

Adults with Congenital Heart Disease
And Family Planning
Decisions

by

KATHRYN A. OSTEEN

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Dedication

I would like to dedicate this dissertation to all of the women I spoke with who gave of their time and allowed me to listen to their story.

I just wanted to thank you for taking the time to speak with me today, and for allowing me to go on and on. When I hung up the phone I felt so normal. I have never felt this normal before and it's a really good feeling. I feel like the scarlet letter has been ripped away from my arm and that I have peace. I can't explain it. I feel empowered. I just wanted to thank you and let you know that you are really helping women in a way you may not realize. Thank you

Anonymous

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Abstract
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Kathryn Osteen PhD

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Supervising Professor: Donelle Barnes

Adults with CHD are living longer into adulthood than ever before, which increases the possibility of childbearing. Researchers have focused on the physiology and risks associated with contraception and pregnancy, but miss the personal stories surrounding these decisions. The adult with CHD has concerns about contraception, pregnancy, childbirth, and passing CHD on to offspring. The purpose of this qualitative narrative study is to describe the personal stories of adults with CHD and their family planning decisions.

Narrative inquiry, guided by the Roy adaptation model, was chosen for this study because it is appropriate to describe the reproductive decisions of adults with CHD. Eligible participants included adults between the ages of 18 and 49 diagnosed with mild, moderate, or severe CHD, living in the United States (US), and English speaking. A single in-depth, semi-structured interview was

completed. After transcription of the interview, the researcher and a consultant with qualitative experience performed structural and thematic analysis. Interviews continued until saturation of themes was obtained.

The final sample included 17 adult females, between 24 and 41 years of age, living in 10 U.S. states. The majority of participants were White, married, and had severe types of CHD. Family planning decisions occurred in phases through their lives, from becoming sexually active to giving birth. The phases included contraception, discovering childbearing options, deciding if/when to have children, pregnancy, and feelings about family planning decisions.

Family planning is an ongoing process for adults with CHD. They desire more information regarding family planning issues and decisions. To maximize the health of the adult with CHD, family planning should be incorporated into primary care. Greater understanding of adult experiences with family planning will be useful in future educational efforts for the adult with CHD and their healthcare providers.

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Chapter 1

Introduction

The leading cause of infant death in the United States is congenital malformations. Cardiovascular congenital defects affect 1% of all infants born in the United States regardless of race (Hoffman & Kaplan, 2002; Xu, Kochanek, & Tejada-Vera, 2009). Surgical advances and innovations in healthcare have given the infant with congenital heart disease (CHD) the opportunity to live longer and into adulthood (Gilboa, Salemi, Nembhard, Fixler & Correa, 2010). Adults with CHD have different physical, social, and psychosocial concerns than children or adolescents with CHD (Kovacs, Sears, & Saidi, 2005; Kovacs & Verstappen, 2011; Moons, Van Deyk et al., 2009; Saidi & Kovacs, 2009). Health issues of the adult with CHD include quality of life, social factors, physical issues, and family planning (Kamphuis et al, 2002; Moons, Van Deyk, De Geest, Geillig, & Budts, 2005; Moons, Van Deyk, Marquet et al., 2005; Perloff, 1991). This chapter will include a description of the background and significance of the adult with CHD population and their health issues. An overview of Roy's Adaptation Model will be described, as the model will be used to guide this qualitative study. The purpose, research questions, and assumptions of the study will also be included in the chapter

Background and Significance

Cardiovascular congenital defects include both treatable or ultimately fatal structural, and functional heart conditions (Gilboa et al., 2010). In 2004, the total cost of hospital stays for all congenital birth defects was 2.6 billion. The same year the highest aggregate cost for hospital stays in the United States, about 1.4 billion dollars, was among cardiovascular birth defects. The mean cost of hospital stays for all cardiovascular birth defects was 29,600 dollars. Of these reported hospital stays, 50.9 percent were male, with a mean age of 19.8 years. In 2004, 33.5 percent of all congenital defect hospitalizations were circulatory congenital anomalies (Russo & Elixhauser, 2007). From 2004 to 2010, adults accounted for 36.5 percent of CHD admissions (O'Leary, Siddiqi, Ferranti, Landzberg, & Opatowsky, 2013).

Surgical advances in CHD have effectively decreased the overall mortality of the CHD population by 24.1%, permitting infants with CHD to live a longer life (Gilboa et al., 2010; Warnes et al., 2008). The overall decrease in mortality has led to an increased prevalence of adults with CHD. Calculating the prevalence of CHD infants and the likelihood of the infant surviving into adulthood, there is an estimated one million adults living with some form of CHD in the United States (Hoffman, Kaplan, & Liberthson, 2004). In 2000, the prevalence of adults with CHD was 4.09 per 1000, and the overall median age was 40 years. The median age of patients with severe CHD in 1985 was only 11 years (IQR, 4 to 22

years), but by 2000 had increased to 17 years of age (IQR, 10 to 28) (Marelli, Mackie, Ionescu-Ittu, Rahme, & Pilote, 2007).

Healthcare needs of the adult population with CHD are different from the pediatric population (Deanfield et al., 2003). Health issues experienced by adults with CHD include quality of life, social factors, physical issues, transition from pediatric to adult care, and family planning. Adults with CHD may experience the perception of a lower quality of life than those around them due to loss of employment, lower educational levels, and diminished functional status (Kamphuis et al, 2002; Moons, Van Deyk, De Geest et al., 2005; Moons, Van Deyk, Marquet et al., 2005; Perloff, 1991). Adults with CHD may have changes in cardiac rhythm and heart function, and may have other adult diseases such as hypertension and atherosclerosis (Patel & Kogon, 2010; Williams et al., 2006). Family planning issues and concerns by both men and women with CHD are described in the literature (Horner, Liberthson, & Jellinek, 2000; Reid, Siu, McCrindle, Irvine, & Webb, 2008).

CHD patients are living longer into adulthood, which increases the possibility of childbearing and childrearing. Family planning issues include concerns about contraception, pregnancy, childbirth, and passing CHD on to offspring (Horner et al., 2000; Reid, et al., 2008). There is an increased risk associated with certain types of CHD related to contraception, pregnancy, and childbirth. Pregnancy is contraindicated with the presence of certain CHD

malformations, especially with the presence of cyanosis, and should be carefully considered (Deanfield et al., 2003; Perloff, 1991). Family planning issues are not addressed consistently with this population (Sable et al., 2011). The adult with CHD needs family planning counseling because of the increased risk associated with certain types of contraception, and the increased physical cardiac demand associated with pregnancy (Freeman & Foley, 2008; Sable et al., 2011; Stout & Otto, 2007). This study will explore the narrative experience of adults with CHD and family planning decisions.

Theoretical Perspective

Sister Calista Roy first developed the Roy Adaptation Model (RAM) during the 1960's, and has continued to further refine, clarify, and extend the concepts over the years to include societal changes (Roy, 1997; 2009). According to Roy, the purpose of nursing is to understand people in order to maximize health and living to the individual's full potential. The goal of nursing is to promote adaptation. The RAM guides the understanding of how an individual adapts to a situation, and as a result has been used internationally in practice and research (Roy, 2009; 2011; Roy & Andrews, 1999). The RAM has guided both quantitative and qualitative research in numerous settings (Perrett, 2007; Phillips, 2002; Roy, 2011). Roy's Model will guide this qualitative narrative study to explore family planning decisions of the adult with CHD.

The philosophy underlying the RAM includes the assumptions of humanism, veritivity, cosmic unity, and a purposeful universe. First, the humanism assumption identifies the importance of knowing and valuing human experience, and believes that humans behave purposefully (Roy, 2009). Second, veritivity is “the principle of human nature that affirms a common purposefulness of human existence” (Roy, 2009, pp. 28). The next assumption of cosmic unity is a state of being united and connected as one with each other through self-expression or self-identity. The last assumption of a common purposefulness notes that all people co-exist in a purposeful ordered universe and environment. Individuals find meaning through interactions with others, a God figure, and the world (Roy, 2009).

From these philosophical assumptions Roy defines the main conceptual elements of person, adaptation, health, and environment. The person is “an adaptive system with cognator and regulator subsystems acting to maintain adaption in the four adaptive modes: physiologic-physical, self-concept-group identity, role function, and interdependence” (Roy, 2009, pp. 12). Adaptation is defined as the use of conscious awareness and choice to respond and integrate to environmental changes (Roy, 2009). Health is the state of being that reflects the mutual coexistence of person and environment. Environment is the external or internal stimuli, including conditions, circumstances, and influences, that affect the individual’s behavior. The RAM identifies internal and external stimuli as

focal, contextual, and/or residual. Focal stimuli are any internal or external stimulus needing attention. Contextual stimuli are all other stimuli present that affect the focal stimuli. Residual stimuli are environmental factors that affect the situation (Roy, 2009; Roy & Andrews, 1999).

