risks of pregnancy. There was poor understanding (< 30% correct answers) about the symptoms of deterioration of the heart disease, characteristics and risk factors of endocarditis on heart disease, and the hereditary nature of the condition to offspring. Five research questions were addressed the relationship between self-care and knowledge in the four domains, separately and by total scores. There were no statistically significant correlations between self-care and the four domains. There were statistically significant correlations between knowledge in the four domains with

age and income. The relationship between age and knowledge was .50 and between knowledge and income was .54.

Adults with congenital heart disease have gaps in their knowledge about their condition. Additionally, the areas of cardiac care are not the same between patients and health care providers. The results of this study can be used as a basis for developing transitional programs and educational interventions to enhance young adult patients' self-care behaviors and health knowledge about their heart disease.

This dissertation, written under the direction of the candidate's dissertation committee and approved by the members of the committee, has been presented to and accepted by the Faculty of the School of Education in partial fulfillment of the requirements for the degree of Doctor of Education. The content and research methodologies presented in this work represent the work of the candidate alone.

<u>Valerie Miller Bosco</u> Candidate	<u>12/18/2009</u> Date
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## CHAPTER I

### INTRODUCTION

#### Statement of the Problem

There are approximately 1.2 million adults with congenital heart disease (CHD), and growth among this population is occurring at a faster rate than the development of specialty clinics to care for them (Hoffman & Kaplan, 2002; Thierren et al., 2001). With surgical advances, 85 to 90% of children born with CHD reach adulthood, whereas, in the 1960s, these patients were not expected to live past childhood (Hoffman & Kaplan, 2002). Individuals born with a congenital heart defect are considered to have a chronic health condition, and the impact of the disease may impose a heavy burden on the individual and his or her family. As a result of advances in treatment, children with CHD become long-term survivors with the majority of CHD survivors having undergone one or more surgical repair(s). Surgery is considered “reparative” and not “curative,” and it is for these reasons that adults with CHD need continued medical surveillance and potential re-operation during their adult lifetime (Perloff & Warnes, 2001).

Adults with CHD initially receive their care from pediatricians, and most are operated on by pediatric congenital surgeons. When they graduate to adult care, they either remain with their pediatricians or are often lost to follow-up. As adults, many patients receive their care primarily from adult cardiologists who do not specialize in CHD cardiology and may not receive adequate care to prevent complications (Somerville, 1997a, 1997b; Webb et al., 2002).

One way to prevent potential complications and promote positive health

outcomes among adults with CHD is to ensure that the amount and quality of self-care used is appropriate to the patient's situation. Thus, appropriate self-care behaviors are very important for adults with CHD; however, there is little research related to self-care behaviors and knowledge levels among the adult CHD population. An integral part of this continued surveillance is patient self-care, whereby patients know how to maintain healthy behaviors and when to seek medical attention for changes in health status. The difference between children with CHD and adults with CHD is that the adults have the capacity for performing self-care behaviors.

Self-care includes three functional capabilities: (a) foundational capabilities, the mental ability to perform a task, (b) power components, the physical ability to perform a task, and (c) self-care operations, the procedural ability to carry out a systematic task (Orem, 1995). Lack of knowledge in these self-care behaviors can result in inappropriate care and undue emotional and financial stress on adult patients with CHD, families, and the health-care system (Knauth, Verstappen, Reiss, & Webb, 2006). Therefore, ongoing education is a vital component of self-care for adults with CHD.

Education plays a pivotal role in providing individuals with self-care monitoring skills. These skills are taught and reinforced by health-care providers and include (a) maintaining an interactive relationship, (b) establishing continuing care to help meet care demand, (c) planning and implementing systems to ensure care is regulated and met, (d) responding to requests for help, (e) coordinating care when multiple health-care providers are involved, and (f) ensuring adequate discharge information and the ability to demonstrate understanding of self-care (Orem, 1995).

The positive impact of self-care instruction has been well documented in the chronic condition of heart failure (Jaarsma et al., 1999). Because of the increased lifespan of CHD survivors due to surgical and medical advances, there is a potential for self-care instruction to have positive benefits for adults with CHD. Few studies have focused on the importance of self-care strategies and instruction on maintaining healthy behaviors in adults with CHD. Therefore, this study will examine self-care strategies and behaviors in adults with CHD.

#### Purpose of the Study

The purpose of this descriptive study was to conduct a survey to investigate the relationship of self-care behaviors (as assessed by four variables) with education in the four knowledge domains for adults with CHD. The four self-care behaviors are self-worth, initiative and responsibility, knowledge and information-seeking, and passivity. The four knowledge domains are as follows: (a) disease and treatment, (b) measures to prevent complications, (c) physical activities, and (d) reproductive issues. A questionnaire composed of two instruments was completed by adults with CHD in a clinic setting during a routine visit to ascertain self-care behaviors and knowledge levels. The self-care questionnaire was based on *Orem's Framework of Self-Care*. Demographics collected included age, gender, ethnicity, education, income level, and place of residence. Table 1 lists the variables assessed in the current study.

#### Significance of the Study

This study was significant because with improved medical advances more children with CHD are surviving into adulthood and few if any procedures are in place to support these adults with self-care monitoring to prevent complications.

Table 1  
Variables in Study Questionnaires

---

Exercise of Self-care Agency (ECSA)
Self-worth
Initiative and responsibility
Knowledge and information seeking
Passivity
Domains of the Leuven Knowledge Questionnaire
Heart disease and treatment
Prevention of complications
Physical activity
Reproduction and contraception

---

It is unclear what adults with CHD actually understand about their individual cardiac defects and how to best maintain their health. This study was the first of its kind to address self-care and knowledge in the four domains within a single study in the US.

Health-care providers are in a key position to facilitate communication skills, teaching skills, knowledge, and an awareness of the multiple factors affecting the nurse-patient relationship during the provision of care. Nursing involvement can promote the exercise of self-care through structured interactions and directed educational efforts with an emphasis on prevention. In contrast, without the benefits of a sound education, patients frequently are lost to follow-up and develop hemodynamic and multisystem complications that could have been prevented. As a result, the cost to the health-care system can be dramatic, and, more importantly, the cost to the patient is often irreparable (Dearani, Connolly, Martinez, Fontanet, & Webb, 2007). Through education, adults with CHD can develop a positive and hopeful outlook for the future despite the knowledge of potential future complications. Giving patients tools to learn about current therapies and encouraging

them to seek new knowledge continuously will enable them to perceive a sense of control over their health and medical management (Clark & Zimmerman, 1990).

### Theoretical Rationale

Orem (1995) proposed a theory composed of three parts: self-care, self-care deficits, and nursing systems. Central to all three parts of Orem's theory is that people function and maintain life, health, and wellbeing by caring for themselves. Orem's Self-Care Theory provides the framework for this research (Orem, 1985). It was first conceptualized in 1956 as a regulatory function that is action driven and deliberately preformed by mature or maturing individuals who are seeking prevention, alleviation, cure, or control of untoward human conditions affecting life, health, or well-being. Self-care is defined by Orem as "learned goal-oriented activity of individuals. It is behavior that exists in concrete life situations directed by persons to self or to the environment to regulate factors that affect their own development and functioning in the interests of life, health, or well-being" (Orem, 1995, p. 435). Self-care involves action directed by individuals to themselves or their environments to regulate their own functioning and development in the interest of sustaining life. It includes maintaining or restoring integrated functioning under stable or changing environmental conditions, and maintaining or bringing about a condition of well-being (Orem, 1986).

Orem (1986) started her work with self-care deficit theory, and it evolved from 1960 through 1980 to include individuals taking deliberate action to meet their therapeutic self-care demand arising from known needs for care. If this demand is not met, a self-care deficit exists, which denotes the need for nursing (Hartweg, 1991;

Orem, 1995). The rationale behind Orem's theory was that persons with acute or chronic illnesses require nursing care in order to take care of themselves independently. The self-care theory was a synthesis of knowledge about self-care, therapeutic self-care demand, self-care deficit, and nursing agency. The role of the nurse is to assess the care demands of the individual patient, assess the ability of the patient to meet independently these self-care demands, and facilitate and improve the patient's ability to meet his or her own therapeutic self-care demands.

Orem (1995) proposed three sets of statements about self-care. First, self-care is purposeful action by mature and maturing persons with the abilities to care for themselves within their environment. It is affected by the maturity level of the person, cultural influences, and knowledge levels. It is also affected by birth order, social status, refusal to participate in self-care actions, and lack of scientific knowledge about health disorders and self-care behaviors.

Second, self-care contributes to psychological health and wellbeing; it must be part of a person's daily activity. Self-care directed toward promotion of health requires it to be scientifically derived. If disease limits the person, from structural or functional changes, specialized self-care measures may be prescribed.

Third, self-care requires knowledge about state of health and physical and social environments, as well as insights into motivation. A deficit in knowledge may lead to interactions with health-care services. Self-care includes seeking and participating in medical care and periodic evaluations of health status. There must be internally orientated activities to help control external environment and communicate



with others. Self-care requires the use of resources to maintain a healthful life and environment.

Adults with CHD represent a population of patients who can benefit from an interdisciplinary intervention based on an Orem Self-Care Framework. Self-monitoring of symptoms among adults with CHD is an important strategy of self-care because of its purposeful action in the interest of maintaining health and wellbeing. For example, knowing antibiotics are necessary before dental work is a deliberate action meant to prevent infection and promote health. These functional principles about self-care are within the framework of nursing practice. Nursing is a helping profession that requires someone who has a need or deficit and can be helped by a nurse (Orem, 1995). Nursing actions promote self-care behaviors in CHD survivors through structured interactions and directed educational efforts. The role of the nurse is to assess the care demands of the individual patient, assess the ability of the patient to independently meet these self-care demands, and facilitate and improve the patient's ability to meet his or her own therapeutic self-care demands (McBride, 1987; Orem, 1985). Adults with CHD require life-long medical surveillance and interaction with nursing to optimize self-care and healthy behaviors.

Self-care agency also is dependent on individual experiences and cultural values. Understanding a patient's perception of need based on such experiences and values is critical to advancing the patient's self-care agency. Self-care agency also is aided by intellectual curiosity and motivation, again facilitated by nurses (Cavanagh, 1991). Finally, the perception of power or control is a distinct element of self-care agency. Power disparity in the provider-patient relationship can place the patient in a

position of vulnerability and dependence and can create unwillingness of the patient to participate in decision-making (Redfern & Norman, 1991; Trnobranski, 1994; Waters, 1996). Nurses can help by creating an equal partnership, enhancing patients' self-agency and thereby increasing their perception of control.

Orem (1995) stated that self-care agency is achieved when individuals are transformed from passive, dependent patients to active partners. Orem's theory has long been used in nursing to improve patient self-care agency (Callaghan, 2006; Carroll, 1995; Chang, 1980; Fawcett, Tulman, & Meyer, 1988; Hart & Foster, 1998). Improved self-care agency, in turn, helps patients live healthier and more empowered lives by being in control of their health needs. The ability to engage in self-care promotes personal development and motivates the individual to establish appropriate goals and adjust behavior to achieve results specified by the goal (Orem, 1995). When individuals are educated to recognize and improve their own self-care abilities and to use health-care services when they identify potential or actual self-care deficits, less inappropriate use of services may result. Furthermore, the emphasis on self-care and recognition of the person's ability to care for him- or herself could lead to more efficient use of health-care services. The current study focused on the use of Orem's Self-Care Theory to examine the knowledge levels of adult with CHD and its applicability to self-care behaviors.

### Background and Need

Congenital heart disease is one of the most common in-born birth defects, with an occurrence of approximately 0.8% of all newborns (Hoffman & Kaplan, 2002). Although the incidence of CHD has not changed, the life expectancy of

survivors has increased substantially. At the beginning of the 21<sup>st</sup> century, there are more adults alive with CHD than children (Webb, 2004). The American Heart Association (Nishimura et al., 2008), the American College of Cardiology (ACC, 2008) and the Adult Congenital Heart Association (ACHA, 2006) estimate approximately 850,000 to 1.3 million adult CHD survivors in the United States. Some adult CHD survivors have lived into their seventh decade of life (Thierren et al., 1997; Webb & Williams, 2001). Among the primary factors influencing this growth are advancements in surgical and interventional procedures developed to treat this population (Perloff & Warnes, 2001; Somerville, 1997a; Srinathan et al., 2005).

Congenital heart defects commonly are divided into two categories: cyanotic and acyanotic lesions. Cyanotic lesions mix desaturated blood (oxygen depleted) with saturated blood (oxygen rich) in the systemic circulation, resulting in blue appearance of the skin. Acyanotic lesions are associated with a primary left-to-right shunt (from systemic to lung) through an abnormal opening in the heart. A list of the incidence of the most common cyanotic and acyanotic lesions are listed in Table 2.

Table 2  
*Common Cyanotic and Acyanotic Lesions in Adults with CHD*

Acyanotic	Cyanotic
Atrial septal defect (ASD)	Tetralogy of Fallot (TOF)
Patent ductus arterious (PDA)	Pulmonary/Tricuspid atresia
Pulmonary valve stenosis	Hypoplastic left heart syndrome (HLHS)
Coarctation of the aorta	Transposition of the great arteries (TGA)
Aortic valve disease	Atrioventricular septal defects
Ebstein's anomaly	Truncus arteriosus (TA)
Ventricular septal defect (VSD)	

Congenital heart anomalies are further divided into levels of complexity: mild, moderate, and severe. Mild defects such as isolated congenital aortic (AV) or mitral (MV) valve disease, mild pulmonary stenosis (PS), or isolated patent foramen ovale (PFO) reasonably can be cared for in the community setting. Moderate complex defects such as coarctation of the aorta or tetralogy of Fallot (TOF) must be seen periodically at regional centers. Cyanotic patients and those with diseases of severe complexity, such as transposition of the great arteries (TGA) and single ventricle physiology, must be seen regularly at regional centers. Over half of adults with CHD are considered moderate to severe in complexity (Webb, 2004).

Perloff and Warnes (2001) described ongoing minor to major residua and sequelae from individual to combined defects. They defined residua as “remains or what is left over” (p. 2638). Sequelae “arise from an earlier event or follow the event” (p. 2640). Surgical treatments for CHD have been shown to modify both anatomy (structure) and hemodynamics (circulation), thus requiring ongoing assessment and evaluation of potential complications throughout adulthood (Perloff & Warnes, 2001; Sajan, Dent, Schwartz, & Nelson, 2004). Listed in Table 3 are the most common residua after reparative surgery for congenital heart disease.