Adaptation level is also considered a stimulus as it affects the ability to have a positive effective response. The adaptation level contains three possible conditions: integrated, compensatory, and compromised (Roy, 2009). The integrated adaptation level involves all the processes, including physical, cognitive, and emotional systems, working together to meet human needs. The compensatory adaptation level is where any human need has been challenged, and the cognator and regulator subsystems are activated. The compromised adaptation level is noted when both the integrated and compensatory processes have failed to adapt. These adaptation levels determine the capacity of the individual to deal with life experiences (Roy, 2009).

The stimuli are channeled through two major internal coping processes called the regulator and cognator systems. These subsystems are internal processes that work together to sustain adaptation to stimuli (Roy, 2009). The regulator subsystem responds to stimuli through physiologic nervous system processes used to maintain individual integrity (Roy, 2009; Roy & Andrews, 1999). This research study is not measuring physical data and therefore inclusion of the regulator subsystem is not appropriate. The cognator subsystem identifies,

stores, relates, and responds to stimuli through four cognitive-emotive channels: perceptual and information processing, learning, judgment, and emotion. The perceptual and information processing channel includes using attention and memory. The learning channel includes the use of reinforcement and comprehension. The judgment channel includes the use of problem solving and decision-making, while the emotion channel includes the use of affective appraisals, or to seek relief from the situation (Roy, 2009; Roy & Andrews, 1999). These concepts are appropriate for this research question to describe how adults with CHD make decisions about family planning.

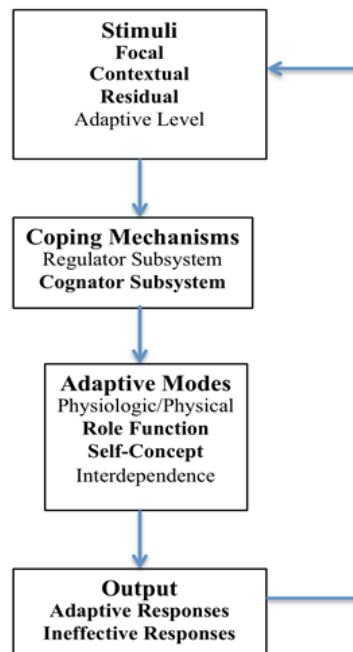
The functioning of the cognator subsystems cannot be observed directly, however the responses of the subsystems are observable using four modes of adaptation (Roy, 2009; Roy & Andrews, 1999). The four modes of adaptation, or ways in which adaptation is manifested are: physiologic-physical, self-concept-group identity, role function, and interdependence. The physiologic-physical adaptive mode is observed by how an individual interacts with the environment to meet basic physical human needs and maintain physiologic integrity. Human needs consist of physiologic process including oxygenation, nutrition, elimination, activity and rest and protection (Roy, 2009; Roy & Andrews, 1999). The physiologic-physical mode of adaptation will not be included in this research study because this study is not measuring physical data. The self-concept-group identity mode is concerned with who a person is and where they fit in society.

Concepts included in the self-concept identity mode include beliefs about the physical and personal self, individual integrity, and self-ideal. Group identity is composed of interpersonal relationships, group image and culture. This study involves interviewing the individual, therefore inclusion of the concept of self-identity is appropriate, however inclusion of the concept of group identity is inappropriate. The role function mode is concerned with primary, secondary and tertiary roles an individual has, and how one is expected to behave in society. The interdependence mode is concerned with how an individual interacts with others in society, and relational integrity. This mode focuses on the group, including the integrity of the group and the relationships with significant others and support systems (Roy, 2009; Roy & Andrews, 1999). The interdependence mode will not be included in this study because groups will not be included in the interview process.

The coping processes and modes of adaptation are interrelated to help the person adapt to any stimuli, and promote an adaptive response. The output behavior indicates the level of adaptation as effective or ineffective. Adaptive behaviors include those behaviors that promote the integrity of the human system. Conversely, ineffective responses are those behaviors that do not contribute to adaptation and can potentially threaten survival (Roy, 2009).

Sister Callista Roy's theory of adaptation is appropriate to guide this study through the development of the interview schedule to discuss the family planning

experience of the adult with CHD. The RAM is appropriate to guide this study because of the underlying assumptions, and the focus on the individual experience. Interview questions will be derived from the major concepts of stimuli, coping mechanisms, adaptive modes, and output behaviors in the RAM. For this study, focal, contextual and residual stimuli will be discussed in the interview. The cognator coping process and the four cognitive emotive channels will also guide the interview, along with the role function, and self-concept modes of adaptation. The model in Figure 1-1 has the concepts, in bold, borrowed from the RAM to guide this study.



Roy, 2009

Figure 1-1 Roy Adaptation Model

Purpose

The purpose of this qualitative narrative study is to describe the personal narratives of adults with CHD and their family planning decisions.

Study Questions

How do adults with CHD make family planning decisions?

What information do adults with CHD obtain to make family planning decisions, and what information do they still need?

Assumptions

Adults with CHD have the potential to get pregnant, and at least some of them want to have children.

Adults with CHD want to tell their story about family planning decisions.

Summary

CHD patients are living longer into adulthood (Gilboa et al., 2010). As CHD individuals age, they experience different health issues than that of the child or adolescent with CHD. This chapter presented an overview of the background and significance of CHD, and the health issues the adult with CHD may experience. A description of Sister Calista Roy's adaptation model was presented, as the RAM will be used to guide this qualitative research study. Concepts of the RAM were defined, and the study purpose, study questions, and assumptions were listed. Greater understanding of adult experiences with family planning will be

useful in future educational efforts of the adult with CHD and the healthcare provider.

Chapter 2

Critical Review of Relevant Literature

Cardiovascular congenital defects occur in 1% of all infants born in the United States regardless of race (Hoffman & Kaplan, 2002). These numerous types of defects encompass structural and functional heart conditions that range from operable with varied outcomes, to the inoperable and ultimately fatal. Due to surgical advances and innovations in healthcare, infants diagnosed with moderate to severe congenital heart disease (CHD) are living longer into adulthood (Gilboa, et al., 2010).

Care of the adult with CHD is significantly different from the child with CHD. The adult experiences different stages of life, and has different specific concerns (Kovacs & Verstappen, 2011; Moons, et al., 2009; Saidi & Kovacs, 2009). These concerns may include physical, social, and psychosocial challenges (Kovacs, et al., 2005). Serious physical health consequences, such as endocarditis and heart failure, can occur because of inappropriate or lack of healthcare (Baumgartner et al., 2010). Significant social challenges include financial issues, such as employment and insurance coverage (Warnes et al, 2008). Psychosocial challenges include coping with quality of life related to disease progression and family planning (Kovacs & Verstappen, 2011). Assisting the patient through these challenges requires an organized, comprehensive approach to care (Gledhill, Rangel, & Garralda., 2000; Kovacs & Verstappen, 2011).

The focus of this literature review is the growing population of adults with CHD and the need for continued research that focuses on their specific challenges. First, a summary of the incidence of infant and adult CHD will be presented along with the changing mortality rates. An overview of the different types of CHD and causes will be provided. Lastly, an examination of the various health issues of the adult with CHD will demonstrate the need to explore family planning in this population. These health issues include quality of life, social factors, physical issues, cost, transitional care, and family planning.

Search Strategy

Databases searched included Google Scholar, PsycINFO, PsycARTICLES, MEDLINE, PubMed, CINAHL, and Social Work abstracts from 2005 until the present. Keywords included “Congenital Heart Disease” and “Adult Congenital Heart Disease”, paired with the words “social,” “women,” “gender,” “age,” “mortality,” “cost,” “demographic,” “nursing,” “pregnancy,” “birth,” “quality of life,” and “transitional care.” The search was limited to peer reviewed journals and articles published in English. A review of reference lists of retrieved articles was completed to identify additional relevant articles that met the criteria of the above-mentioned words.

Congenital Heart Disease Incidence and Prevalence

Infant CHD

The estimated incidence of CHD in infants is 12 to 14 per 1,000 live births (Hoffman & Kaplan, 2002). The prevalence of all children with CHD in Canada, alive in 2000, was 11.89 per 1,000 children (Marelli, et al., 2007).

It is difficult to report an exact incidence of CHD due to the lack of standard reporting practices and registries resulting in varying statistics (Canfield et al., 2006; Hoffman, et al., 2004; Warnes et al., 2001). Defects that are more serious may be noted earlier in life due to complications, whereas defects that are less serious may not manifest observable complications until later in life. CHD diagnosis occurs more frequently and is reported more often in infancy than in adulthood. However, an infant with multiple defects can be reported under several disorders depending on the structural defects (Canfield et al., 2006; Hoffman, et al., 2004; Warnes et al., 2001).

Adult CHD

Adults with CHD include those who have had surgery and do not require further surgery, those who have not had surgery and do not anticipate the need for surgery, and those deemed inoperable except for transplantation (Baumgartner et al., 2010; Perloff, 1991). Similar to infant data, in the U.S. adult prevalence data continues to be hard to obtain because of lack in uniformity of reporting. Some adults with CHD are not diagnosed until complications have manifested however,

some adults with CHD are not counted in prevalence because they are not involved in care (Gilboa et al., 2010; Warnes et al., 2001).

Calculating the prevalence of CHD infants and the likelihood of the infant surviving into adulthood, there is an estimated one million adults living with some form of CHD in the United States (Hoffman et al. 2004). Universal healthcare data from Canada was used in an attempt to measure the prevalence, age distribution, and proportion of adults and children living with severe CHD in 2000 in both Canada and the United States (Marelli et al. 2007). The prevalence of CHD in the adult population in 2000 was 4.09 per 1000 adults, or approximately 856,000 in the United States. Of those adults, an estimated 80,000 were living with severe heart defects. The median age of the total CHD population in 2000 was 40 years (IQR, 27 to 60 years). The median age of patients with severe CHD 2000 was 17 years (IRQ, 10 to 28 years) up from 11 years (IRQ, 4 to 22 years) in 1985 (Marelli et al., 2007). Khairy et al. (2010), in another population based study between 1987 to 2005, found the overall median age at death in 2005 was 75 years (IQR, 3 to 76 years), and 23 years (IQR, 1 to 56 years) for those living with severe CHD.

Changing Mortality Rates for CHD

Pillutla, Shetty, and Foster (2009) used a death registry to determine the trends in mortality of individuals with CHD from 1979 to 2005. In this retrospective population-based broad study, the researchers relied on correct

coding of congenital defects. The main cause of death for adults with cyanotic CHD was arrhythmia, although there has been a decrease in the incidence from 0.26 to 0.2 deaths per million (Pillutla et al., 2009). The main cause of death for adults with non-cyanotic CHD before 2000 was arrhythmia. After 2000, the main cause of death was myocardial infarction followed by arrhythmia and heart failure. This change in cause of death may be due to early recognition of arrhythmia and the increasing use of defibrillators. Currently myocardial infarction is the main cause of death for the adult with non-cyanotic CHD, however, the incidence has decreased from 0.86 to 0.41 deaths per million. Arrhythmia, as a cause of death for adults with non-cyanotic CHD, has steadily declined from 0.96 to 0.88 deaths per million. Adults and children with CHD are living longer with steadily declining death rates, however, mortality risk continues to be high (Pillutla et al., 2009).

Mortality rates among children and adults with CHD in the United States between the years 1999-2006 were calculated by Gilboa et al. (2010). Comprehensive results are extensive and available according to age group, gender, type of CHD, and race-ethnicity. Higher mortality rates are seen in non-Hispanic Blacks at 2.19 per 100,000, compared to Hispanics at 1.53 per 100,000 and non-Hispanic Whites at 1.76 per 100,000, (see Appendix A). This discrepancy in mortality may be due the lack of early diagnosis with appropriate treatment in non-Hispanic Blacks. Male mortality rates are greater at 1.89 per

100,000 than the mortality rate for women at 1.67 per 100,000 (Gilboa et al., 2010). Overall, mortality decreased overall 24.1%, from 1.37 per 100,000 to 1.04 per 100,000 (see Appendix B). In a comparable Canadian study using universal healthcare data, Khairy et al. (2010) found similar results regarding reduced mortality in the CHD population. Mortality in severe forms of CHD decreased significantly and consistently among all subtypes.

Mortality predictors for the CHD population have been studied using Canadian universal healthcare data (Verheugt et al. 2010). The age of the individual, the severity of the defect, the number of interventions performed, and the number of complications experienced had a significant impact on individual mortality. Between 2001 and 2009, according to the Dutch CONgenital CORvita (CONCOR) registry, 48.8 was the median age at death (range: 20.3 to 91.2 years) and the complication responsible for the majority of deaths was heart failure. Arrhythmia and pulmonary hypertension most strongly predicted sudden death (Verheugt et al., 2010).

Types of CHD

Congenital heart diseases are structural anomalies of the heart (Hoffman & Kaplan, 2002) that are categorized as mild, moderate, and severe (Gilboa et al., 2010). The types of CHD are numerous, and to list them is beyond the scope of this paper. The most common types of CHD are noted in Table 2-1. Examples

within each category and the care required of the adult with CHD will be briefly described.

Table 2-1 Birth prevalence (per 1,000 live births) of the eight most common subtypes of CHD worldwide

Subtype	Prevalence	95% Confidence Interval
Ventricular Septal Defect	2.62	2.59 to 2.65
Atrial Septal Defect	1.64	1.61 to 1.67
Patent Ductus Arteriosus	0.87	0.83 to 0.91
Pulmonary Stenosis	0.50	0.48 to 0.52
Tetrology of Fallot	0.34	0.31 to 0.37
Coarctation of the Aorta	0.34	0.32 to 0.36
Transposition of Great Arteries	0.31	0.28 to 0.34
Aortic Stenosis	0.22	0.20 to 0.24

Van der Linde et al., 2011

Mild CHD has the highest incidence and is considered the lowest risk group (Landzberg et al., 2001). This category includes the following anomalies: small ventricular septal defect (VSD), small atrial septal defect (ASD), small patent ductus arteriosus, mild pulmonic stenosis (PS), and bicuspid aortic valve (Hoffman & Kaplan, 2002). The lesion may be surgically corrected in infancy with no continuing complications or the lesion may spontaneously resolve. Adults may have mild murmurs that are typically asymptomatic (Hoffman & Kaplan, 2002), and require the care of a well-trained cardiologist that does not need specialized training in CHD (Hoffman et al., 2004; Deanfield et al., 2003). Adults

with mild types of CHD are recommended to have an office visit every three to five years (Landzberg et al., 2001).

Examples of moderate types of CHD include mild to moderate aortic stenosis, moderate PS, noncritical coarctation of the aorta, large ASD, and complex VSD (Hoffman & Kaplan, 2002). Aortic stenosis resulting from bicuspid aortic valve is common and categorized as moderate even though it can be quite severe (Hoffman et al., 2004). Moderate types of CHD require expert care by a cardiologist specializing in CHD with yearly office visits (Deanfield et al., 2003; Hoffman et al., 2004).

Severe CHD is a smaller category where complex anatomy and physiology issues are present, and includes all CHD anomalies with cyanosis. Cyanosis is associated with high or low pulmonary blood flow as a result of the specific underlying complex anomaly (Warnes, 2008). Examples of severe types of CHD include d-transposition of the great arteries, Tetralogy of Fallot, Hypoplastic right and left heart, single ventricle, double outlet right ventricle, Truncus arteriosus, critical PS, critical coarctation of the aorta, and Eisenmenger syndrome (Hoffman & Kaplan, 2002). Adults with severe types of CHD have multiple health problems and require expert care by a cardiologist specializing in CHD (Williams et al., 2006). Office visits at an adult CHD center are recommended every six months to one year depending on severity of symptoms (Deanfield et al., 2003; Landzberg et al., 2001).

Causes of CHD

Although direct causes of CHD are unknown, risk factors discussed in the literature for the development of CHD include inherited (genetic links and familial relationships) and non-inherited (maternal illness and environmental factors) (Bruneau, 2008; Jenkins et al., 2007; Oyen et al., 2009; Pierpont et al., 2007).

Several techniques are available to evaluate genetic alterations in children with CHD. Cardiac malformations can occur with chromosomal, microdeletions, or mutations of DNA structures. Because of the high variability in clinical presentation of changes in DNA structures, there is debate whether a single change in DNA is the cause of a specific type of CHD (Bruneau, 2008; Pierpont et al., 2007). Genetic and inheritance research is continuing to discover new mutations never before thought to be associated with CHD (Pierpont et al., 2007).

The inheritance of CHD is strongly associated with a first-degree relative having any form of CHD (Bruneau, 2008; Nemer, 2008). A strong relationship has been found between first-degree relatives having CHD and the risk of being born with CHD (Oyen et al., 2009). Due to the high variability in clinical presentation that can affect cardiac manifestation in family members (Nemer, 2008), the pattern of disease progression through the family is unclear (Bruneau, 2008).

Non-inherited factors associated with the development of CHD have been difficult to evaluate and remain largely unknown due to insufficient evidence (Jenkins et al., 2007; Oyen et al., 2009). Maternal illnesses of rubella, gestational diabetes, and exposure to therapeutic and non-therapeutic medications during pregnancy have been associated with higher incidence of CHD (Jenkins et al., 2007). Environmental factors including contamination of ground water, organic solvents, and the use of herbicides, pesticides, and rodenticides may contribute to an increased risk of CHD in offspring (Jenkins et al., 2007).