According to Perloff (1991), repeat operations are more common among older adults with CHD than primary operation. Most patients with repaired congenital heart disease have residual hemodynamic burdens. Patients need education regarding these residual hemodynamic issues, their implications for the future, and the signs and symptoms that should raise concern.

Table 3

*Residua After Reparative Surgery for Congenital Heart Disease*


---

Electrophysiological (arrhythmias and devices)
Valvular
Ventricular
Chamber morphology
Chamber mass
Chamber function
Myocardial connective tissue
Vascular
Anatomic (morphological) vascular anomalies or defects
Elevated resistance and/or pressures; systemic, pulmonary

---

Reprinted with permission from Dr. Perloff, 5/06

Given what currently is known about repaired CHD and based on the specific defect(s), predictions can be made of the likelihood of surgical interventions and complications during their lifespan. For these reasons, CHD patients benefit from management at regional centers with highly trained staff.

The burden of developing regional centers with adequate staff is well recognized. For example, the 32<sup>nd</sup> Bethesda Conference (Webb et al., 2001) focused on recommendations for educating cardiologists who care for patients with CHD from adolescence to adulthood. This consensus conference was designed to facilitate the consideration of the important issues surrounding cardiology practice with regard to patient care, research, and training in the adult CHD population. The conference recommended that all cardiology trainees have education in CHD and know when to refer patients with CHD to regional centers (Child et al., 2001). Further, cardiologists specializing in adults with CHD must have a minimum of 2 years of advanced and intensive training in the area of congenital disease at a regional center. In addition to general cardiology education, the advanced training includes in-patient and out-

patient delivery of care. With a limited number of regional centers in the US, the problem of training future ACHD physicians is compounded.

At the Bethesda Conference, Foster et al. (2001) led Task Force 2 with specific recommendations for medical surveillance in adults with CHD. These guidelines provided a framework for individualized care outlining the special health-care needs for adults with CHD. There are unique medical issues adherent to adults with CHD, and they should be seen regularly in regional adult congenital heart disease (ACHD) centers. For example, cyanotic patients are at risk for complications from excessive erythrocytosis from increased blood viscosity. The treatment for this condition is phlebotomy, but if not performed properly this can result in hypotension, increased right to left shunting, seizure, stroke, and potential death.

Similar to the 32<sup>nd</sup> Bethesda Conference (Webb et al., 2001), the Working Group on research in adult congenital heart disease (ACHD) convened in September 2004 under the sponsorship of the National Heart, Lung and Blood Institute (NHLBI), the Office of Rare Diseases (ORD), National Institute of Health (NIH), and Department of Health and Human Services (DHHS). The Working Group focused primarily on prevention of secondary disabilities with relation to the severity of the defect and ensuring these patients were followed at regional centers with adequate surveillance and prevention of disease-related problems. The group's recommendations highlighted the three most common complex congenital malformations: TOF, TGA, and single ventricle physiology. Williams et al. (2006) recommended outreach and educational programs for adults with CHD, developing a network of specialized ACHD centers and research in diagnostic imaging. The group

endorsed the 32<sup>nd</sup> Bethesda Conference recommendations for future education of physicians for this population.

Additionally, the Euro Heart Survey (EHS) program analyzed data on 4,110 patients from 1998 to 2003, with a median follow-up of 5.1 years (Engelfriet et al., 2005). This population was predominantly young with substantial morbidity but relatively low mortality over a 5-year period. The following survival rates were reported for eight cardiac defects: coarctation of the aorta 99.3%, atrial septal defect (ASD) 98.9%, TOF 98.7%, ventricular septal defect (VSD) 98.4%, Marfan 98.3%, TGA 97.1%, single ventricle physiology 91.8%, and cyanotic defect 87.4%. The researchers reported a decrease in NYHA functional class in cyanotic (21%) and single ventricle (17%) patients. Nineteen percent of patients underwent surgery or catheter-based interventions. Such statistics for survival can provide future trends for adults with CHD.

Studies have shown that CHD survivors may not be as well informed in the areas of disease management and health maintenance (Chessa et al., 2005; Kamphuis, Verloove-Vanhorick, Vogels, Ottenkamp, & Vliegen, 2002; Kantoch, Collins-Nakai, Medwid, Ungstad, & Taylor, 1997; Moons et al., 2001; Veldtman et al., 2000). Of the research that has been conducted, few studies have addressed the comprehensive educational needs of adults with CHD. There remains a need for further investigation of illness understanding in adults with CHD and of the connection between knowledge levels about their heart conditions and adequate healthy behaviors, including understanding their disease and preventing complications over a lifetime.

Few studies have investigated illness understanding from parents to adolescents in preparation for adulthood and later transfer to adult cardiology-centered care (Cannobio, 2001; Cheuk, Wong, Choi, Chau, & Cheung, 2004; Veldtman et al., 2000). Veldtman et al. found that having an illness in childhood was associated with emotional stress and delayed developmental growth of the child. Overall, the researchers found poor understanding of illness knowledge in young patients and parents with regard to anatomy and physiology of their heart condition. Understanding the anatomy and physiology of the defect is a foundation for subsequent education. They did report positive evidence suggesting the ability to cope with a chronic cardiac condition was enhanced by good illness understanding.

Cheuk et al. (2004) found important knowledge gaps in parents of children with CHD. The researchers reported parents knew the name of their child's defect but were not able to identify the cardiac structure (anatomy). They concluded that parents of children with cyanotic lesions, a more severe form of heart disease, were more aware of the anatomy of the defect and disease prevention. Over half of the parents knew of the need for antibiotics for dental procedures but did not recognize the term "infective endocarditis." Many parents reported excessive exercise restrictions on their child, demonstrating a lack of illness understanding and appropriate exercise limits.

Not all adults with CHD understand the implications of endocarditis and why they are more likely than the general population to suffer this complication (Cetta & Warnes, 1995). Patients need to be educated about the implications of endocarditis. They need to be educated about how to reduce the risk of endocarditis through



attention to oral health and the use of appropriate antibiotic prophylaxis, and how to recognize the signs and symptoms of endovascular infection so they know to promptly seek medical attention.

Moons, Deyk, Dedroog, Troost, and Werner (2006) suggested adults with CHD may be prone to developing coronary artery disease, which is an adult-focused problem. They also found among 1,976 patients that men had a higher incidence of smoking and elevated blood pressure, whereas women were more active but often more obese. Approximately 20% of men and women followed a heart-healthy lifestyle and were without evidence of risk factors. These findings support the need for primary prevention as part of medical management in adults with CHD.

There are a number of repaired lesions that are associated with arrhythmias due to surgical scarring (Graham, 2007; Murphy, Gersh, & Mair, 1993). Arrhythmias are a relatively common complication experienced by patients with congenital heart disease. The most common are atrial flutter and fibrillation, which can cause serious symptoms and cardiac deterioration. It is important that patients understand what atrial and ventricular arrhythmias are, their etiology, and the relative risk or hazard of each. Engelfriet et al. (2005) reported 1 in 5 patients was hospitalized for supraventricular arrhythmias, and 1 in 20 for ventricular arrhythmias among 4,110 patients within a 5-year period. Adults with CHD need adequate understanding of which arrhythmias are simply an annoyance, which may be life threatening, how to recognize the signs and symptoms, and what symptoms should raise concern. Patients should understand the importance of screening tools and the potential need for other diagnostic tests when concerning signs or symptoms arise.

Treatments for arrhythmia management include medications, radiofrequency catheter ablation, surgical ablation, and device therapies (pacemakers and defibrillators). Many of the arrhythmias can be treated with drugs or electrophysiology ablation but must be identified early to prevent complications. If not managed appropriately and in a timely fashion, patients with CHD can develop arrhythmias, heart failure, and even sudden death (Gatzoulis, 2006).

Pregnancy is feasible for many adult patients with congenital heart disease. Pregnancy should be well planned to minimize risks to the mother and unborn child, especially in woman with complex congenital heart disease (Lupton, Oteng-Ntim, Ayida, & Steer, 2002). Prior to conception, the potential risks to the mother and unborn child should be understood, as well as the severity of the patient's underlying disease and relative risk of complications during pregnancy, delivery, and postpartum phase. There are possible risks to the fetus such as poor growth, premature labor and delivery, and the chance of congenital heart disease. Fetal echocardiography and genetic counseling are standard of care for high-risk pregnancy and most often provided in tertiary facilities. Finally, a realistic plan regarding the timing of and most appropriate number of pregnancies needs to be included in counseling.

Patients need to be aware about the issues regarding noncardiac surgery and the importance for the treating team to be fully informed about their heart condition(s). Except for the simplest outpatient procedures, noncardiac surgeries in complex patients should be performed in a tertiary hospital where cardiac anesthesiologists, as well as other members of the surgical and critical care teams, are

comfortable with the care of adults with congenital heart disease. Knowledge about these issues allows patients to serve as their own advocates.

Because the goal of all health care is ultimately to improve the quality of life for the patient, caring for adults with CHD goes beyond the medical realm and includes topics such as lifestyle, quality of life, marriage and family planning, education, employment, and life and health insurance. The importance of healthy eating and physical fitness, the risks of poor nutrition and obesity, and the need for salt and fluid restriction (if warranted) cannot be ignored.

Growing up with CHD is not limited to physical complications. There are issues related to lifelong care such as the lack of insurance in young adults, risk taking, education, employment, and genetic counseling. Research has shown that adults with moderate to complex CHD are less likely to have health insurance, be employed, or attend college and more likely to still be living with their parents when compared with the general population of the same age (Crosslan, Jackson, Lyall, Burn, & O'Sullivan, 2005; Kamphuis et al., 2002; Tong et al., 1998). One study from Finland reported over half (53%) of CHD patients needing follow-up care had dropped out of regular scheduled visits (Nieminen et al., 2003). In the US, it has been estimated that less than half of adults with CHD receive regular cardiac care (ACHA, 2006; Landzberg & Ungerleider, 2006).

Concise understanding of chronic illness is associated with less distress, less confusion, improved satisfaction with medical care, better compliance with treatments, and better emotional status. These benefits are keys to good health-related quality of life (Chessa et al., 2005), thus supporting that adults with CHD need

information regarding disease and treatment, measures to prevent complications, physical activities, and reproductive issues.

Education is an integral aspect of self-care that can enhance patients' understanding of their heart disease and serve to achieve better outcomes (Kantoch et al., 1997). Patients must be educated about future diagnostic testing required to keep these matters under appropriate surveillance. In addition, they need information about the possible medical, catheter-based, or surgical options for treating these problems if or when they are needed. It is also important to educate patients about new advances in cardiovascular medicine including advances in medical management, cardiac catheterization, and cardiovascular surgery. Nurses are in a pivotal position to provide education, resources, and support to adults with CHD.

In the US, there are a limited number of transition programs, and, as the population of adults with CHD continues to grow, not enough time and resources to develop them. One factor that may account for the limited number of transitional programs is the lack of professional expertise in adult CHD because this subset of patients does not fit into any single category: CHD children have evolved into adults with cardiac birth defects. Adult cardiologists treat adults with normally structured hearts who have acquired heart disease. Pediatricians have expertise in cardiac birth defects but do not have the training to deal with adult health issues (Deanfield et al., 2003; Webb et al., 2001). As a result of this situation, patients are burdened with the responsibility for knowing their diagnosis, drugs, and treatments. They are also left to recognize symptoms of cardiac compromise and when to seek medical attention on their own, without the benefit of formal transitional education.

Proper education to build the knowledge base for the specific defect of each CHD child may enable them to determine self-care and self-efficacy as an adult toward this disease. Self-efficacy is the belief in one's ability to succeed in specific situations (Bandura, 1977). This concept of self-efficacy may play a major role in how the CHD child approaches goals, tasks, and challenges of self-care monitoring. Many elements of self-efficacy such as observational learning and social experience are important components in the education of CHD children.

This study suggested that with education and knowledge of proper self-care, people with CHD are more likely to develop high self-efficacy, that is, those who believe they can perform well are more likely to view self-monitoring as something to be mastered rather than something to be avoided. Therefore, there is a need for the development of educational resources that provide tools for self-care monitoring among adult survivors with CHD.

#### Research Questions

This study addressed five research questions:

1. To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of heart disease and treatment in adults with CHD?
2. To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of measures to prevent complications in adults with CHD?

3. Are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of physical activities in adults with CHD?
4. To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of reproduction and contraception in adults with CHD?
5. To what extent does the knowledge in the four domains of congenital heart disease vary by the demographics of age, gender, ethnicity, income, and level of education?

#### Definition of Terms

The operational definitions of key terms are provided in this section. There may be other definitions of the terms listed below; however, for the purpose of this study, the stated definitions will apply.

*Acyanotic* is a heart defect with a primary left-to-right shunt through an abnormal opening (Perloff, 1998).

*Adult with Congenital Heart Disease* for this study an adult with congenital heart disease is an individual who is 18 years or older and was born with a congenital heart defect (Perloff, 1998).

*Bacterial endocarditis* also referred to as infective endocarditis is a bacterial infection in the blood commonly associated with two pathogens: *Staphylococcus aureus* and *Streptococcus viridans* (Gatzoulis, Webb, & Daubeney, 2003).

*Common ventricle* is the underdevelopment of one side of the heart with mixed circulation (Perloff, 1998).

*Congenital Heart Disease (CHD)* is present at birth and occurs when the heart or blood vessels near the heart do not develop normally before birth (American Heart Association, 2008).

*Cyanotic defects* are where there is mixing of desaturated blood with saturated blood in the systemic circulation (Perloff, 1998).

*d-Transposition of the Great Arteries (d-TGA)* is a defect where ventricular-arterial relationship is discordant meaning the aorta arises from the right ventricle and the pulmonary artery from the left ventricle leaving a systemic right ventricle (Gatzoulis, et al., 2003) .

*Disease and treatment* refers to the name of the heart defect, its medical and surgical interventions, intervals for follow up, symptoms of deterioration, and prognosis.

Disease and treatment are measured by the Leuven Knowledge Questionnaire (Moons et al., 2001).

*Initiative and responsibility* is the attitude of acting on one's own actions and includes motivation and connotes accountability (Kearney & Fleischer, 1979). Initiative and responsibility is measured by the ECSA.

*Knowledge* will be assessed by the *Leuven Knowledge Questionnaire* (Moons et al., 2001) using the four knowledge domains of heart disease and treatments, measures to prevent complications, physical activities, and reproduction and contraception.

*Knowledge and information seeking* is referred to as an interest in learning, seeking information, and clearly understanding it (Kearney & Fleischer, 1979). Knowledge and information seeking is measured by ECSA.

*Medical surveillance* is the recommended follow-up for individual medical conditions.

*Passivity* is a response that lacks energy, or has neglect, is deferred, and rarely an act of resolution (Kearney & Fleischer, 1979). Passivity is measured by the ECSA.

*Prevention of complications* refers to ongoing care and medical surveillance to prevent secondary problems such as endocarditis. Prevention and complications are measured by the Leuven Knowledge Questionnaire (Moons et al., 2001).

*Physical activities* refers to capacities and restrictions as they relate to the cardiac defect. Physical activities are measured by the Leuven Knowledge Questionnaire (Moons et al., 2001).

*Reproductive issues* refers to contraception, genetics, and pregnancy and its impact on the cardiac defect. Reproductive issues are measured by the Leuven Knowledge Questionnaire (Moons et al., 2001).

*Residua* is what remains or is left over from a previous event, such as after surgical correction (Perloff & Warnes, 2001).

*Sequelae* are what follows or arises from a previous event (Perloff & Warnes, 2001).

*Self-care* is human regulatory function, deliberately preformed to bring about or maintain internal and external conditions for health, well-being, and development (Orem, 1991). For this study, self-care will be assessed using the modified Exercise in Self-care Agency scale (ECSA) by Kearney and Fleischer (1979).



*Self-worth* is the cognitive view of self defined by Kearney and Fleischer (1979) and includes self-esteem and self-confidence. Self-worth is measured by the ECSEA.

*Tetralogy of Fallot (TOF)* is a common cardiac defect with four anomalies:

Ventricular septal defect (VSD), right ventricular outflow tract (RVOT) stenosis associated with pulmonary valve (PV) stenosis, overriding aorta, and right ventricular enlargement (Gatzoulis et al., 2003).

*Transition* is a planned and anticipated process. Medical transition is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum et al., 1993).

#### Summary

This chapter presented the population addressed in the current study, adults with congenital heart defects, and their need for ongoing care as adults. Also, the medical and educational requirements for this population were described along with the limited resources available to adequately provide their unique medical care. Because of the complexities and uniqueness of each cardiac defect, adults with CHD benefit from knowing their defect and which symptoms to report to ensure adequate self-care.

This study sought to employ a theoretical model that applied to adults with CHD and chronic health conditions. It is believed that individuals taking deliberate action to meet their therapeutic self-care demand arising from known needs for care are in better position to maintain their health needs (Orem, 1986, 1995). Adults with CHD are in the best position to recognize and seek medical attention if health

conditions change. Also, education has a vital role in providing individuals with self-care monitoring skills. For these reasons, adults with CHD represent a population of patients who can benefit from an interdisciplinary intervention based on an Orem Self-Care Framework.

The background and need related to this problem was explained along with the clinical significance as related to the issues facing adults with CHD. It is believed that providing adults with CHD appropriate knowledge and resources will give them confidence to care for themselves. The significance of this study stems from knowing that CHD survivors are “corrected” but never “cured.”

According to the 32<sup>nd</sup> Bethesda Conference (Webb et al., 2001), ultimately there is educational significance since health care providers are responsible for the education of adults with CHD. Understanding of chronic illness has been associated with less distress, less confusion, improved satisfaction with medical care, better compliance with treatments, and better emotional status (Chessa et al., 2005).

The second chapter provides a review of current literature related to the current study. Also, within this chapter detailed review of studies that link the conceptual framework for this study with research that supports its use as a framework for adults with CHD offered. Within the third chapter, the methodology used to investigate the research questions is presented as well as demographics of the participants. Results from the research conducted are specified in Chapter IV, and a discussion of the results and future research are presented in Chapter V.

## CHAPTER II

### REVIEW OF THE LITERATURE

The purpose of this descriptive study was to conduct a survey to investigate the relationship of self-care behaviors (as assessed by four variables) with education in the four knowledge domains for adults with Congenital Heart Disease (CHD). This chapter is divided into three sections of the current literature of self-care theory, the uses of the self-care agency scale, and knowledge of congenital heart disease. The first section is a review of the evolution of Orem's self-care theory. The second section is a review of previous research using the exercise in self-care agency (ESCA) scale. The third section is a review of the most current research on knowledge levels and congenital heart disease and is grouped into three sections: (a) research in the four domains of CHD, (b) illness understanding, and (c) preventive measures and complications in adults with CHD (Chessa et al., 2005; Moons et al., 2001).

This research study involved conducting a survey to investigate the relationship of self-care behaviors (as assessed by four variables) and education in the four knowledge domains with adults with CHD. The four self-care behaviors are self-worth, initiative and responsibility, knowledge and information-seeking, and passivity. The four domains are as follows: (a) disease and treatment, (b) measures to prevent complications, (c) physical activities, and (d) reproductive issues. A questionnaire composed of two instruments was distributed to adults with CHD in a clinic setting during a routine visit to ascertain self-care behaviors and knowledge levels.

### *Evolution of Orem's Self-care Theory*

The concept of self-care agency has been well described by Dorothy Orem (1985). The evolution of this theory has spanned over the past 30 years since compiled by the Nursing Development Conference Group in 1979 and has encompassed three types of personal attributes for the performance of self-care activities: foundational, enabling, and operational (Orem, 2001). Foundational traits are described as personal capabilities for self-care with regard to sensation, perception, memory, and orientation. Enabling traits, which represent the power components of self-care agency, are those specific personal capabilities necessary for the performance of self-care activities, such as self-care knowledge and education, self-care skills, and energy for self-care. Operational traits are the personal capabilities that enable an individual to recognize their personal and environmental resources, conditions, and factors that might be significant to self-care. These capabilities include judging and making decisions about what self-care activities one can perform, should perform, and actually do perform. Thus, leading an individual toward self-care activities on his or her own behalf to maintain life and promote health and well-being. As one of the key concepts of Orem's theory of self-care, self-care agency is acquired and developed throughout an individual's life span and applies to adults with CHD and chronic illness. The development and maintenance of self-care agency depends on several personal and environmental factors, called conditioning factors, such as age, gender, developmental level, pattern of living, and availability and adequacy of resources. Therefore, the goal of developing and maintaining self-care agency is to enhance an individual's performance of self-care

activities that might lead to the promotion of health and well-being and both the management and prevention of diseases or complications throughout one's lifetime.

Orem (1985, 2001) stated that her general theory refers to the condition that validates the existence of a requirement for nursing in an adult is the health-associated absence of the ability to maintain continuously that amount and quality of self-care that is therapeutic in sustaining life and health, in recovering from disease or injury, or in coping with their effects. With children, the condition is the inability of the parent or guardian associated with the child's health state to maintain continuously for the child the amount and quality of care that is therapeutic.

Throughout nursing education, nursing students receive instruction about nursing theory and conceptual model use and are encouraged to use these in their practice (Orem, 2001). Orem's self-care nursing theory is used and accepted by nurses and is a frequently used theory in general nursing practice. Self-care agency has been used in nursing research to examine its relationship with conditioning factors and other concepts of the Orem theory of self-care.

#### *Exercise in Self-care Agency Research*

Kearney and Fleischer (1979) developed the Exercise of Self-care Agency (ESCA) to measure Orem's (1985) concept of self-care. This scale was used by Stockdale-Woolley (1984) to examine the effects of group education classes on self-care among individuals with chronic obstructive pulmonary disease (COPD). Individuals with COPD have a chronic condition that involves daily participation in a therapeutic regime of medications, breathing exercises, physical and respiratory therapy, and adjustments of daily activities (Voelkel, 2000). Because education can

promote self-care through adjustment of daily routines, the researcher hypothesized that individuals involved in education would have significantly higher self-care scores after classes than before classes.

In the study by Stockdale-Woolley (1984), an experimental pretest-posttest design was used with convenience sample of individuals ( $n=25$ ) with lung disease enrolled in a series of group educational classes about their disease sponsored by the American Lung Society in an Eastern state. The four independent variables used were the presence of a significant other (support), severity of disease, social status, and type of lung disease. Each person served as their own control with pretest scores compared with posttest scores to evaluate changes in self-care. The four independent variables were presence of significant other, severity of disease, social status, and type of lung disease.

The researcher hypothesized that individuals attending classes would have statistically significant higher levels of self-care agency at the conclusion of the group educational classes than before. Pretest ESCA scores were lower ( $M=157.28$ ,  $SD=26.567$ ), with posttest scores ( $M=163.4$ ,  $SD=25.085$ ) supporting the intended assumption. Using a dependent-sample  $t$  test to compare the two sets of results, as each person served as his or her own control. Stockton-Woolley (1984) reported statistically significant greater ECSA scores after the educational class than before. The majority of the participants (80%) had a significant other from whom they gained emotional support. Severity of disease was grouped into four functional capacity categories of fully functional (16%), slightly diminished (44%), significantly diminished (20%), and minimal remaining capacity (20%). Social status was based on

education and occupation with ranges of class from I to V with I being the lowest. Most individuals were class III to V (84%). Sixty percent of the participants had mixed disease of bronchitis and emphysema or COPD.

The implication for validating education in individuals with lung disease was supported by the higher ESCA scores after instruction. Self-care may be affected by the severity of the disease. Stockton-Woolley (1984) concluded that this study validated the importance of education on chronic illness, such as COPD.

Lakin (1988) conducted a study to define the relationships among education of self-care agency toward the individuals' locus of control, health value, health status, and general fitness. Prior to this study, self-care was depicted as a patient activity carried out under direct physician supervision who ordered a variety of treatments for chronic diseases with little input from the patient or support providers. During the early 1980s, many studies examined self-care and self-care agency as a series of independent preventive health-care behaviors, such as, the study by Wallston, Wallston, Kaplan, and Maides (1976) that examined the relationship between the locus of control and health status or the relationship between lifestyle and healthy behaviors and self-care knowledge. No study sought to examine the relationship between heretofore independent variables of education of support providers, health values, and locus of control until Lakin (1988).

The purpose of Lakin's (1988) descriptive study was to examine if a relationship could be established between disposition to engage in self-care practices and following variables: locus of control, health values, satisfaction with health, and general fitness. Survey data were collected to analyze the behaviors of a healthy

group of professional women. A group of 104 faculty women were selected randomly at a Midwestern university to participate in a survey questionnaire. Four survey instruments were used to ascertain the following questions: (a) whether a relationship between positive internal locus of control and Exercise in Self-Care Agency (ESCA) existed, (b) a negative relationship between chance externality locus of control and ESCA, (c) a negative relationship between powerful others externality and ESCA, (d) high health value rankings have higher ESCA scores than lower health rankings, (e) satisfaction with health will have higher ranking ESCA scores than those with lower ranking, and (f) favorable health rankings will have higher ESCA scores than those with lower ranking. The ESCA was compared with two other behavioral scales and one demographic background information scale was used to compare the respondents with each other.

The first instrument, the ESCA, originally consisted of 43 items with high scores indicating greater ability to undertake self-care actions. The second instrument, a multidimensional locus of control, contained three subscales measuring internal, powerful others, and chance of locus of control (Levenson, 1973). The third instrument was a personal needs scale that ranked order the importance of 10 items including health and general fitness (Thomas, 1983). The final instrument was a demographic and background information scale to rate current health status on a four-point Likert-scale to identify current health problems, demographic status, and the type of collegiate appointment that was developed by the researcher.

One hundred and four individuals received a self-administered survey. Data were collected over a 3-month period with one follow-up reminder one week after the



initial reminder. The results of the demographic survey showed statistically significant differences among faculty women with regard to marital status. Two-thirds of the women in health-related appointments were married (66.7%) compared with 42% in other departments. There was statistically significant difference in divorce rates between health-related appointments (5%) versus nonhealth-related appointments (26%). There were no other statistically significant demographic differences; therefore, the data were pooled into three categories: single, married, and separated, divorced, or widowed. Data were analyzed using measures of central tendency, *t* test, and Pearson product-moment correlation coefficients.

Based on the six research questions, the results showed that there was (a) a statistically significant moderate positive correlation between ESCA and internal locus of control ( $r = .5$ ), (b) a moderate negative correlation between ESCA and chance externality locus control ( $r = .48$ ), and (c) and there was no statistical significance between powerful others externality and ESCA ( $r = .11$ ). A post hoc comparison showed that there were no statistically significant differences between ESCA and faculty with high health and general fitness values when compared with those with moderate or low health and general fitness values, and health satisfaction and ESCA comparisons showed faculty satisfied with their health and general fitness had statistically significant high levels of ESCA ( $M=128.73$ ) than colleagues' dissatisfied with their health ( $M= 115.5$ ), with results of  $t(102) = 3.34$ . Faculty who rated their current health status as excellent, had a statistically significant higher ESCA mean ( $M=132.39$ ) when compared with those who rated their health status as

good (M=120.79) or fair (M=116.43). There were no differences between age and marital status and ESCA scores.

This was a pioneer study comparing the relationship self-care and health appraisal using multiple variables. The results of this study suggest that the disposition of an individual to engage in self-care practices was related to their values and locus of control. The significance of this study was its inclusiveness to combine multiple assessment variables in the analysis of health-related behaviors and self-care agency.

Carroll (1995) used the ESCA scale that described and tested a model of recovery based on the theories of self-care and self-efficacy with elderly patients recovering from coronary artery bypass (CABG) surgery. The purpose was twofold: to describe the changes in self-care agency, self-efficacy expectations, and self-care recovery behaviors of an elderly population with coronary artery disease and to investigate the effects of self-efficacy expectations on self-care behaviors during the recovery phase after CABG. The researcher proposed that the relationship between the self-care agency (decision-making phase) and self-care recovery behavior (productive phase) during the recovery process is affected by how people perceived their own capabilities and self-efficacy expectations.