Health Issues of Adults with CHD

Persons with CHD are living longer and, as adults, have different health related issues than during childhood and adolescence. The adult with CHD needs specialized comprehensive care due to changes in cardiac status, health functioning, and the potential for other adult disease processes. Quality of life, social factors, physical issues, transition from pediatric to adult care, and family planning are health issues experienced by adults with CHD (Kamphuis et al, 2002; Moons, Van Deyk, De Geest, et al., 2005; Moons, Van Deyk, Marquet et al., 2005; Perloff, 1991).

Quality of Life

Quality of life is a broad and multidimensional concept that encompasses many physical, social, and psychological aspects of a patient's life. Compared to the general population, the CHD individual leads a healthier lifestyle, however,

even with milder forms of CHD there is considerable impact in adult life (Ternestedt et al., 2001; Zomer et al., 2012). Repeated hospitalizations of the individual with CHD during childhood and adolescence can have a psychological effect (Saliba et al., 2001). Most adults with CHD function normally, although those with moderate to severe CHD can experience poor emotional and social adjustment including low self-esteem, anxiety, depression, insecurity, and vulnerability due to physical malformations or manifestations of the disease (Perloff, 1991; Saliba et al., 2001).

For the adult with CHD, disease severity is only marginally associated with quality of life (Moons, Van Deyk, De Geest et al., 2005). Social factors, such as employment and educational level, functional status, and the course of the illness are predictive factors for the perception of quality of life (Kamphuis et al., 2002; Moons, Van Deyk, De Geest et al., 2005; Moons, Van Deyk, Marquet et al., 2005; Perloff, 1991). Lower quality of life is associated with lower educational level, employment status, disability, instability of the congenital disease, and functional status (Moons, et al., 2009).

Subjective health status has an impact on perceived quality of life (Kamphuis et al., 2002). The individual perception of health problems and the subsequent psychological response can determine quality of life (Kamphuis et al., 2002; Ternestedt et al., 2001; Zomer et al., 2012). Along with health status, support from family and friends is another factor that affects quality of life for the

adult with CHD. Moons, Van Deyk, Marquet et al. (2005) found that the most significant factor for quality of life in adults with CHD was having family members active in their life, followed by health status and having friends. The importance of having family members increased as the adult with CHD aged. The type of heart defect was not found to affect quality of life (Moons, Van Deyk, Marquet et al., 2005).

Social Factors

Social factors associated with CHD include employment, insurance limitations, and possible impaired social functioning. The potential physical limitations of the adult with CHD can determine employment eligibility and available insurance coverage. Employability is affected by the type of CHD and the resulting physical limitations or disabilities (Warnes et al., 2008). Zomer et al. (2012) found that employment rates for patients with mild, moderate, and severe CHD were significantly lower than a reference group without CHD.

Insurance coverage for preexisting conditions remains difficult to obtain and expensive, and can be a source of frustration. Dearani, Connolly, Martinez, Fontanet, and Webb (2007) found in one CHD clinic site that 51% of patients had commercial insurance, 28% had Medicare/Medicaid, and 21% were uninsured. Comparatively, the U.S. Census Bureau reports 67.7% of individuals in the United States are covered by private insurance, 27.3% are covered by Medicare/Medicaid, and 15.9% are uninsured (DeNevas-Walt, Proctor, & Smith,

2009). Insurance coverage may exclude cardiac treatment and is dependent on the potential risk of an individual utilizing health services and resources (Baumgartner et al., 2010; Warnes et al., 2008). For no apparent reason, some CHD disorders may be covered by medical insurance before and after repair while others may not (Deanfield et al., 2003). Life insurance, an important aspect of financial planning, is frequently refused to individuals with cardiac disease, or can have a higher premium than those without CHD (Baumgartner et al, 2010; Deanfield et al., 2003).

Physical issues and real or perceived physical limitations can leave the adult with CHD at risk for impaired social functioning. Social isolation may occur because of physical limitations or restrictions related to health concerns (Saliba et al., 2001). Feelings of being different influence social functioning, especially in the formative and adolescent years. Overprotective parents of children with CHD can inadvertently lead to an adult with altered relationships and a personal perception of awkwardness and isolation, which can prohibit adult independence (Kovacs, et al., 2005). In a study by Kovacs et al. (2009), one-third of adult patients reported a desire for coping and stress management peer support services. Combined with the physical care of the adult with CHD, psychosocial interventions can help improve the ability to cope with any actual or perceived social limitations (McMurray et al., 2001).

Physical Issues

The adult with CHD may experience a variety of physical issues associated with the severity of the specific abnormality. These issues are numerous, therefore only the most common complications will be discussed. Physical health problems may be complex depending on the underlying pathology and include heart failure, arrhythmia, and complications from reoperation affecting functional capacity (Kenny & Stuart, 2008; Williams et al., 2006). Myocardial infarction, pulmonary hypertension, and complications associated with hematologic changes and infection are also common (Kenny & Stuart, 2008).

Adults with severe CHD may experience complications associated with compromised pulmonary function due to persistent underlying cardiac abnormalities (Allan 2011). Arrhythmia accounts for most of the hospitalizations in this group, and is experienced by 50% of adults with CHD during the lifespan (Allan, 2011). Endocarditis is also frequently diagnosed in the CHD population, and can vary in risk and severity depending on the specific CHD abnormality (Baumgartner et al., 2010; Deanfield et al., 2003).

Differences in complications between men and women also exist. Men with CHD are at higher risk for arrhythmia, systemic hypertension, and endocarditis. Women with CHD have a higher risk for pulmonary sequelae such

as pulmonary hypertension, but are at lower risk for endocarditis and aortic outcomes (Verheugt et al., 2008).

Cost

Appropriate coordination of care can improve or prevent physical limitations and psychosocial issues that occur with the presence of the disease (McMurray et al., 2001). An understanding of these unique challenges can assist the adult with CHD to make the appropriate transition from pediatric to adult care and, theoretically, decrease the cost of repeated hospitalizations and mortality (Brown, Dearani, & Burkhart, 2009; Williams et al., 2006). In 2004, the total cost for all hospitalizations in the United States for any condition was 276.4 billion. That same year the total cost of hospital stays for all congenital birth defects was 2.6 billion. The highest aggregate cost for hospital stays, about 1.4 billion dollars, was among cardiovascular birth defects. The mean cost of hospital stays for all cardiovascular birth defects was 29,600 dollars. Of these reported hospital stays, 50.9 percent were male, with a mean age of 19.8 years. In 2004, 33.5 percent of all congenital defect hospitalizations were circulatory congenital anomalies (Russo & Elixhauser, 2007). From 2004 to 2010, adults accounted for 36.5 percent of CHD admissions (O’Leary, Siddiqi, Ferranti, Landzberg, & Opotowsky, 2013). A comparison of hospitalization cost for all birth defects, all cardiovascular birth defects, and all other conditions is noted in Table 2-2.

Table 2-2 Comparing hospitalization cost for all cardiovascular birth defects, all birth defects, and all other conditions

	Hospital stays for all birth defects	Hospital stays for all cardiac and circulatory anomalies	All other hospital stays
Number of hospital stays (percentage of all hospital stays) (percentage of all birth defect stays)	139,100 (0.4%)	46,500 (33.5%)	33,759,500 (99.6%)
Mean length of stay, days	6.3	8.2	4.9
Mean hospital cost	\$18,600	\$29,600	\$8,200
Aggregate costs (percentage of total national cost)	\$2.6 billion (0.9%)	\$1,368,822,600	\$276.4 billion (99.1%)
Percent Male	53.3%	50.9%	46.5%

Russo & Elixhauser, 2007

Transitional Care

The transition from pediatric to adult care is an important health issue for adults with CHD. Large numbers of adult CHD patients either do not transition to adult care by continuing in the pediatric clinics, or are lost to any type of cardiac health care as they age (Sable et al., 2011; Williams et al., 2006). Using data from universal healthcare patients, Mackie et al. (2009) found that 79 percent of individuals with CHD over 18 years old did not any receive cardiac health care. Predictors for lack of continuation with specialized cardiology care were being male and having a non-severe lesion (Mackie et al., 2009). Of the 893 patients with tetralogy of Fallot known to be alive and living in the United Kingdom,

Wray, Frigiola, and Bull (2013) found that 216 (24%) were not registered with a cardiologist.