The study took place at two large urban teaching hospitals on the East Coast using a convenience sample of 133 elderly patients (men =101; women =32) admitted for bypass surgery. The ages ranged from 65 to 87 with the mean age of 72. The majority of patients (77.5%) reported severe functional limitations prior to surgery. The design of the study was longitudinal with repeated measures taken at admission,

discharge, 6 weeks, and 12 weeks after CABG. The study measured self-care agency, self-efficacy expectations, and the performance of self-care recovery behaviors. Self-care agency was measured with the ESCA scale. Self-efficacy expectation and the performance of self-care behaviors were measured by Jenkins Self-Efficacy Expectation Scales and Activity Checklists (Jenkins, 1989). Data were collected for the following specific behaviors: walking, climbing stairs, resuming general activities, and the performance of preexisting roles prior to surgery.

Data analysis was conducted using descriptive statistics, repeated measures of analysis of variance (ANOVA) to investigate changes in self-care agency, in self-efficacy expectation, and in self-care and recovery behaviors, and regression estimates for self-efficacy expectations were used as mediator at discharge. The results were as follows. The ESCA was administered at each of the four measurement points showed the lowest means for perceived self-efficacy expectations at discharge ( $M=121.9$ ) and the highest at 12 weeks ( $M=126.7$ ) suggesting a higher degree of self-care agency at the end of recovery. Postoperative results from the Jenkins Scale at discharge were lowest for walking, stairs, and assuming prior roles at discharge with more than half (54%) resuming presurgical status at 12 weeks. An independent-sample  $t$  test was used to investigate if there differences between men and women with self-care recovery behaviors. There were no statistical differences between the groups at any point in the study.

To examine whether self-care recovery behavior was dependent on self-care agency alone or whether it was a result of self-efficacy mediating between self-care agency and recovery behavior, three regression equations for self-efficacy as a

mediator at discharge were tested using the Jenkins Scale. There was a statistically significant influence of self-efficacy expectations as a mediator between self-care agency and general activities at discharge ( $r^2=.89$ ). The regression equation for data at 6 weeks post-CABG found statistically significant behaviors between self-care agency and all self-care recovery behaviors. At 12 weeks, the regression equation for self-efficacy expectation as a mediator on self-care agency and recovery behaviors were statistically significant as well.

Overall, self-efficacy expectation increased recovery behaviors over self-care agency throughout the study. The results of this study suggested that self-efficacy expectation may be an essential element to complete self-care agency from an educational perspective for the development of independent self-care behaviors. They further suggested that the nurse may play a pivotal role in influencing the self-efficacy expectations of the elderly providing education, coaching, and assistance after surgery to perform self-care behaviors. After discharge, phone support may further enhance the realistic activity goals while improving self-efficacy expectations of the elderly with reasonable expectations for behavior and activity levels after CABG.

In the country of Turkey, Akyol, Cetinkaya, Bakin, Yaraali, and Akkus (2007) conducted a descriptive, analytical, and cross-sectional study on self-care. The researchers used a convenience sample of 120 patients to evaluate self-care agency in patients with hypertension (82=females and 38=males) and over half were over the age of 60 (50.8%). The goal of the study was to describe self-care agency of hypertensive patients and factors concerning self-care. Six facilities participated in

the study over a one- month period. The instrument used was a two-part questionnaire using the ESCA scale and independent variables considered to have an impact on self-care agency including sociodemographic characteristics designed by the researchers.

In this study, Turkish women whether or not employed reported a more restrictive lifestyle thereby leaving insufficient time for self-care activities and increased health problems. In support of this finding, sociodemographic results revealed few individuals with higher education (3.3%) and more than half had primary education (54.2%). The majority of the patients (87%) lived in the city. A large portion lived with a partner (64.2%) compared with those living alone. The majority were unemployed (87.5%). As expected, the incidence of hypertension was higher in patients over 60 years (50.8%).

Results from the ESCA scores were at the moderate level (64.2%) in this patient population. The analyses of the demographic factors revealed that education level and health insurance had no statistical significance on self-care agency among the women because of possible cultural restrictions against all females as opposed to another study conducted on Midwestern women in the US where education and economics were a factor (Lakin, 1988). Studies in this section suggest that self-care may be affected by disease severity, locus control, and socioeconomic status. The current study investigated the role that education, and other demographic factors such as age, gender, and socioeconomic status may have on self-care behaviors with patients with CHD.

### *Knowledge in Adults with Congenital Heart Disease*

A number of studies have been published regarding the need for continued follow-up care regarding educational issues for adults with CHD but few studies provide empirical research on the ways that self-care agency influences knowledge in adults with CHD. The review of the current research literature on knowledge in adult with CHD was grouped into three sections. The first section provides research of studies conducted in the four domains of CHD (Chessa et al., 2005; Moons et al., 2001). The second section provides research studies conducted with illness understanding with patients with CHD (Dore, de Guise, & Mercier, 2002; Kamphuis, Verloove-Vanhorick, Vogels, Ottenkamp, & Vleigen, 2002; Veldetman et al., 2000). The third section provides research studies conducted in preventive measures and complications in adults with CHD (Kantoch, Collins-Nakai, Medwid, Ungstad, & Taylor, 1997; Simko, McGinnis, & Schembri, 2006).

### *Research in the Four Domains of Congenital Heart Disease*

There is limited empirical research on care of the adult with CHD. Moons et al. (2001) described four domains young adults with CHD need to be educated about self-care: first, disease and treatment that involves the ability to understand the type of heart defect, the required surveillance, and future prognosis; second, measures to prevent complications include understanding of endocarditis prevention and behaviors to prevent it; third, physical activities aimed at both ability to exercise and recognition of restrictions; and fourth, reproductive issues that involve appropriate method of contraception, genetic counseling, and pregnancy. Potential complications

that should be understood before conception may occur for females who become pregnant (Canobbio, Morris, Graham, & Landzberg, 2006).

Moons et al. (2001) used the “Leuven knowledge questionnaire for congenital heart disease” that measured knowledge levels in all four domains within a single study. The purpose of this study was to assess how much adults with CHD knew about their disease and the preventive measures to avoid complications. This descriptive, cross-sectional study was conducted in Belgium at the outpatient clinic of the university hospitals of Leuven. All participants were Dutch speaking and over the age of 18 years, median age of 23 years. Patients under the age of 18 years or with a learning disability were excluded.

A total of 62 participants were eligible for the study, with 76% males and 24% females. Because of their young age, most of the participants were still living at home with their parents (55%). Approximately 60% were working, and 29% were students. After being seen by a cardiologist, participants were asked if they received adequate knowledge about their disease. They were next invited to fill out the survey with the researcher available for clarification.

The researchers found that the majority of the patients (97%) were satisfied with the information provided by their congenital cardiologist. Fewer patients (16%) knew the definition of endocarditis and less (15%) were aware of the most typical symptom related to it. The majority of patients (71%) did not understand the impact of smoking or alcohol consumption on heart disease. Good understanding was reported (70%) with regard to physical activity and choice of occupation (89%). Fewer patients (27%) were aware of the potential genetic influence their condition

may have on their children. Adequate understanding (80%) was reported by female patients about oral contraceptives but less about contraindications for using an intrauterine device (27%) or whether pregnancy (87%) would pose additional health risks. Males were better at locating their defect (57%) than females (26%) and more knowledgeable about physical activities (76%) than females (46%). Patients who managed their health (22%) knew more about endocarditis than those who depended on someone else (7%). Differences between mild and complex disease were discovered: patients with simple defects (80%) easily locate their defect on a diagram compared with complex disease (7%).

Overall, 80% of the participants were knowledgeable regarding medical treatments, frequency of follow-up visits, dental practices, employment choices, and contraception. The researchers also found poor understanding (50%) about the purpose of follow-up, recognition of symptoms of declining cardiac function, endocarditis, effects of drinking and smoking on the heart, genetics, and alternate birth control methods such as an intrauterine device (IUD). Their results were similar to previous studies with regard to age entering the clinic. They also reported lack of knowledge in follow-up care. The researchers concluded that poor knowledge of cardiac disease might have harmful consequences on adults with CHD. The current study of adults with CHD in the US may yield different results from those obtained in Belgium. Limitations of the study included possible bias by the researcher directly questioning the participant. The participants were also younger than other studies discussed. This study has merit in the development of the instrument that assesses several topics in a single study.



Chessa et al. (2005) reported there were no formal transition programs in Italy and evaluated CHD patients in the four domains of medical diagnosis, medications and side effects, treatment, and contraception using the Leuven questionnaire. They also assessed knowledge for potential re-operation, which was a variance from the original instrument by Moons et al. (2001). The purpose of the study was similar to Moons et al. (2001) to assess knowledge levels among adults with CHD about their heart condition. The survey was mailed to 200 participants, with a response rate of 52%, who were chosen randomly from a local clinic with a diagnosis of CHD. A balanced number of males (48) and females (56) participated in the study and half of the patients had a high-school education and were considered blue-collar workers.

The researchers reported that participants were informed about their diagnosis (80%), treatment received (100%), prognosis (68%), and taking part in physical activity (74%). They were moderately (55%) aware of medication usage. The participants had less understanding (46%) of the anatomy of their heart defect and factors contributing to endocarditis (40%). The effects of alcohol (86%) and smoking (94%) on the heart were well understood. Only 6% correctly responded to genetic influence on offspring. The lack of endocarditis prevention was similar to findings by Dore et al. (2002). The majority of females understood oral contraceptive method was preferred method of birth control (71%), and pregnancy would cause additional risk to their health (60%). Similar to Moons et al. (2001), the study yielded positive results in several domains. Education did not appear to influence responses as reported in other studies, but the researchers reported participants less than 35 years answered correctly questions about physical activities, sports, and pregnancy. In the

younger patients, the influence of Internet and electronic resources may have played a role in the number of correct responses.

The results of these studies suggest that patients have knowledge of some aspects of their disease that pertain to basic understanding of the disease. Patients could follow scheduling and maintenance of health as related to doctor care such as in follow-visits or dental practices. There was some knowledge on the impact of heart disease and employment choices. These studies also suggested, however, that patients with CHD lacked fundamental understanding of symptoms of complication of cardiac condition and preventive measures for increased risk such as nonsmoking and limited alcohol intake. With regard to gender specific conditions of pregnancy and contraception, female patients with CHD showed a poor understanding of contraception knowledge and the effects of pregnancy on the heart.

#### *Illness Understanding*

In the domain of illness understanding, Veldtman et al. (2000) from the United Kingdom (UK) undertook a formal investigation of knowledge among young patients with chronic cardiac conditions using semistructured interviews based on Leventhal's illness representation model that explored beliefs children have about their illness, how they interpret it, and how they act upon their understand. The purpose of this study was to evaluate illness knowledge and understanding in young patients ages 7 to 18 years of age (M=13) and whether understanding was related to age, gender, or complexity of the cardiac defect. Standard content analysis was applied to the transcribed interviews and coded by the researchers. To ensure coding reliability, 5% of the transcripts were double coded by a second evaluator. Analysis

of variance (ANOVA) was used to compare knowledge and understanding at different ages.

The researchers reported 33% of the patients had partial understanding, 30% had good understanding, 22% had poor understanding of diagnosis, and 36% did not understand the nature of their abnormality. Examples of poor understanding were reported in younger patients becoming sophisticated with age. The level of good understanding was age-related was identified by a mean age of 15. The researchers concluded poor knowledge in the event of an emergency could be fatal if patients could not articulate their condition. They also suggested that the ability to demonstrate self-care was undermined by the absence of fundamental illness understanding. Older and more developed children could better cope with the impact of their illness on the future. Although patients were younger in the study compared with others presented in this review, it provides insight into the timeline of beginning independent education to patients with CHD.

A descriptive study by Dore et al. (2002) from Canada used a brief questionnaire to assess patient knowledge of congenital-heart abnormalities. All new patients, males (42) and females (62), referred to the adult congenital-heart clinic over an 8-month period were asked to complete a four-question survey designed to assess knowledge level of their heart condition. The median age was 24 years. The survey instrument addressed subjects related to patient knowledge of heart condition, antibiotic prophylaxis, and pregnancy. Questions regarding the length of time between the patients' last visit to the pediatric cardiologist or general physician and the first-time visit to the adult congenital service were assessed.

With regard to cardiac disease, 34.6% of the patients were unaware of their cardiac diagnosis, which ranged from simple to complex cardiac anomalies and 15% had poor understanding of their cardiac diagnosis. The age of the patient was not a factor in knowledge level in this study. The majority of patients (79%) were aware of the need for antibiotic therapy for endocarditis prophylaxis prior to dental procedures. When patients were asked why they needed antibiotics, half were able to provide a rationale.

The risk of pregnancy was pertinent for the female patients. In this study population, 37 women (66%) had never discussed the subject with either a cardiologist or another physician. The researchers found that pediatric cardiologists were less likely to discuss pregnancy when compared with other physicians (76% vs. 47%). Lastly, the length of time since last visit in cardiology was statistically significantly longer in patients who were unaware of their cardiac defect. Specifically, of those patients who had no follow-up visit to cardiology for more than 10 years, six patients were referred for the most serious of complications related to their cardiac anatomy, such as heart failure (Eisenmenger, Ebstein anomaly), syncope (operated and unoperated tetralogy of Fallot), and arrhythmias (atrial septal defect, unoperated tetralogy of Fallot). The clinical diagnosis was completely unknown by more than one-third of the patients.

Overall, the last visit from pediatric cardiology to adult cardiology varied from one month to 25 years but was statically significantly shorter when compared with other physicians. The study showed that some patients had no follow-up for more than 5 years (28%) and some greater than 10 years (13.4%). Six (5%) of the

patients were referred to the adult congenital clinic because of new or progressive symptoms. The researchers concluded that a large percentage of adults with CHD show poor understanding of knowledge about their cardiac defect. One limitation of this study was the lack of generalizability due to the location of participants being confined to one region. The researchers agreed that their primary goal was to gather information about patients' knowledge levels and guide them in creating teaching materials for patients at their clinic. The current study of adults with CHD may yield different results from those obtained in Canada.

A descriptive study from The Netherlands (Kamphuis et al., 2002) carried out cross-sectional research of a convenience sample randomly selected from a database in the department of pediatric cardiology to investigate patients with mild and complex heart disease. The purpose of their study was to evaluate satisfaction with level of knowledge and difficulties in daily life as they related to their cardiac disease. The researchers also sought to assess the health-related counseling used by these patients. Of the 224 selected patients, 156 completed the questionnaire (69% response rate). Complex patients had a higher response rate (88%) compared with patients with mild disease (59%). The researchers reported statistically significant difficulties in daily life among patients with complex disease compared with those with mild disease. The most relevant difficulties with complex patients were problems with life insurance, employment (either being excluded or having to give up a job), unable to attain higher education, unable to participate in a sport, advised not to have children, and life restrictions. In contrast with the US, laws are in place to prevent discrimination on the basis of health-related bias.