Transition from pediatric to adult cardiology care can be challenging. Limited access may be due to limited resources including scarcity of adult care centers, decreased physician expertise of adult CHD needs, or insurance restrictions (Patel & Kogon, 2010; Williams et al., 2006). Knowledge deficits of the patient, family, and physician, and/or lack of access to adult care clinics are formidable barriers (Kovacs et al., 2005; Kovacs & Verstappen, 2011; Perloff, 1991). According to a survey by Peter, Forke, Ginsburg, and Schwarz (2009), internists stated a need for more training regarding congenital conditions. The absence of education for the general cardiovascular specialist regarding adults with CHD decreases the number of potential health care providers and directly influences accessibility to care (Baumgartner et al., 2010; Deanfield et al., 2003; Warnes et al., 2008).

At this time, there are few providers available to administer care to the anticipated number of adults with CHD. The lack of providers is directly related to a lack of training. There is a substantial time commitment involved to become an adult CHD certified physician (Deanfield et al., 2003; Warnes et al., 2008). For cardiologists who wish to work with the adult CHD population, educational training requirements are extensive. Three levels of training have been identified. Level one training is required of all adult cardiologists, and consists of exposure

to the CHD patient, anatomy, physiology, clinical presentation, and management. Level two training includes core curriculum exposure to CHD, and adds one year of additional training in an adult CHD center. Level three includes all aspects of levels one and two, and adds an additional year of training in an adult CHD center (Child et al., 2001). Many specific competencies are required of the cardiology fellow to be considered a specialist in adult CHD. Among these competencies, the fellow is required to be competent in medical, surgical, and postoperative management of the adult with CHD. Also, an extensive knowledge of management of cardiovascular and cardiopulmonary disease is required (Child et al., 2001).

Transitional care research supports the increasingly important role of education in the CHD population. A knowledge deficit of the patient, family, or pediatric physician can lead to the adult with CHD failing to recognize the importance of continued care (Williams et al., 2006). Recommendations from research include ongoing education of the patient and family that begins in childhood and continues through adolescence and into adulthood. The educational program should be comprehensive and include age specific concerns (Kovacs & Verstappen, 2011; Moons, et al., 2009; Saidi & Kovacs, 2009; Williams et al., 2006).

There is a lack of formal transition from pediatric to adult care systems (Deanfield et al., 2003; Sable et al., 2011; Saidi & Kovacs, 2009). This absence of

an organized transition is a barrier to adults receiving specialized, long term, health care until a major event occurs. The consistent pattern of decline in CHD mortality is a changing population trend that further emphasizes the need for a transitional care program. The challenge is to identify the needs of the CHD adult and provide appropriate resources to meet this need (Khairy et al., 2010; Pillutla et al., 2009).

Family Planning

CHD patients are living longer into adulthood, which increases the possibility of childbearing and childrearing. Childbearing may be unintentional or intentional involving much decision-making, thought, and knowledge. The lack of transition or late transition to adult CHD care can result in missed opportunities to discuss family planning issues including contraception, pregnancy, and birth (Sable et al., 2011; Williams et al., 2008). Family planning is an important issue to discuss with the patient due to the varied contraceptive choices available, and the changes in cardiovascular status that occur during pregnancy (Miner, 2004). Pediatric facilities are inadequate for adult care specifically, those issues related to family planning. During adolescence and early adulthood the CHD patient may have many unanswered questions. Pregnancy and childbirth is not addressed with consistency among healthcare providers, not at all in the pediatric setting, and marginally when transitioning to an adult setting (Sable et al., 2011).

Family planning for the adult with CHD is an emotional topic. Horner, et al., (2000) studied the coping skills and resiliency of adults with CHD. The emotions of the study group ranged from a feeling of survival to anger when difficulties of decreasing heart function and complications arose from CHD. Women and men had concerns regarding family planning and a shortened life expectancy along with the potential for disability. Women and men reported anxiety and fear related to passing on CHD to their children (Horner et al., 2000; Reid, et al., 2008). Women had specific concerns with fertility issues, personal health during pregnancy, and preterm birth (Reid et al., 2008). Women also acknowledged emotional turmoil and devastation at their potential or permanent inability to have children (Horner et al., 2000).

The healthcare provider should discuss family planning including contraception and pregnancy, with the adult with CHD (Canobbio, Perloff, & Rapkin, 2005). While there are many contraception options for a woman with CHD, individual assessment and understanding of any potential lesion-specific complication is needed to make an informed, safe decision (Canobbio, 2004; Miner, 2004; Vigl et al., 2011). Vigl et al. (2011) found that of 536 women with a median age of 29 years (range 18 to 75 years), 43% never received contraception counseling, while 48% never received counseling regarding pregnancy related risk associated with their CHD type. In this study, 44% of the women brought up the topic with their physician (Vigl et al., 2011). Kovacs, Harrison, Colman,

Sermer ,and Siu (2008) found that 34 % of high-risk women with CHD did not recall receiving information regarding the increased risk of cardiac complications in pregnancy. Access to appropriate family planning counseling could enable women with CHD to make informed decisions regarding contraception and pregnancy (Canobbio et al., 2005; Harris, 2011; Miner, 2004).

The pregnant woman with CHD

Changes in cardiac status during pregnancy increase the demand on the heart in an already demanding existence (Stout & Otto, 2007). A third heart sound is noted in 80% of pregnant woman with normal heart function, and a ejection systolic murmur is noted in 90% of pregnant women with normal heart function (Head & Thorne, 2005). The pregnant woman with CHD is at higher risk for heart failure, arrhythmia, and thromboembolism compared to the general population (Freeman & Foley, 2008). Cardiovascular changes during pregnancy that affect CHD include increased blood volume, increased heart rate, decreased blood pressure, increased ejection fraction, and increased cardiac output (Desai, Moodley, & Naidoo, 2004; Head & Thorne, 2005; Stout & Otto, 2007).

Pregnancy tolerance and outcome is lesion specific. The type of congenital defect, with the corresponding severity of side effects of that lesion, will determine pregnancy tolerance, prenatal care, and outcomes (Colman & Siu, 2003; Freeman & Foley, 2008). Care of the pregnant woman with CHD includes a provider with knowledge regarding congenital lesions and high-risk obstetrics (Harris, 2011).

Most women with mild to moderate CHD can tolerate pregnancy and delivery with low risk for complications (Harris, 2011). Pregnancy is contraindicated with the presence of certain CHD malformations and should be carefully considered (Deanfield et al., 2003; Perloff, 1991). Each specific type of CHD and the appropriate interventional medical care is listed in the American College of Cardiology (ACC) and American Heart Association (AHA) guidelines, along with recommendations for pregnancy and follow-up care (Warnes et al., 2008). Pregnancy is considered a low or moderate risk for most of the mild and moderate types of CHD. Women with cyanotic CHD who become pregnant are at higher risk for life threatening complications and even death (Colman & Siu, 2003; Harris, 2011). Pregnancy is contraindicated in patients with severe pulmonary arterial hypertension and Eisenmenger syndrome (Baumgartner et al., 2010; Warnes et al., 2008). These women are discouraged from becoming pregnant due to high risks for both mother and fetus. These specific cyanotic CHD problems require specific knowledge and expertise from a CHD trained cardiologist and healthcare team (Hoffman et al., 2004).

Clinical assessment of the woman with CHD, along with maternal and fetal risk evaluation, is ideal prior to the woman becoming pregnant (Harris 2011; Head & Thorne, 2005). Clinical assessment should include, but not be limited to, electrocardiogram, echocardiogram, and chest x-ray (Head & Thorne, 2005). Initial risk assessment for cardiac events during pregnancy can be evaluated using

the NYHA functional classes nomenclature. High-risk patients include those with a NYHA functional status III or IV (Freeman & Foley, 2008; Head & Thorne, 2011).

A risk factor index assessment tool created by Siu et al. (2001) evaluates the risk for adverse cardiac events in pregnancy specifically for the adult with CHD. Predictors of a primary cardiac occurrence during pregnancy are prior cardiac event, base line NYHA functional class greater than level two, left heart obstruction, and reduced ejection fraction. One point is assigned for each predictor present. The adverse pregnancy event risk associated with zero, one, and greater than one point is 5%, 27%, and 75% (Siu et al., 2001). Appropriately assessing the risk level and providing comprehensive care will help to achieve the best outcomes (Head & Thorne, 2005).

Outcomes of pregnancy in the CHD population vary from maternal complications, including hypertension, arrhythmia, and congestive heart failure, to fetal complications, including fetal loss, congenital heart disease, and fetal death after birth. The severity of maternal disease directly relates to the maternal and fetal outcomes (Drenthen et al., 2007). Preconception counseling should include emphasis on the risks associated with pregnancy, and the persistent, extensive emotions surrounding this topic. Any change in care should be planned with considerable thought given to optimal pregnancy and cardiac outcomes (Kovacs et al., 2005). With appropriate assessment, diagnostic evaluation, and

intervention most women with CHD have successful pregnancies and childbirths (Reimold & Rutherford, 2003; Stout & Otto, 2007).