Patients with mild disease reported insufficient knowledge, and 61% wanted more information about their disease. Fifty-five percent were interested in future consequences and wanted more information. Among complex disease patients, 1/5<sup>th</sup> to 2/3<sup>rd</sup> of the patients reported problems related to their condition with future consequences and family planning. Patients with mild disease made greater demands for more detailed information about their condition than those with complex disease. The researchers reported 33% of complex patients had difficulty with employment and over 50% had felt restricted in job choice. Another 33% had to pay a higher premium for life insurance because of their disease. The majority of patients (62%) reported insufficient knowledge about their condition.

Overall, complex patients reported the most restrictions because of their disease when compared with patients with mild disease. The researchers concluded that efforts to improve counseling would close the gap in knowledge, especially career, exercise, educational choice, and healthy behaviors. This study highlights some of the difficulties encountered by patients with complex disease. Typically, there are more involved with the health-care system and have increased opportunities for repeated education and reinforcement of information. Limitations of the study were that a single center may not represent the general population. The study contributed to the care of patients with CHD.

*Preventive Measures and Complications in Adults with Congenital Heart Disease*

Kantoch et al. (1997) in a descriptive study assessed patients' knowledge about their CHD using a two-part questionnaire designed for the study. Participants were a convenient sample of 50 consecutive patients visiting the ACHD clinic in

Alberta, Canada. There were an equal number of participants of males and females (25) who ranged from 18 to 60 years ( $M=25$ ). The purpose of this study was to assess patient knowledge about their congenital cardiovascular disease. At the time patients were given the questionnaire, they had visited the clinic from 1 to 22 times and 1 to 6 different cardiologists were involved in their care as adults. Eight questions covering two domains were assessed: heart condition and the need for antibiotic prophylaxis. To corroborate patient responses, patient medical records were reviewed. Although more than half (54%) were able to identify their diagnosis, only 44% could explain their cardiac anomaly. About one fourth (26%) marked their defect correctly on a heart diagram. Frequency of visits and different number of providers was not related to patient knowledge. The researchers reported statistically significant knowledge levels of diagnosis and overall knowledge level of CHD among patients who graduated from college when compared with their counterparts with elementary or high-school education. Of those patients with college education, 70% scored at adequate or above knowledge level; however, patients with high-school education scored 50% at adequate or above knowledge level. Patients with an elementary education scored 16% at the adequate or above knowledge level when compared with those patients with CHD with higher education.

With regard to endocarditis, three of the participants had documented incidents of endocarditis, but only one knew the cause and preventive measures. Most patients (72%) could not explain correctly the terms endocarditis or antibiotic prophylaxis. Additionally, patients demonstrated misconceptions of contributing risk factors for endocarditis. In both questionnaire sections, the researchers reported no

correlation between patient knowledge and age, gender, number of clinic visits, or number of cardiologists who patients saw in the past. The researchers suggested that patients may have limited understanding of normal heart function possibly learned in high school or college and not from medical resources. The findings of this study were similar to those by Cetta and Warnes (1995) from Mayo Clinic, who reported poor knowledge with regard to endocarditis prophylaxis. Limitations to this study include a small number of patients and the way the questions were constructed may have influenced patient responses. The researchers concluded that there was a significant lack of patient knowledge regarding cardiac defects in this population.

Simko et al. (2006) used a prospective, cross-sectional, case-controlled study design to identify educational needs in adults with CHD and compared them with healthy controls (mean age 26.4 CHD and 26.5) in the US. Participants were recruited from a pediatric cardiology practice at a university-affiliated practice that was not considered an ACHD center. The researchers did not use a standardized tool, but rather developed one for the study. Patients with CHD were asked to rate themselves on the New York Heart Association (NYHA) Functional Classifications scale. The purpose of the study was to identify educational needs of adults with CHD and the influence on education-related characteristics of social status, independence, health and life insurance, employment, occupation, pregnancy, and genetic issues.

Overall, the researchers concluded that income, marital status, number of children, having insurance, and life insurance was similar between the two groups. They reported that a lower percentage of adults with CHD employed (71%) compared with healthy subjects (83%) and were more likely to live at home with their parents



(46%) than the healthy controls (35%). Complexity of the disease did influence employment as less cyanotic patients (62%) were working (77%, controls) and continuing to live with parents (34% vs. 56%). No statistically significant differences were reported for having health insurance or life insurance between the two groups. As expected, fewer cyanotic patients were NYHA Class I (35%) compared with acyanotic patients (71%). Perloff (1998) reported inconsistencies in the use of the NYHA Functional class intended for patients with ischemic heart disease not for CHD. He developed the University of California, Los Angeles (UCLA) CHD Functional Classification to evaluate symptoms in patients with congenital defects.

There were no differences between the two groups with regard to birth control, pregnancy, and genetic counseling, but both groups agreed equally that their questions had not been answered adequately. Acyanotic adults with CHD were more likely to be employed and living independently than cyanotic adults. The researchers discovered information that conflicted with previous studies and presented adults with CHD in a positive light with satisfaction in their life status, owing to the differences in other countries. The findings may reflect a limitation with the accuracy of self-reporting. The researchers acknowledged gaps in education for adults with CHD and the need for developing structural educational programs in the future.

### Summary

Examined in this literature review are the following: the evolution of Orem's Self-care theory, the application to self-care agency using the ESCA scale, and previous literature regarding illness understanding and knowledge in adults with CHD. Researchers have reported relationships between self-care agency and specific

conditioning factors like age, gender, marital status, ethnicity, available resources, income, and education. They have investigated the association between self-care agency and self-care activities such as identifying and managing meaningful symptoms, seeking appropriate health-care advice, choosing, and monitoring the progress of diseases. In addition, researchers have studied and found significant relationships among self-care activities, health, and well-being.

Most of the knowledge studies in adults with CHD focused on one or two domains per study with the exception of the two that looked four domains from Belgium. Clearly, patients have not been educated adequately about their specific cardiac defect, what to anticipate, and how to manage their health effectively as adults. The studies in this literature review do not investigate self-care and knowledge in adults with CHD. This study was needed because few if any studies combine self-care agency with knowledge in all of the areas concerning adults with CHD. This study was an empirical research study that focused on self-care agency and education in the four domains of knowledge among individuals with CHD within a single study.

## CHAPTER III

### METHODOLOGY

Many children afflicted with complex childhood illnesses that historically caused early death are now surviving childhood with the potential for meaningful and productive adult lives. These patients ultimately will need to assume responsibility for their own health and engage in self-care behaviors. As the population of adults with congenital heart disease (CHD) continues to increase, little is known about the connection between self-care behaviors and knowledge about their heart condition including understanding their disease, preventing complications over a lifetime, physical activity, contraception, and pregnancy.

The present study assessed the relationship between self-care behaviors and knowledge levels on health-related decisions in adults with CHD. In this section, descriptions of the research design, participants involved in the study, sampling procedures, instrumentation, research questions are restated, human subjects' considerations, and the researcher's role are provided.

#### Research Design

This study was a descriptive research design that assessed CHD adults' knowledge about their cardiac defect in four areas (disease and treatment, complications, physical activity, and reproduction and contraception). In addition, this study used four subscales from the Exercise in Self-Care Agency (ECSA) of self-worth, initiative and responsibility, knowledge and information seeking, and passivity to examine if four variables were related to CHD adults' knowledge of their cardiac defect.

## Participants

Participants were a convenience sample selected from the Adult Congenital Heart Disease (ACHD) clinics at a large university medical center in Northern California. Ages ranged from 18 to 45 years. Scheduled patients being seen for the first time in the ACHD clinics from June 2009 through October 2009 were invited to participate in this study. New patients were chosen to assess their baseline knowledge levels before they received teaching from the institution. Data were collected on 30 individuals. Demographic characteristics are given in Table 4. Only a few individuals were 36 to 45 years, with the majority between 18 and 35 years. The sample was predominantly females, European Americans, English speaking, graduated from college, professionals, and lived with a spouse and 27% lived with a parent.

Inclusion criteria for participants in this study were as follows: English speaking, over the age of 18 years, and a confirmed diagnosis of congenital heart disease. Although the last criterion seems obvious, patients are often referred because of a new murmur or an erroneous diagnosis made in childhood. Patients with cognitive impairments were excluded from this study.

## Sampling Procedures

Potential participants were contacted by telephone prior to their scheduled visit to the ACHD clinics and requested to participate in the study. Before meeting with the physician, participants were given study questionnaires, which took approximately 20 minutes to complete. Participation was voluntary, and patients were free to decline participation if they wish to do so. At this visit, they were seen by an

adult cardiologist specializing in the care of adults with CHD, a cardiology fellow or resident in training, and a family nurse practitioner.

Table 4

<i>Demographic Characteristics of Participants in the Study</i>		
Variable	f	%
Age		
18 to 25	12	40
26 to 35	13	43
36 to 45	5	17
Gender		
Females	18	60
Males	12	40
Ethnicity		
Caucasian	20	67
Hispanic	5	17
Asian	3	10
Black	1	3
Other	1	3
Language		
English	26	87
Non-English	4	13
Education		
High school	4	13
Some college	8	27
Undergraduate Degree	14	47
Graduate Degree	4	13
Occupation		
Student	7	23
Non-professional	6	20
Trade	1	3
Professional	15	50
Disabled	1	3

Table 4 continues

Table 4 continued

<i>Demographic Characteristics of Participants in the Study</i>		
Variable	f	%
<b>Income</b>		
<20, 000	12	40
20, 000 to 40, 000	5	17
41, 000 to 60, 000	5	17
> 60,000	8	27
<b>Living Arrangements</b>		
Spouse	10	33
Parents	8	27
Significant Other	4	13
Roommate	3	10
Dorm	2	7
Other	3	10

The Adult Congenital Heart Disease Clinics are housed in a Tertiary Medical Facility in Northern California. Adult cardiology clinics are held weekly with a total of four separate clinics. There are currently approximately 1,500 patients seen annually in the clinics with an average of four to six new patients per week. Thirty-two new patients were identified as eligible to participate in this study. Of the thirty-two patients invited to participate, two declined the invitation.

#### Protection of Human Subjects

The use of human subjects in this study was approved by the Institutional Review Board for the Protection of Human Subjects at the University of San Francisco (IRBPHS #08-0184) and by the Committee On the Rights of Human Subjects at the research site (Approval #H61540-32740-01). Specific criteria were met for the boards' review and approval of the study aims, design, procedures, data-

collection instrument, and the plan for assuring confidentiality and informed, voluntary consent of the study participants, which included a signed consent form, insurance of confidentiality, and security of data collection as proscribed by the University of San Francisco and the hospital's protocol.

### Instrumentation

Two instruments were used in this study to collect data on the variables in the study. Each instrument measures four subscales: either knowledge variables or self-care variables. These subscales measured the eight variables in this study. The *Exercise of Self-Care Agency Scale* (ESCA) was developed by Kearney and Fleischer (1979). It was designed to measure four subscales of self-care agency: self-worth, initiative and responsibility, knowledge and information seeking, and passivity. The maximum score on the modified scale is 140. The values are divided into three groups: high (106 to 140), moderate (71 to 105), and low (0 to 70). A score of 0 is assigned to the item response choice "Very Unlike Me" and a score of 4 is assigned to the item response choice "Very Like Me." Higher scores reflect greater exercise of self-care agency.

Multiple researchers have used the ESCA scale. Riesch and Hauck (1988) used the ESCA scale to measure the change in self-care agency in 100 expectant women and their partners after participation in prenatal classes. They showed a statistically significant increase in ESCA scores ( $t [176] = 2.84$ ), with an eta squared of .04 indicating a medium effect. Rundahl (1980) showed that adolescents who reported higher levels of self-concept and health knowledge also reported higher levels of self-care agency ( $r = .47$ ). The Exercise in Self-Care Agency (ESCA)

consisted of 43 items rated on a 5-point Likert scale across four subscales: self-worth, initiative and responsibility, knowledge and information seeking, and passivity.

The reliability, stability, and internal consistency of the instrument were established with samples of nursing and psychology students. The scale was reviewed for content validity by 11 nurse experts. Kearney and Fleischer (1979) tested the ESCA score concurrent validity by comparing students' scores on the ESCA scale with scores on the Adjective Check List. They reported a test-retest reliability coefficient of .77 for 76 nursing students after 5 weeks and split-half reliabilities of .77, .80, and .81 for 79 and 84 Nursing students and 153 Psychology students, respectively. These values are acceptable for this type of instrument.

The ESCA scale was then validated and modified by Riesch and Hauck (1988). To accomplish this revision, they pooled data from three studies in which the ESCA scale was used (n=506). The individuals were self-selected and included 100 expectant mothers and their partners, 110 healthy adolescents, and 296 university faculty, students, and staff. Then the construct validity of the ESCA was examined by the principal components method. The four factor solution accounted for 40% of the variance. Items with loadings of .40 or above on a factor were retained. As a result, 8 items were dropped from the instrument, resulting in a 35-item instrument: 12 items for self-worth, 12 items for motivation, 5 items for knowledge and information seeking, and 6 items for passivity. Cronbach's coefficient alpha for the four factors on the sample of 506 individuals are .81 for self-worth, .82 for initiative and responsibility, .76 for knowledge and information seeking, and .73 for passivity, which are all within the acceptable range for this type of instrument. The total scale



had a Cronbach's coefficient alpha of .90. Analysis of variance was used to test for discriminate validity among the four factors generated by the principal components. The independent variable was the different samples, and the results showed statistically significant differences for all four of the subscale factor scores.

The items by subscale breakdown are as follows. Twelve items constitute self-worth. An example of this component is "I take responsibility for my own actions." Twelve items constitute the initiative and responsibility subscale. An example of this type of item is "I take pride in doing the things I need to do in order to remain healthy." Five items constitute the knowledge and information seeking subscale. An example of this item is "I understand my body and how it functions." The final subscale, passivity, has six items. An example of this type of item is "I tend to neglect my personal needs."