Needed Research

As CHD becomes more of an adult cardiology concern, the care given to these individuals needs to be appropriate and comprehensive (Dearani et al., 2007). Further studies focusing on the health issues of the adult with CHD and the psychosocial challenges these patients encounter are needed (Hoffman et al., 2004). These studies need to include further evaluation of contraception and pregnancy risk potential of women of childbearing age and the counseling they receive (Gilboa et al., 2010; Verheugt et al., 2010). The exploration of counseling and clinical decision making between the healthcare provider and the patient regarding family planning will help evaluate the need for further patient and provider teaching (Harris, 2011).

Family is a significant factor in determining quality of life for the adult with CHD (Moons, Van Deyk, Marquet et al., 2005). Family planning is an emotional topic that is not addressed consistently by the healthcare provider in any setting (Horner et al., 2000; Sable et al., 2011). Physical complications associated with the specific type of CHD can increase the risk for adverse cardiac events associated with pregnancy and birth (Coleman & Siu, 2003; Freeman & Foley, 2008). If family planning is not addressed, the adult with CHD will not have the knowledge to make informed decisions about contraception, pregnancy,

and birth (Canobbio et al., 2005; Harris, 2011; Miner, 2004). There is little research on the experience of adults with CHD and the family planning counseling they receive. Exploring the personal narrative experience regarding family planning of the adult with CHD will enable the researcher to gain insight into family planning decisions and needs for comprehensive care. This study will explore the personal narrative experience of adults with CHD and the counseling and decision-making associated with family planning.

Conclusion

This literature review focused on the growing population of adults with CHD. The incidence and prevalence of infant and adult CHD were presented along with changing mortality rates. An overview of the major types and causes of CHD was provided. Health issues experienced by the adult with CHD were discussed including quality of life, social factors, physical issues, cost, transition from pediatric to adult care, and family planning. Gaps in the literature were identified regarding family planning and decision making of the adult with CHD.

The results of this literature review support the need for further research exploring family planning in the population of adults with CHD. The existing literature does not fully describe the contraceptive, pregnancy, and birth decision-making experience of the adult with CHD. Current literature focuses on the physical aspects and risk associated with contraception, pregnancy and birth, but misses the personal story surrounding these decisions. Greater understanding of

adult experiences with family planning will be useful in future educational efforts of the adult with CHD and the healthcare provider.

Chapter 3

Methods and Procedure

This chapter will include a description of the narrative inquiry method and why it is appropriate for this study. A description of the target population and sample including inclusion and exclusion criteria will be provided. The data collection method, data analysis, and human subject protection will be described.

Method

The narrative method is a form of inquiry that is used by researchers to explore how individuals make sense of their lives, and how individual experiences shape self-identity (Clandinin & Connelly, 2000; Duffy, 2012). Narrative inquiry allows the researcher to gain insight into an individual's understanding of life events (Sandelowski, 1991). The narrative methodology was chosen for this study because the researcher sought to understand the group through the individuals' experience (Marshall & Rossman, 2006).

Historically narrative methods have been used since the 19th century, and have recently become more popular among researchers as a way to explore and appreciate the human experience (Spector-Mersel, 2010). The philosophy of narrative inquiry and analysis is rooted in many disciplines including anthropology, psychology, sociology, and psychiatry (Clandinin & Connelly, 2000). Narrative inquiry draws from these disciplines to emphasize the story as fundamental to human existence. Narrative inquiry assumes that a relationship

exists between reality and the narrative story, and that stories are how humans understand self-identity (Spector-Mersel, 2010). Narrative inquiry explores the meaning of an experience through stories, interviews, journal records, and historical writings as data sources (Duffy, 2012; Savin-Baden & Niekirk, 2007).

Narrative inquiry has no unified rules about data collection or analysis techniques, however, three central characteristics are noted (Clandinin & Connelly, 2000; Riessman, 1993). First, narrative analysis needs narrative texts as data. A narrative is a story that has a plot, can be told in a chronological order or timeline, and has major and minor characters (Duffy, 2012; Holloway & Freshwater, 2007; Riessman, 1993). These stories can be autobiographical, biographical, or both (Duffy, 2012, Riessman, 1993; Savin-Baden & Niekirk, 2007). Second, language is the tool to discover the interpretation and application of experiences that shape and determine identity. Lastly, narrative inquiry requires an understanding of the concepts of temporality, subject, causality, action, and context (Clandinin & Connelly, 2000; Riessman, 1993).

Temporality is the ordering of the events in the experience and is central to determine how the event is characterized in narrative inquiry (Clandinin & Connelly, 2000; Lai, 2010). Temporality involves seeing the event as it is in the here and now, or seeing the event as it is on a continuum. In narrative inquiry, the subject is in the process of continual change, and the action or event has interpretive meaning to influence the change. Causality is the element of

understanding why things happen. Knowing the context of the narrated event is needed to make sense of the events meaning to the narrator (Clandinin & Connelly, 2000). New events are experienced and then interpreted by the narrator in the context of the understanding of older events (Poirier & Ayers, 1998).

Data Collection

Narrative inquiry involves collecting stories either by listening as the story is told by a single participant or group in an interview setting, or by reading a journal or historical writing (Savin-Baden & Niekerk, 2007). The interview is the primary source of data collection and is conducted in a comfortable environment for the participant in an unstructured manner (Clandinin & Connelly, 2000; Savin-Baden & Niekerk, 2007). Where the interview takes place and the way the researcher responds to information presented will affect the participants recounting of the story. A comfortable environment for the participant and non-judgmental responses by the researcher are ideal (Clandinin & Connelly, 2000). Interview questions are mainly open-ended and allow for the participant to reflect and elaborate on the story (Riessman, 1993; Savin-Baden & Niekerk, 2007). Follow up questions are encouraged, if needed, for clarification of information and to gain more information to allow for more effective analyzing of the story (Savin-Baden & Niekerk, 2007).

People use stories to make sense of an experience and understand the meaning behind what happened (Marshall & Rossman, 2006). Individuals

represent and understand self-identity through many narrative life stories (Clandinin & Connelly, 2000; Duffy, 2012; Marshall & Rossman, 2006). The narrative researcher should be aware that telling a life story may be a sensitive and emotional process. The researcher should elicit details and the meanings of these details during the storytelling interview but avoid being forceful or overbearing. The participant may have an emotional experience related to the topic discussed. Each participant must be approached with sensitivity and respect and the interview process should be a positive one (Duffy, 2012).

Data Analysis

Riessman (2002) offers three approaches and techniques for analysis of a narrative: structural, thematic, or interactional. Structural analysis focuses on how and in what order the story is told, with each phrase or clause closely analyzed for function in the narrative (Holloway & Freshwater, 2007; Riessman, 2002).

Thematic analysis places emphasis on what is said and the content of the text rather than how it is said. Interactional analysis focuses on the dialogic process between the narrator and interviewer. This type of analysis is noted in conversational situations, such as in a medical office, where both the interviewer and narrator participate in the storytelling, and there is a collaborative creation of meaning (Holloway & Freshwater, 2007; Riessman, 2002). For this study, the structural and thematic approaches and techniques were used. The researcher

interviewed individuals and not groups therefore the interactional technique was not used.

Labov and Waletzky (1997) asserted that all narratives are structured the same way and have six common elements: abstract, orientation, complication, evaluation, result, and coda. Abstract is the summary of the narrative, orientation is the time, place situation, and participants of the narrative, complication is the event, evaluation is the significance or meaning of the action, result is what happened, and the coda is when the participant brings the event into the perspective of the present time (Labov & Waletzky, 1997; Riessman, 1993).

After evaluating the narrative for structure, the researcher performed a thematic analysis from a psychological perspective that focused on the meaning and interpretation of the event for the individual (Riessman, 2002). This type of analysis requires a close time-consuming reading and analysis of the narrative for nuances of speech and response. This type of approach is not appropriate for large studies, therefore a small sample size is recommended (Reissman, 1993, 2002). The researcher must focus on the meaning given to an experience and the interpretation of the reality associated with that experience. Researchers may note inconsistencies, repetition, and silences as significant meaningful events in the narrative process. These tactics by the narrator can represent confusion, avoidance, or discomfort with the subject being discussed (Poirier & Ayers, 1997).

The purpose of this study was to describe the personal narratives of adults with CHD regarding family planning decisions. A structural analysis of the narratives was performed according to the Labov and Waletzky (1997) framework, followed by a thematic analysis as suggested by Riessman (1993, 2002). Understanding the structure, interpretation, and meaning of this experience can guide future efforts to educate and counsel adults about their family planning needs.

Sample

The population of interest was adults with mild, moderate, or severe CHD of childbearing age who have, within the last five years, made a decision regarding family planning. Mild CHD includes small ventricular or atrial septal defect, small patent ductus arteriosus, and bicuspid aortic valve and is considered a low risk group for cardiac events (Hoffman & Kaplan, 2002; Landzberg et al., 2001). Moderate CHD includes large ventricular or atrial septal defect, moderate pulmonary stenosis, and non-critical coarctation of the aorta (Hoffman & Kaplan, 2002). Severe CHD includes complex anatomy issues such as tetralogy of Fallot, single ventricle, Eisenmenger syndrome, and any anomalies with cyanosis (Hoffman & Kaplan, 2002; Warnes et al., 2008). Adults of any ethnicity were included. Childbearing age was defined as 15 to 49 years (Wilmoth, 2009), however only individuals 18 to 49 years were included. Individuals from 15-17 years are minors and require parental consent.

The sample size for this study was at least 15 but no more than 30 adults, or until saturation of themes was reached. Recruitment took place by word of mouth through nursing colleagues, and the Adult Congenital Heart Association (ACHA) website. The ACHA is a nonprofit organization that serves adults with CHD through educational, outreach, advocacy, and research opportunities. A study notice was placed on the ACHA website, a note about the posting was placed on the ACHA homepage, and a link was placed in the monthly newsletter. The link included sections regarding the rationale of the study, participant eligibility, risks and benefits of participation, and an email link for interested participants.

Study approval was first sought from the ACHA organization, and then from the University of Texas at Arlington where the researcher is a student. After posting the study notice on the ACHA website, 33 CHD adults responded to the posting through email. Each potential participant was emailed an initial response to verify that they met the study's inclusion criteria. If the participant answered the initial email, and met the inclusion criteria, they were emailed the consent form. Nineteen potential women replied to the researcher after each recruitment email, and seventeen were included in the study. Two potential women never replied after the consent was sent to them. Once participants indicated that they had read the consent in a return email to the researcher, an interview time was arranged. One potential participant was excluded because she was out of the age

range of 18-49. After the interview was completed, a twenty-dollar Amazon gift card was sent through email to the participant.

Inclusion criteria

Participants in the study included adults of childbearing age that have been diagnosed with mild, moderate, or severe CHD at birth or during childhood and adolescence. Individuals between the ages of 18 and 49 that reside in the United States and are English speaking were included. Men and women were included in the study since both have concerns regarding family planning (Horner, Liberthson, & Jellinek, 2000; Reid, Siu, McCrindle, Irvine, & Webb, 2008). Participants included all those individuals that have made family planning decisions in the last five years, including but not limited to contraception, pregnancy, and childbirth.

Exclusion criteria

Participants were excluded from the study if they were currently hospitalized, have been diagnosed with a mental illness, or were cognitively impaired so that they cannot participate in an interview. Individuals between 15 and 17 years were excluded because they are minors and would require parental consent.

Data Collection

A single in-depth, semi-structured interview was performed with participants using an interview schedule developed by the researcher (See

Appendix C). Phone interviews took place using the researcher's personal phone in the researcher's home office at the predetermined time set by the participant and the researcher. Because a large enough sample was difficult to obtain from any single hospital in any single city, and because the CHD population is widely scattered geographically, phone interviews were necessary for data collection. After potential participants were screened for the inclusion criteria, the study was explained and verbal informed consent obtained at the beginning of each interview.

Each participant was informed of potential risks and benefits involved with the study. Sharing the individual story of family planning with others in the CHD community and with health care providers may benefit this population by increasing awareness of their needs. The risks associated with the study included the loss of time involved with speaking over the telephone, and the potential emotional distress involved with discussing an emotional subject. Each participant was informed that the interview would be audio-recorded and immediately transcribed by the researcher, using no identifiers included in the transcript to maintain the confidentiality of the participant. Each participant was informed that the recordings would be destroyed as soon as transcription occurred.

The researcher conducted all of the interviews. The interviews lasted between 20 minutes to one and a half hours, and were concluded when the participant and researcher felt there was nothing more to discuss, or the

participant became uncomfortable and wished to stop the interview. Interviews were recorded using a phone recorder.

Data Analysis

The transcripts were read several times and scrutinized both individually by the researcher and with the dissertation chairperson. Data analysis first focused on the narrative as a whole including what was stated and how it was stated within the context of the narrative. Further analysis identified common themes in the transcripts associated with the narrative story of the participant. Analysis consisted of reading through each transcript as a whole, extracting descriptive words from the text, determining meanings from the text, organizing these meanings into themes, and formulating a description of the themes.

Methodological and analytical memos were used during the data analysis process.

Rigor

In qualitative research, rigor authenticates the findings of the study and establishes trustworthiness of the data. Trustworthiness signifies that the data and the findings reflect the true experience of the participant (Polit & Beck, 2004). Trustworthiness consists of credibility, dependability, and transferability (Guba, 1981; Lincoln & Guba, 1985; Schwandt, Lincoln, & Guba, 2007).

Credibility can be established with triangulation, where many points of view are considered to draw conclusions from the data (Polit & Beck, 2004).

Types of triangulation include data triangulation, time triangulation, space

triangulation, person triangulation, investigator triangulation, theory triangulation, method triangulation, analysis triangulation, and multiple triangulation (Polit & Beck, 2004). For this study, investigator triangulation was used through careful scrutiny of the transcripts, both individually by the researcher and with the dissertation chairperson.

Credibility can be established through researcher credibility (Polit & Beck, 2004). Researcher credibility contributed to the credibility of this study as the researcher has experienced similar circumstances in her life. The researcher was born with a bicuspid aortic valve, a common and mild type of CHD. The researcher was given limited information as a young woman about contraception, pregnancy, and childbirth. The researcher experienced aortic valve repair surgery at 34 years of age after the delivery of her third child.

Dependability is established through the use of an audit trail (Polit & Beck, 2004). The researcher maintained methodological and analytical memos during the data analysis process. A descriptive research report is needed for transferability or generalization of the data. The descriptive research report is needed for other researchers to be able to evaluate the applicability of the findings to other populations (Polit & Beck, 2004). Through investigator triangulation, researcher credibility, an audit trail, and a descriptive research report, trustworthiness and rigor will be established.

Human Subject Protection

Participants gave verbal informed consent after participating in the consent process via telephone. Participants were informed of the rationale of the study, the risks and benefits associated with the study, and how long the interview may take. Participants were told that they could skip any question that they do not want to answer, and they could stop the interview at any time without penalty. Participating in the study would no affect on their health care or on their relationship with the ACHA. If participant become upset during the interview, the researcher would pause or terminate the interview. Since the researcher is also a Registered Nurse, she was capable of assessing the participants' emotional state and terminating the interview as needed to avoid emotional trauma. At no point in the interviews was it necessary for the researcher to terminate an interview. At the completion of the interview, the participant was sent a twenty-dollar Amazon gift card through email.

All recordings were transcribed verbatim within two days of the conclusion of the interview. To maintain confidentiality and anonymity, no identifying personal information of the participants was included in the transcripts, and consent was verbal only. Personal, physician, and hospital names were deleted when stated within the transcript. Transcripts were numbered according to the order the interview was completed. Electronic transcripts will be

maintained with the Faculty Advisor on an appropriate UTA encrypted device for three (3) years.

Chapter 4

Findings

Narrative analysis of the women's stories revealed that family planning for the adult with CHD is a deliberate, thoughtful process that occurs in phases. The family planning decision making process begins with decisions regarding contraception, moves to discovering childbearing options, deciding if/when to have children, pregnancy, and finally feelings post family planning decision. Each phase has definitive points where decisions must be made that will determine whether the individual will continue on to other phases or not. The travel through each phase however, is not necessarily linear. Depending on life circumstances at any point in time, the individual may circle back to a phase. This chapter will describe sample characteristics and the stories these women tell to describe their decisions about family planning. Quotes from women will highlight each phase and decision of the family planning decision process.

Sample

Nineteen potential women replied to the researcher after each recruitment email, and seventeen were included in the study. Two potential women never replied after the consent was sent to them. The sample ranged in age from 24 to 41 years. All participants were women living in 10 different states with various forms of CHD ranging from mild to severe. Most of the women had multiple anomalies, as is common in this group, and therefore multiple types of CHD are

noted (see Table 4-1). The final study sample characteristics are presented in Table 4-2.