More recently, Callaghan (2006) used the modified ESCA scale with multiple patient populations ranging from the elderly to adolescents. The data collected from adolescents were normally distributed and met the homogeneity of variance requirement, an assumption for conducting analysis of variance (ANOVA). Of a possible range of scores from 0 to 140 with a midpoint of 70 on the 35 scored items, individuals' scores ranged from 20 to 132 with a mean of 89.50 and a standard deviation of 19.36 (n=256).

Knowledge was measured using the *Leuven Knowledge Questionnaire* (Moons et al., 2001). This questionnaire was developed by Philip Moons and his group in Leuven, Belgium, to assess how well adults with congenital heart disease understand their heart defect, its treatment, and the preventive measures necessary to

avoid complications. During the developmental phase of their instrument, they evaluated face and content validity using an expert panel. They subsequently demonstrated its use in a population of young adults with complex congenital heart disease and were able to demonstrate that this population had gaps in knowledge based on the questionnaire.

The four domains of the Leuven Knowledge Questionnaire are knowledge and treatment of heart disease, prevention of complications, physical activities, and reproduction and contraception. There are 31 items on the questionnaire and 27 multiple-choice questions. Scoring was based on percentage of correct answers from the multiple-choice questions. Moons et al. (2001) classified scores into one of three groups of adequate (> 80% correct), moderate (50% to 80%), and poor (< 50%). The number of items by domain is as follows: Ten items constitute the knowledge and treatment domain. An example of this type of item is “What is the name of your heart defect?” Ten items constitute the complication domain. An example of this item is “What is endocarditis?” Four items constitute the physical activity domain. An example of this type of item is “Is maintaining physical activity important for people with heart disease?” The final domain reproduction and contraception has three items. An example of this component is “During pregnancy are you at risk for developing worsening heart problems?” See Appendix A for the complete Leuven Knowledge Questionnaire.

For this study and with their permission, slight modifications in word choice (to adjust for language differences between Belgium and the United States) were made. Additionally, changes were made to conform to current American Heart

Association recommendations, for example, contraception and endocarditis. Subsequently, the questionnaire was emailed to Dr. Moons, who provided his approval. Otherwise, the Leuven Knowledge Questionnaire is the same as it was originally developed. The percentage of correct answers for each of the four domains was used for data analysis purposes for this study. Items were identified as correct by the researcher who checked the individual's medical file.

Demographics were collected on the Demographic Data Section of the questionnaire from all participants and included date of birth, age, gender, ethnicity, religion, primary language, level of education, occupation, income level, and place of residence. Figure 1 shows the four subsections of the ECSA and the Leuven Knowledge Questionnaire as were related to address the first four research questions.

#### Restatement of Research Questions

1. To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of heart disease and treatment in adults with CHD?
2. To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domains of measures to prevent complications in adults with CHD?
3. To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately

and collectively related to the knowledge domain of physical activities in adults with CHD?

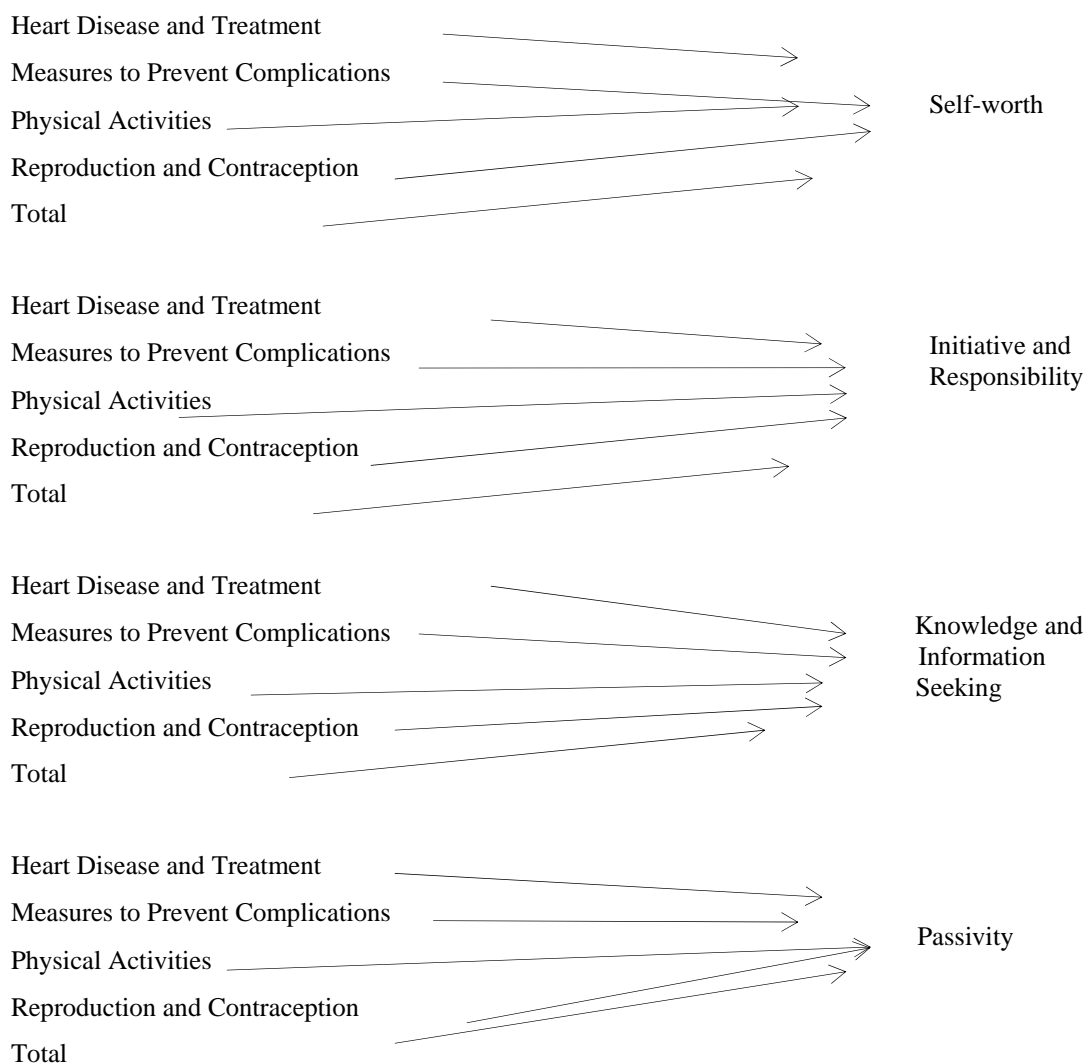


Figure 1. The four domains of the Leuven Knowledge Questionnaire and the four subscales of the Exercise in Self-care Agency (ECSA)

4. To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of reproduction and contraception in adults with CHD?

5. To what extent does the knowledge in the four domains of congenital heart disease vary by the demographics of age, gender, ethnicity, income, and level of education?

### Data Analysis

Statistical procedures were used to investigate self-care behaviors related to knowledge of disease, preventive measures, physical activity, and reproductive issues with individuals with CHD. To address the four research questions, frequency tables were created and Pearson product-moment correlation coefficients were calculated for the four constructs of self-care (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) and the four domains (heart disease and treatment, prevention of complications, physical activity, and reproduction and contraception) using a total percentage score. Analyses were discussed and organized according to the five research questions. For the fifth research question, Pearson product-moment correlation coefficients were calculated for the four domains and age, gender, ethnicity, income, and level of education.

### Qualifications of the Researcher

The researcher for the current study is a fulltime clinical nurse coordinator and certified family nurse practitioner for the ACHD clinics. She has been employed at the current institution where the study was conducted for over 20 years. She holds appointments in pediatric and adult cardiology as the nursing coordinator of the Adult Congenital Heart Disease Practices. She functions as the advanced practice nurse in the clinical practice, assessing the patient's medical, educational, psychosocial, and developmental needs, planning and providing the necessary interventions, and

monitoring the patient's progress. She has an extensive background in clinical cardiology nursing, both inpatient and outpatient practice. The researcher has served as a clinical instructor for baccalaureate and graduate nursing programs in the geographical area where the research is being conducted.

## CHAPTER IV

### RESULTS

The purpose of this descriptive study was to investigate the relationship of self-care behaviors (as assessed by four variables) with education in the four knowledge domains for adults with congenital heart disease (CHD). Questionnaires composed of two instruments were completed by adults with CHD at an initial routine clinic visit to ascertain self-care behaviors and knowledge levels. The self-care questionnaire, Exercise of Self-Care Agency (ESCA), is based on *Orem's Framework of Self-Care*. The Leuven Knowledge Questionnaire assesses how well adults with CHD understand their heart defect, treatment, and preventive measures. A total of 30 participants completed the questionnaire, which took approximately 20 minutes in the clinic prior to their initial visit with a cardiologist, fellow or resident, and nurse practitioner.

Two statistical analyses were performed. The first analysis resulted in overall knowledge and self-care levels. Frequencies and means were calculated for each of the subscales individually and for the total. The second analysis resulted in correlation coefficients that examined the relationship between each of the self-care subscales and individual knowledge domains separately and collectively. Pearson product-moment correlation coefficients were calculated between the ESCA subscales and the Leuven domains separately and for the total. In addition, Pearson product-moment correlation coefficients were calculated for the knowledge scores on the Leuven Knowledge Questionnaire with the following demographics: age, gender, ethnicity, income, and level of education.

A summary of the overall ESCA scores and Leuven knowledge scores is presented before the results of the analyses. This chapter is organized according to overall scores and the five research questions. Results are presented for each of the five research questions and summary of results ends the chapter.

#### Overall Scores

For the ESCA, total scores ranged from 85 to 120 out of a possible total score of 140. The means and standard deviations of the ESCA are given in Table 5. The majority of the responses (80%) were at the moderate self-care level (n=24). The other 20% were at the high level of self-care (n=6). No participants scored at the low level. The current study differed from Callaghan (2006), who reported a mean of 89.50, standard deviation of 19.36 that ranged from 20 to 132 (n=356). Using a smaller sample size (n=30), this study yielded a mean of 99.60 and standard deviation of 8.11.

Table 5

<i>Means and Standard Deviations of Exercise of Self-Care Agency</i>		
Scale	Mean	SD
Total	99.60	8.11
Self-worth	41.70	3.16
Initiative	37.43	7.71
Knowledge	13.77	2.46
Passivity	6.07	5.45

For the Leuven knowledge questionnaire, 77% of the scores were in the moderate range (n=23), 17% were in the poor range (n=5), and 7% were in the



adequate range (n=2). Table 6 gives the results of overall Leuven knowledge scores.

The majority of the participants had scores in the moderate range, with only two participants having adequate scores.

Table 6  
*Leuven Knowledge Questionnaire Scores*

Scale	Overall Score (f)	Percent of Total (%)
Poor <.50	5	16.6
Moderate .50-.80	23	76.7
Adequate >.80	2	6.6

For the Leuven Knowledge Questionnaire, the percentage correct was 56% with a range of the subscales of .23 for reproduction to .67 for knowledge (see Table 7). Upon review of individual items, two items in the domain of knowledge of heart disease scored in the lowest levels (less than 30% of the respondents answering correctly): symptoms occurring if your heart condition gets worse, 30%, symptoms for which you should call your cardiologist immediately, 23%. Seventy percent of participants knew the name of their defect, and 53% were able to identify it on the diagram for the domain of knowledge. In the domain of measures to prevent complications, 26% responded correctly to the question of what is endocarditis. Responses for the typical symptoms of endocarditis and for behaviors that increase the risk of endocarditis were lowest, both at 17% correct. In the domain of physical activities, there were no responses below 30%. In the domain of reproduction and contraception, 17% responded correctly to chances of your child having CHD. Among women, 23% responded correctly about contraceptive use and safety.

Table 7

<i>Percentage Correct for Leuven Knowledge Questionnaire</i>	
Leuven Knowledge Questionnaire	Percent Correct
Total	56
Knowledge	67
Preventive Measures	54
Physical Activities	61
Reproduction	23

#### Research Question 1

To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of heart disease and treatment in adults with CHD?

Using the total score, there was no correlation between knowledge of heart disease and treatment with self-care ( $r = -.04$ ). Separately, there was only one slight correlation between knowledge of heart disease and treatment and knowledge and information seeking ( $r = .12$ ). Table 8 gives the correlation matrix for self-care subscales for total scores and separately related to each domain. The correlation coefficients ranged from  $-.05$  to  $.12$ , which are not statistically significant.

#### Research Question 2

To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and

collectively related to the knowledge domains of measures to prevent complications in adults with CHD?

Table 8

*Pearson Product-Moment Coefficient Correlation of Leuven Knowledge Questionnaire and Exercise in Self-Care Agency*

Leuven Knowledge	<u>Exercise in Self-Care Agency</u>				
	Total	Self-worth	Initiative	Knowledge	Passivity
Total	.04	-.03	-.11	.31	.09
Knowledge	-.04	-.04	-.05	.12	-.01
Prevention	.02	-.06	-.17	.28	.18
Physical Act	.08	.06	-.11	.19	.15
Reproduction	.15	.00	.13	.37	-.14

Collectively, there was no correlation between self-care behaviors and measures to prevent complications ( $r=.02$ ). There were slight correlations between measures to prevent complications and knowledge and information seeking ( $r=.28$ ) and passivity ( $r=.18$ ). There was a slight negative correlation between measures to prevent complications and initiative and responsibility ( $r= -.17$ ). None of the correlation coefficients are statistically significant.

### Research Question 3

To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of physical activities in adults with CHD?

Overall there was a slight correlation between self-care behaviors and physical activities ( $r=.08$ ). There were slight correlations between physical activity and initiative and responsibility ( $r= -.11$ ), knowledge and information seeking ( $r=.19$ ), passivity ( $r=.15$ ), and self-worth ( $r=.06$ ). None of the correlation coefficients were statistically significant.

#### Research Question 4

To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of reproduction and contraception in adults with CHD?

Collectively, there was a slight correlation between self-care and reproduction and contraception ( $r=.15$ ). There was a moderate overall correlation between reproduction and contraception and knowledge and information seeking ( $r=.37$ ). There was a slight correlation between reproduction and contraception and initiative and responsibility ( $r=.13$ ). There was a slight negative correlation between reproduction and contraception and passivity ( $r= -.14$ ). None of the correlation coefficients were statistically significant.

#### Research Question 5

To what extent does the knowledge in the four domains of congenital heart disease vary by the demographics of age, gender, ethnicity, income, and level of education?

There was a moderate correlation between knowledge in the four domains of congenital heart disease and age ( $r=.50$ ). There was moderate correlation between

knowledge in the four domains of congenital heart disease and income ( $r=.54$ ). There were slight correlations between knowledge in the four domains of congenital heart disease and gender ( $r=.20$ ). There was a slight correlation between knowledge in the four domains of congenital heart disease and level of education ( $r=.20$ ). There was a slight negative correlation between knowledge in the four domains of congenital heart disease and ethnicity ( $r= -.16$ ). Ethnicity was collapsed into two categories: European American and all others because of the small numbers in the categories.

#### Additional Findings

Reviewing the written comments on the Leuven questionnaire, female participants expressed concerns about the impact of pregnancy on their overall health and sought multiple resources to educate themselves about family planning. The relationship between age and knowledge is .49 and a moderate relationship between income and knowledge scores of .54. The relationship between ages of 30 to 45 years and income level had a moderate influence on knowledge score. Younger participants were more likely to bring a parent to the initial visit and allow them to respond to medical history questions, which resulted in the younger participants having lower scores. The same relationship between income and knowledge indicates that those with less income have less knowledge than those with higher income and more resources.

There was an additional finding by female participants regarding concerns of pregnancy and heart disease. They often reported feelings of anxiety about this subject because many were told they could never have children or the subject was not addressed by pediatric cardiologists. Younger participants were fearful of dating and

marriage because of their heart condition. Participants did indicate that they would like more information about family planning and pregnancy and would like to discuss it with a provider during their clinic visit.

### Summary

This study investigated the relationship between self-care behaviors and knowledge levels in four domains among adults with CHD. The majority of the participants in this study had overall scores at the moderate level for both ESCA (80%) and Leuven (76%). When reviewed by domains, participants were less knowledgeable about when to seek medical advice for symptoms of worsening heart condition or when to contact their cardiologist immediately. Participants were less aware of symptoms and behaviors to prevent endocarditis. Both females and males were unable to correctly answer the chances that their child could be born with a possible heart defect

Between the four subscales of the ESCA and the four domains of the Leuven questionnaire, slight correlations existed for the subscale of knowledge and information seeking within the domains of knowledge of heart disease, measures to prevent complications, and physical activity. These results were not statistically significant at the .05 level. There was a moderate relationship between reproduction and contraception and knowledge and information seeking. There was a moderate relationship between knowledge in the four domains of congenital heart disease for age and income, which was statistically significant at the .05 level.

CHAPTER V  
SUMMARY, LIMITATIONS, DISCUSSION, RECOMMEDATIONS, AND  
CONCLUSIONS

This descriptive study was an analysis of self-care behaviors assessed by four variables with education in the four knowledge domains for adults with congenital heart disease (CHD). A total of 30 participants were seen at the Adult Congenital Heart Disease (ACHD) clinics for the first time at a large university medical center in Northern California. Ages ranged from 18 to 45 years. All contacts with participants' transpired from June 2009 through October 2009. The findings of this study are presented according to research questions, implications are addressed for practical importance and future research recommendations.

Summary

Research question one was to what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of heart disease and treatment in adults with CHD?

Results for research question one found correlation coefficients ranged from -.05 to .12 and were not statistically significant. There were no correlations between self-care and knowledge of heart disease and treatments. There was a slight correlation between knowledge of heart disease and information seeking.

Research question two was to what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of measures to prevent complications in adults with CHD?

Regarding research question two, none of the correlation coefficients were statistically significant. For total scores there were no correlations between self-care behaviors and measures to prevent complications. There was a slight correlation preventive measures and information seeking and a slightly negative correlation between preventive measures and initiative and responsibility.

Research question three was to what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of physical activities in adults with CHD?

For research question three, none of the correlation coefficients were statistically significant. There were slight correlations for total score and physical activities, and between initiative and responsibility, knowledge and information seeking with physical activities.

Research question 4 was to what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of reproduction and contraception in adults with CHD?

Regarding research question four, none of the correlation coefficients were statistically significant. Total scores between self-care and reproduction and



contraception were moderate. There was a slight correlation between reproduction and contraception and knowledge and information seeking and a slight negative correlation between reproduction and contraception and passivity,

Research question 5 was to what extent does the knowledge in the four domains of congenital heart disease vary by the demographics of age, gender, ethnicity, income, and level of education?

Concerning research question five, there was a statistically significant relationship between knowledge in the four domains of CHD with age and income. Correlation coefficients were moderate between knowledge in the four domains of CHD with age and income. There were slight correlations between knowledge in the four domains of CHD with gender and level of education. There was a slight negative correlation between knowledge in the four domains of CHD with ethnicity.

#### Limitations

There are several limitations to this study. First, this study used a small convenience sample of 30 patients from a single institution in Northern California, limiting the generalizability of the findings to other populations. A sample of convenience was chosen because participants met inclusion criteria, was available and agreed to participate, and the institution supported the study. Second, the majority of the participants were European American (n=20), five Hispanic Americans, three Asian Americans, one mixed ethnicity, and one African American. Although minorities were represented, African Americans were underrepresented. All participants had to carry medical insurance and over one-fourth reported incomes over \$60,000.

Second, survey research is self-reporting. Surveys are structured to encourage honesty and participation is voluntary. In this survey, only two patients approached to participate declined, and those who completed the survey did so willingly. One advantage of this survey research was that respondents believed they had something to contribute to adults with CHD, thus encouraging truthful responses. For these respondents, they were assured that there were no right or wrong answers. Surveys were completed with no missing responses. Another issue facing surveys is obtaining accurate information, which is similar to the same problems with everyday communication. Participants' responses may be what they think the researcher wants to hear and not how they necessarily feel.

The present population-based study of adults with congenital heart defects included primarily residents of Northern California within a single institution. In this study, the questionnaires were self-administered and completed prior to the office visit. Potentially, patients may have been anxious before meeting a new physician and could have been distracted while answering questions. Although self-reported measurements are subjective, they can reveal behaviors and feelings that have been experienced in real situations (Northrup, 1996). The most basic way to determine whether respondents give honest answers to survey questions is to use a validation measure external to the interviewing situation to verify respondents' answers. Assignment of patients to the clinics was not randomized. For this study, answers for the Leuven Questionnaire by participants in this study were validated through the review of their medical records.

There was little correlation between self-care and knowledge levels in adults with CHD. The possibility could exist because they evaluate different aspects of patient care. Although both are applicable to ongoing patient care, the Leuven addresses daily activities pertinent to heart disease, whereas the Exercise in Self-Care Activity (ESCA) is a Likert scale that may be influenced by a person's self-image. Because the Likert scale is an ordered, one-dimensional scale on which respondents choose one option that best aligns with their view, responses may vary depending upon life circumstances. Problems can occur if participants become influenced by the way they have answered previous questions or are forced to make extreme choices.

### Discussion

The findings of this study add to the increasing body of knowledge in the area of knowledge and self-care among adults with CHD. This study also identified gaps in knowledge in young adults with CHD. Although there are no published studies using the four domains of knowledge within a single study, the findings of this study are congruent with previous works using different aspects of the knowledge domains. The findings are discussed with respect to each research question.

### Research Question 1

To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of heart disease and treatment in adults with CHD?

In accordance with previous studies (Chessa et al. 2005, Dore et al. 2002, Moons et al. 2001), the responses were similar with poor understanding. The domain of knowledge about heart disease contributes to self-care issues of daily life that require knowledge about their state of health and physical and social environments, as well as insights into motivation. This lack of knowledge may lead to failure to interact with health-care providers as well as failure to participate in medical care and periodic evaluations of cardiac status.

In comparison with Carroll (1995), ECSA scores were higher among an older population that ranged from 65 to 87 years. The population in this study was younger with ages ranging from 18 to 45 years. Self-care is likely a skill that is developed over time. Many of the young participants in this study continued to rely on parents to participate in their care. In this study, participants sought information in areas that they perceived as important but lacked knowledge of the areas providers view as essential to care. It may be that more education needs to be delivered at the pediatric level, ensuring that as young CHD patients mature, they will have information specific to their heart disease and potentially recognize and prevent cardiac complications from occurring.

#### Research Question 2

To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of measures to prevent complications in adults with CHD?

There were three questions in the domain of measures to prevent complications that were poorly understood regarding endocarditis. When results of this study for the domain of heart disease and treatments were compared with Chessa et al. (2005), Dore et al. (2002), and Moons et al. (2001) studies, responses were similar with poor understanding for endocarditis. In similar studies, the researchers (Cetta & Warnes, 1995; Kantoich et al., 1997) reported poor understanding of endocarditis preventions notwithstanding a few of the participants having endocarditis. In the current study, participants had good understanding about the harmful effects of smoking and drinking. The concern for endocarditis prevention is well established among CHD cardiologists. Currently, controversy exists over the new American Heart Association and American College of Cardiology (AHA/ACC, 2008) guidelines for antibiotic prophylaxis, and many physicians continue to recommend oral antibiotics for dental procedures. Patients often will report confusion over which recommendations to follow. In this study, participants correctly reported needing antibiotics before dental procedures but did not document it in under current medications on the questionnaire. Clinically, many patients do not associate prophylaxis medications with those taken daily, but these medications do need to be included in medication profiles.

The results of this study suggested that participants were knowledgeable in the domain of heart disease and treatments but poorly understood the symptoms of worsening heart conditions or when to call their cardiologist for medical advice within the domain.

This study also reported good understanding of need for seasonal flu shots, which may be due to heightened awareness for the Fall 2009 flu season. The preventive measures domain plays an active role in health maintenance because many of the areas within this domain pertain to routine health and not cardiac health only. Younger patients demonstrated passive behavior allowing their parents to answer for them. There was a slight correlation between passivity and measures to prevent complications. In view of this passive behavior, ACHD patients may benefit from strategies that could encourage them to be their own health-care advocates.

The population in the current study was younger and accustomed to using computers and cell phones. Younger patients may be more receptive to communicating this way if they encounter a problem instead of calling the doctor's office. The institution where the research study was conducted lags in this technology for patient communication. To date, there are institutions where a patient can email their doctor and get a response within 72 hours. The response then becomes part of the patient's medical record. At the institution where the research was conducted, this service was not available; however, patients can informally email a physician at his or her institutional email address.

### Research Question 3

Are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of physical activities in adults with CHD?

The findings of this study suggested that adults with CHD had good understanding of the knowledge domain of physical activities in three questions.

These findings were consistent with Chessa et al. (2005) and Moons et al. (2001) with equal understanding. The majority of the participants in this study were college graduates and half held professional jobs. The risk imposed by manual labor was not an issue in this population that differs from previous studies. Higher incomes could be attributed to the expense in relocating to Northern California and the need for higher income-level employment.

Research question 3 addressed the manner that patients were instructed regarding physical activities 20 years ago. Most patients were told “You can’t do anything, you can’t play sports, you need to sit on the bench, and you can’t go to P.E.” Now, as they are seen in ACHD clinics, they are told “You can get on a treadmill, and have an exercise prescription specific for your heart disease.” Patients often exhibit confusion because previously they were not allowed to participate in exercise programs.

#### Research Question 4

To what extent are self-care behaviors (self-worth, initiative and responsibility, knowledge and information seeking, and passivity) separately and collectively related to the knowledge domain of reproduction and contraception in adults with CHD?

The results of this investigation suggested poor understanding with regard to potential risk of having a child with CHD. Both males and females were unable to correctly respond to this question. There also was poor understanding among female participants regarding a safe method of birth control. Although not below the poor level of understanding (30% or below), 67% of females were not aware that

pregnancy could potentially cause a decline in cardiac function. When responses for this study were compared with Moons et al. (2001), they were similar for genetic influence of CHD on offspring, safe contraceptive methods, and potential decline of health during pregnancy. The majority of female participants in this study were of child-bearing age.

Pregnancy in a woman with CHD affects the mother and her fetus. Today, with successful cardiac surgery, the risk of pregnancy is reduced in women with CHD. As a result, women who previously had been unable to bear children or who would not have reached reproductive age are now seeking pre-pregnancy counseling after reparative cardiac surgery. This is a serious undertaking and involves coordinated care between the obstetrician and cardiologist who ultimately are responsible for the welfare of mother and fetus.

Pregnancy is a high-risk undertaking and not to be taken casually. It is not uncommon for teenage girls to inquire whether they can *have* children, not to get pregnant, but if the possibility exists with their heart condition. Pediatricians do not discuss pregnancy because it is not a subject commonly discussed with pediatric patients.

#### Research Question 5

To what extent does the knowledge in the four domains of congenital heart disease vary by the demographics of age, gender, ethnicity, income, and level of education?

The findings of this study suggested that gender, ethnicity, and education level had little association with knowledge levels in adults with CHD. There was a



moderate relationship with age and level of income on knowledge levels. Unique to this study was half of the participants were professionals and over one-fourth had highest level of income. This group of participants could have potentially had the means to obtain higher levels of medical care and seek a second opinion.

The participants in this study were unique in that half of them were professionals, had higher incomes, and were married. Much of the affluence in demographics pertains to the cost of living in the San Francisco Bay Area. There was a moderate correlation between heart disease and income and age that was statistically significant. Participants with higher incomes and resources demonstrated higher levels of knowledge in the study. The Internet has changed patient care for everyone. For the clinician, time during clinic visits can be spent clarifying misinformation obtained from the Internet. Often, patients will present with preconceived ideas of what procedures can be done and are prepared to debate with their own research. Often, the information may not all be factual but represents a beacon of hope in their care. Clinicians need to be sensitive to patients' individual needs.

#### Recommendations for Future Research

The findings of this study have implications for future nursing research. This study used a questionnaire approach to better understand the relationship of self-care behaviors (as assessed by four variables) with education in the four knowledge domains for adults with CHD. Because there were no previous studies examining self-care and education in the four domains, the findings of this study could be used as a foundation for further research in self-care and knowledge for adults with CHD.

More broadly, ages could be expanded to include teenagers to 55 years of age and more minorities should be studied. A better understanding about how teenagers transition to adult cardiac care and their perceived health-care needs may have implications for nurse practitioners, physicians, and future research.

Further research could establish if educational interventions over time would influence self-care and knowledge levels in adults with CHD. Additional research might utilize an alternative tool to measure self-care. This study provided a better understanding of self-care and how knowledgeable adults with CHD are about their heart defect in the four domains.

#### Implications for Practice

The findings of the current research identified a gap between what health-care providers think is important and what patients think is important regarding their congenital heart disease. As identified, the focus needs to be on younger patients and preparing them for adulthood. Younger patients need to be encouraged to be less passive about their self-care and are amenable to the use of technology for this education.

Health-care providers consider recognizing the signs and symptoms of worsening heart condition vital to care. In the current study, participants had poor responses to recognizing symptoms of worsening heart condition and when to contact their cardiologist. One suggestion may be presenting findings from the current research to pediatricians and collaborating with them in developing educational materials for young CHD patients. Based on responses and the comprehensiveness of

the Leuven questionnaire, the format of the questionnaire may be used to develop education tools for patient care that would include the four domains of knowledge.

In this study, the Leuven Knowledge Questionnaire was used and included the four domains of knowledge within a single study. The original author scored moderate knowledge as .50 to .80. Although 77% of responses were at the moderate range (n=23), this response is lower given the importance of disease specific health-care knowledge for adults with CHD. One consideration may be to adjust the scoring ranges as >.85 adequate, .65 to .85 moderate, and <.65 poor.

This study identified that counseling prior to conception is an area of much needed future research and involves a multidisciplinary approach involving cardiologists and obstetricians for women with congenital heart disease contemplating pregnancy.

### Conclusions

Six key findings emerged from this study. First, the use of the Leuven Knowledge Questionnaire provided adequate assessment in the four domains. Participants scored at the adequate and moderate levels overall. The results were consistent with previous research both separately and collectively. The use of this questionnaire can be replicated for further research using a larger population.

Second, participants were not aware of the signs and symptoms that would represent a worsening heart condition and were not able to recognize symptoms of endocarditis. Lack of knowledge in the domain of measures to prevent complications is of concern because patients need to be aware of when to seek medical attention to prevent potential complications from occurring.

Third, although participants had high and moderate levels of self-care using ESCA scale, these levels of self-care were not associated with knowledge levels. The ESCA scale is a useful tool and may be beneficial with educational programs using repeated measures.

Fourth, pregnancy is an issue for females with CHD and their choice to have children. The findings from this study suggested a lack of knowledge regarding the burden of pregnancy on cardiac function with CHD. Young female patients need to be fully aware of the ramifications of family planning and the intense surveillance when undergoing pregnancy.

Fifth, the current study was the first in the US using the Leuven questionnaire in a single study and has implications for clinical practice. The young adults with CHD who were seen in adult cardiology were not adequately informed of their disease and measures for self-care. This study reported a discrepancy between being able to describe a cardiac defect (knowledge) and being able to recognize symptoms of a worsening heart condition (preventive measures). Telling a person about their disease does not ensure that they will be able to understand specific measures of self-care strategies and how to implement them.

Sixth, a structured plan to help patients transition from pediatric to adult CHD care is needed for this population. There are opportunities for advanced practice nurses to be involved in transition programs to help with individual patient education regarding cardiac diagnosis and specific health behaviors.

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APPENDIX A

ADULT WITH CONGENITAL HEART DISEASE QUESTIONNAIRE

# Self-Care & Heart Disease Survey

Thank you for agreeing to complete this survey.

The survey should take about 20 minutes or less to complete.

Do the best you can in responding to each of the questions. Remember that all of this information will be held in confidence.

There are eight sections.

The first section is NOT specific to patients with congenital heart disease, but is an established survey that has been used many times in the past to look at how patients take care of themselves in general.

The rest of the survey is specific to patients with congenital heart disease.

Please circle all responses or write in information to the right of the questions.

**Part Three: Knowledge About Your Heart Disease and Treatment**

<p>1. What is the name of your heart defect?</p>	<p>Don't know</p>	
<p>2. Indicate with circles on the diagram where your heart defect is located (circle all that apply).</p>	<p>Don't know</p>	

3. How often should you see your cardiologist (circle one)?	Every 6 months	Every year	Every 2 years	Every 5 years
	Only as needed	Other:		Don't know
4. What is the main purpose for these follow up visits?				Don't know
5. Do you need to continue to see your cardiologist even when you are feeling healthy or he/she is satisfied with how you are doing?	Yes	No	Don't know	
6. How has your heart condition been treated to date (circle all that apply)?	Surgery	Medications	No treatment	Don't know
If surgery, list procedures, hospital, year:				
Have you had any procedures in the cardiac catheterization or Electrophysiology lab?	Yes	No	Don't know	
If yes, list procedures, hospital, year:				

7. Are you currently taking any medications?	Yes	No	Don't know		
<p>If you are taking medications for your heart condition, please fill in the following table:</p>	Name of medication	Dose	Times per day	Reason	Side effects
8. Are you supposed to follow a special diet?	Yes	No	Don't know		
<p>If you answered yes above, please tell us the type of diet (circle all that apply):</p>	Low salt	Low fat	Fluid restriction	Don't know	
	Low sugar	Other:			



9. Which symptoms can occur if your heart condition gets worse (circle all that apply)?	Fever	Vomiting	Diarrhea	Fast heart rate
	Chest pain	Dizziness	Fainting	Swollen hands or feet
	Loss of appetite	Feeling more tired than usual	Shortness of breath with activity	Don't know
10. For which symptoms should you call your cardiologist immediately (circle all that apply)?	Fever	Vomiting	Diarrhea	Fast heart rate
	Chest pain	Dizziness	Fainting	Swollen hands or feet
	Loss of appetite	Feeling more tired than usual	Shortness of breath with activity	Don't know

**Part Four: Prevention of Complications**

1. What is endocarditis?					Don't know
2. Which are the most typical symptoms of endocarditis (circle all that apply)?	Fever lasting more than 3 days	Chest pain	Palpitations	Painful urination	
	Dizziness	Feeling more tired than usual	Swollen gums	Don't know	
3. Which of the following can increase your risk of getting endocarditis (circle all that apply)?	Needle contamination (street drugs)	Smoking	Bacteria from skin infections	Dental abscesses	
	Sexual activity	Poor nail and skin care	Body piercing and tattooing	Don't know	
4. How often should a patient with congenital heart disease have a dental check-up (circle one)?	Every 6 months	Every year	Every 2 years	Every 5 years	
	Other			Don't know	
5. Should you take antibiotics before every visit to the dentist?	Yes	No		Don't know	
6. Should you clean your teeth at least once a day?	Yes	No		Don't know	
7. Are smoking and drinking alcohol more harmful for people with congenital heart disease than for other people?	Yes	No		Don't know	

<b>8. Is the flu shot important for people with congenital heart disease?</b>	<b>Yes</b>	<b>No</b>		<b>Don't know</b>
<b>9. Is maintaining good physical fitness important for someone who has congenital heart disease?</b>	<b>Yes</b>	<b>No</b>		<b>Don't know</b>

<b><i>Part Five: Physical Activity</i></b>
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<b>1. Do you have any limitations to physical activity?</b>	<b>Yes</b>	<b>No</b>		<b>Don't know</b>
<b>If yes, what are the limitations?</b>				
<b>2. Can you take part in competitive sports that require daily training?</b>	<b>Yes</b>	<b>No</b>		<b>Don't know</b>
<b>3. With your congenital heart disease, do you have any restrictions on the type of occupation/work that you can choose?</b>	<b>Yes</b>	<b>No</b>		<b>Don't know</b>

<b><i>Part Six: Reproduction and Contraception</i></b>
--

1. What is the chance that your children will have congenital heart disease (circle one)?	The chance is not increased	The chance is slightly increased	The chance is moderately increased	The chance is greatly increased	Don't know
For women only: 2. Which contraceptives are safe for you to use in light of your congenital heart disease (circle all that apply)?	Contraceptive pill	Intrauterine device	Barrier method	Don't know	
For women only: 3. During pregnancy, are you at risk of developing worsening heart problems?	Yes	No		Don't know	

<b>Part Seven: Social History</b>
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1. Do you smoke?	Yes	No		
If you smoke, how many years have you been smoking?				
If you smoke, how many cigarettes do you smoke per day?				
2. Do you drink alcohol?	Yes	No		
If you drink alcohol, how many years have you been drinking?				
If you drink alcohol, how often do you drink?	Daily	Weekly	Monthly	Other:
If you drink alcohol, how much do you drink each time?	1-2 drinks	3-4 drinks	5 or more drinks	
3. Do you use illegal or "street" drugs?	Yes	No		
If yes:	How often (daily, weekly, monthly, other)?		How many years?	
4. Are you sexually active now or have you been in the past?	Yes	No		
If yes, answer 5-7 below:				
5. Do you use protection to prevent pregnancy?	Always	Sometimes	Never	
6. Do you use protection to prevent sexually transmitted diseases (i.e. condoms)?	Always	Sometimes	Never	
7. Do you currently have multiple partners?	Yes	No		

<b><i>Part Eight: Information About You</i></b>
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<b>Date of birth:</b>				
<b>Gender</b>	<b>Female</b>		<b>Male</b>	
<b>Race (optional)</b>				
<b>Religion (optional)</b>				
<b>Primary language (optional)</b>				
<b>Highest completed level of education:</b>	<b>High School</b>	<b># of years:</b>	<b>Graduated:</b> Yes      No	
	<b>College</b>	<b># of years:</b>	<b>Graduated:</b> Yes      No	
	<b>Graduate School</b>	<b># of years:</b>	<b>Graduated:</b> Yes      No	
<b>Occupation:</b>				
<b>Income level:</b>	<b>&lt; \$30,000</b>	<b>\$31,000- \$50,000</b>	<b>\$51,000- \$70,000</b>	<b>&gt; \$70,000</b>
<b>Place of residence:</b>	<b>With parents</b>	<b>Alone</b>	<b>Roommate</b>	<b>Spouse</b>
		<b>Significant other</b>	<b>Other:</b>	
<b>Are you expecting any of the above information to change in the next six months?</b>	<b>Yes</b>		<b>No</b>	
	<b>If yes, please explain:</b>			

*This concludes the survey. Thank you for your time and confidential information.*

APPENDIX B  
PATIENT LETTER

Dear Patient:

I am conducting a study assessing the influence of self-care on knowledge levels among adults with congenital heart disease. This is toward completion of my doctoral studies in the School of Education at the University of San Francisco. Your involvement in this study will help inform health care providers of educational needs when caring for adults with congenital heart disease. I am requesting for you to volunteer about 45 minutes or less of your time to complete a survey.

Participation in this study is voluntary. If you choose to participate, please complete the attached survey and consent and return it in the self-addressed envelope provided. If you choose not to participate, please return the self-addressed postcard. If you have additional questions about the study or wish to obtain results, you may call me at XXX XXX-XXXX or e-mail me at xxxxxxxxxxxx. Approval for this study has been obtained from the director of the Adult Congenital Heart Disease Practice, the XXXXXXXXXXXXXXXXXXXX Review Boards, and the XXXX Committee on Human Research. Thank you for your interest in and contribution to my research on knowledge levels in adults with congenital heart disease.

Sincerely,

Valerie Bosco, RN, MS, FNP-C



APPENDIX C  
PATIENT CONSENT

## Survey of Influence of Self-Care on Knowledge Levels among Adults with Congenital Heart Disease

### **Purpose and Background**

Valerie Bosco, a graduate student in the School of Education at the University of San Francisco, is conducting a survey about the influence of self-care on knowledge levels in adults with congenital heart disease (CHD). Adults with CHD have not participated in transitional care programs and are expected to know the fundamentals of their disease and measures to prevent complications. The survey is designed help assess patient's illness understanding and self-care behaviors. This information may benefit health care providers to deliver appropriate information during clinic visits. I am being asked to participate because I am part of the patient population of adults with CHD at XXXXXXXXXXXXXXXX.

### **Procedures**

If I agree to be a participant in this study, the following will happen:

1. The researcher will mail me a survey letter before my clinic visit. A follow-up phone call will take place two to three days prior to my visit to discuss my participation.
2. The survey should take about 45 minutes or less of my time.
3. I understand that my participation is on a voluntary basis, and there will be no penalty for not participating. Patients who elect not to participate may acknowledge their decline over the phone or at the clinic visit.

### **Risks and/or Discomforts**

4. It is unlikely that any of the items on the questionnaire will make the participants feel uncomfortable, but they are free to decline to answer any question.
5. Participation in research may mean a loss of confidentiality. Study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from the study. Study information will be coded and kept in locked files at all times. Only Valerie Bosco and study Staff Member will have access to the files.

### **Benefits**

There will be no direct benefit to patients from participating in this study. The anticipated benefit of this study is a better understanding of how adults with CHD understand their condition, exercise self-care, and where the gaps of knowledge exist. A summary of my results will be provided to patients who elect to participate.

### **Costs/Financial Considerations**

There will be no financial costs to me as a result of taking part in this study.

### **Reimbursement/Compensation**

There is no reimbursement or compensation for participating in this study.

### **Questions**

If I have any questions or comments about participation in this study, I should first talk with the study researcher, Valerie Bosco, RN, MS, FNP-C at XXX-XXXX. If for some reason I do not wish to do this, I may contact the IRBPHS at the University of San Francisco, which is concerned with protection of volunteers in research projects. I may reach the IRBPHS office by calling (415) 422-6091 and leaving a voicemail message, by e-mailing [IRBPHS@usfca.edu](mailto:IRBPHS@usfca.edu), or by contacting the XXXXXXXXXXXXXXXXXXXXXXXX.

### **Consent**

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline at any time during the study. My decision as to whether or not to participate in this study will have no influence on my present or future status with the XXXXXXXXXXXXXXXXXXXXXXXX.

My signature below indicates that I agree to participate in this study.

Subject's signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_

Date \_\_\_\_\_

APPENDIX D  
DIRECTOR APPROVAL

DATE: October 28, 2008

Dear Dr. XXXXXXXXX:

This letter confirms that you have been provided with a brief description of my study concerning self-care and knowledge levels among adults with congenital heart disease at the XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX. Your signature below indicates that you give your consent for me to request volunteer participation of patients that are part of the Adult Congenital Heart Disease. Patients will be contacted by phone and those who agree to participate will be consented and complete the survey instrument during a routine clinic visit.

Participation will be entirely voluntary and results will be kept confidential and anonymous.

Please feel free to contact me if you have any further questions about this project.

Sincerely,

Valerie Bosco, RN, MS, FNP-C

M.D. signature