Table 4-1 Study sample CHD diagnosis

Mild	Moderate	Severe
ASD	Large ASD	Epsteins Anomaly
VSD	Complex VSD	Tricuspid Atresia
Mitral Valve Prolapse	Pulmonary Stenosis	Truncus Arteriosus
	Mitral Valve Regurgitation	Unicuspid Aortic Valve
		Tetrology of Fallot
		Single Left Ventricle
		Double Inlet left ventricle
		Shone's syndrome
		Transposition of the great arteries

Table 4-2 Study sample characteristics

Characteristic	Frequency
Age	
18-27	7
28-37	7
38-49	3
Number of Surgeries	
1-2	9
3-4	6
5 or more	2
Marital status	
Married or in a committed relationship	12
Engaged	2
Single	3
Ethnicity	
African American	1
Asian	1
White	15
Number of children	
0	10
1	5
2	2
Therapeutic Abortion	1
Surrogacy	1
Adoption	0
Sterilized	2

Phases of Family Planning Decisions

For the adult with CHD the decision to have children is made with deliberate contemplation, research, and conversation regarding their specific type of CHD and the consequences of pregnancy and childbirth. Whether or not to have children is a life changing, potentially life-threatening decision. For most adults with CHD, thoughts about family planning begin during discussions with

their physician about contraception and continue through adulthood into marriage.

Phases of the family planning decision-making process extracted from the interviews are: contraception, discovering childbearing options, deciding if/when to have children, pregnancy, and future worries. Each phase can be entered multiple times depending on the circumstances in the individual's life.

Phase 1. Contraception

The women's stories of family planning began with the decision to be sexually active and choose a form of birth control. Contraception included any means to prevent pregnancy such as the pill, intrauterine device (IUD), and sterilization of themselves or their partners. These women made contraceptive decisions based on their life situation at the time, including if they had ovarian cysts, if they became sexual active or got married, or if they experienced an unplanned pregnancy. One woman stated, "I was put on birth control when I was around 16 because I had ovarian cysts that they needed to kind of manage." Another woman was placed on birth control due to heavy periods. "I think part of the whole heart things was that I had really heavy periods so I was put on the Depo shot. So that covered both ends (laughter) and then we just stayed on it." A third woman stated, "I was a virgin until I got married. So, I didn't need to worry about that. When I got married I got an IUD."

Triangulation: Patient-cardiologist-obstetrician.

Once these women decided to begin using contraception, they attempted to obtain information from online websites, and/or attempted to discuss the topic with an obstetrician and/or cardiologist. Some women had a positive experience when discussing contraception with their physician, some received no information on contraception, and others felt caught in the middle between two providers. Some physicians regularly communicated with each other – gynecologist with cardiologist - and with the patient. One woman stated, “I mean I have an open email policy with all my doctors and I email them any questions and I ask them so many questions.” Another woman stated, “I consider my cardiologist like my second family.” For some, all it took was a phone call. “When I went to the OBGYN they called my family doctor and asked if it would be ok if I took the prescription and they agreed to it.”

While some women with CHD received appropriate and adequate information, other women did not receive any guidance from their health care provider about the type of contraception that would be appropriate for them. One woman never had a conversation with their physician and stated, “That was never even discussed.” Another woman stated, “No. It was basically like I was any other child, any other young adult wanting to go on a birth control pill.” In these cases, the women decided to obtain contraception at clinics without regard to the potential complications and their type of CHD, or without consulting their

cardiologist. For example, one woman went to Planned Parenthood and the school clinic for her contraception. “I didn’t have a regular doctor when I was in college so I’d get regular birth control pills at Planned Parenthood or the school clinic. I wasn’t too concerned about my heart condition. I’d never heard anything about problems.”

Some of the women in the study felt like a messenger between one doctor (OBGYN) and the other (cardiologist).

I used to live in a small town, and they were all really good communicating with one another; my cardiologists, my family doctor, and my OBGYN. Everybody knew before I was actually given the prescription for it. And that hasn’t actually occurred in my adult life (laughter). I mean no one actually cares to call and check on anybody else

One physician would prescribe a medication, and the other physician would send the patient back to the first physician to have the medication changed. “The cardiologist that I am currently seeing has said, ‘You should not be on that birth control. Ask your gynecologist to prescribe something different.’” When talking with another woman about different types of contraception and her conversations with the gynecologist and cardiologist, she stated there should be change. “So that the patient does not feel like they are stuck in the middle of that. Cause I did feel that way for a long time...I think they use me as their intermediary.”

Fear

Discussions with the provider about appropriate contraception typically began during adolescence, but may have occurred later. At times, these conversations were frightening when discussing the side effects of the type of contraception related to their type of CHD. Women with CHD had to be careful with the type of contraception used depending on the severity of their disease and the increased potential for clotting that accompanied most types of contraception. “I’ve been told it (contraception) increases the risk for blood clots, and with my particular diagnosis I’m already at a risk for clotting. But obviously, you have to control for birth (laughter), you don’t want to get pregnant either.”

Women with CHD expressed fear of contraceptives because of the risks associated between the contraceptive and their heart, or because they did not feel confident that the contraceptive would be safe. “My biggest fear was the blood clot risk that comes with all contraceptives.” Another woman stated, “I’m kinda scared of birth control pills. To be honest, I don’t know why. I feel like, I don’t know, I just don’t think that there’s enough research out there and so, I never wanted to be on them, so I didn’t.” Some women were fearful because they felt confused about what choice to make.

When I first started asking what contraceptives would be safe, my cardiologist really wasn’t into me being on anything. But then he also wasn’t into me getting pregnant either and so I felt like... well we have to choose one or the other. And it also made me very nervous and jumpy when I went to my OB discussing which

medications I could take. I was scared. Is this the right decision? Is this going to cause a complication? But then on the other hand, what else are you going to do?

Permanent solutions

The woman's medical condition contributed to choices surrounding birth control. A more severe heart condition meant the woman needed to seriously consider her own mortality if she should become pregnant or give birth. Women with more severe heart conditions decided to pursue sterilization of either themselves or their partner. One woman and her husband decided that he should be sterilized to prevent a further pregnancy. "He had a vasectomy when our daughter was 4 months old. That's our form of contraception because there was no other option. Multiple cardiologists had told me that if I got pregnant again I wouldn't survive. It was a life or death thing." Another woman had experienced multiple surgeries throughout her lifetime and was considered high risk for any type of contraception. She and her husband also decided he should be sterilized. "It wasn't advisable for me to get my tubes tied or anything so we said what about getting a vasectomy? Then after my last heart surgery in 2010, we talked about it... and that's when he got the snip snip."

When these young women with CHD decided they did not want to carry their own children, they began requesting a more permanent contraceptive solution. While some young women were able to have sterilization procedures performed without any issues, some had to wait due to life circumstances or lack

of health care provider support. One woman began asking to be sterilized at 19 years old. It took quite some time to find a doctor that would perform the procedure. “Generally, I think every message I got was no one is going to sterilize a 19 year old. And then it was no one is going to sterilize a 21 year old.” She had a sterilization procedure done when she was 25 years old. “I found a gynecologist who was really behind me, and she was willing to do it even though I was only 25.” Another woman repeatedly requested sterilization at 18 years old due to her severe heart defect, and was repeatedly denied. At the time of the interview, she still had an IUD in place.

I went to a gynecologist and asked if I could have my tubes tied, when I was about 18 years old. I wanted to do something for myself then I wouldn't have to worry about it (pregnancy) as much. They were unwilling because I never had a pregnancy. So when I was 18 I had periguard IUD put in.

Making the choice to be sterilized was frustrating to the women in the study, especially when the women felt that all the options available had been considered and sterilization was the option she chose. The women felt as if they were making a smart choice that would not only keep them from getting pregnant, but also keep them from experiencing the harmful side effects of birth control.

I felt really frustrated because I felt like I was trying to make the best choice for my health, and everyone on my care team obviously had that goal as well, and they weren't being supportive. I felt frustrated that it (sterilization) wasn't one of the options on the table that I was given. I understand that no one wants to come in and totally advocate for that, I felt like that was something that I should have been given and not had to go seek out. The fact that I

was going into it for really good reasons, not because I wanted to go and be incredibly promiscuous, but because I wanted to make sure that I was off oral contraceptives, but still not get pregnant. I really felt like I should have been given a gold star (laughter). Instead, I was treated with a lot of resignation. And I think that they just have this fear that I'm going to come back in 5 years with a partner and have regrets. I think it's hard given that no one ever wanted me to be pregnant, and yet they didn't really empower me to make the steps that felt right for me.

Unplanned pregnancy

Some women mentioned unplanned pregnancy and the effect it had on their choices for birth control. Women with CHD can unintentionally become pregnant but be unable to physically support the pregnancy. When this occurred, to either continue with the pregnancy or obtain a therapeutic abortion was a difficult decision. The women had to thoughtfully consider the impact of the pregnancy on her health and the unborn child's health. The decision regarding the pregnancy also prompted the women to consider a more permanent type of contraception. One woman had an unplanned pregnancy at age 17, aborted the pregnancy, and made sure she was on contraception from then on. Before her unplanned pregnancy, contraception was not discussed. "It was never, that was never even discussed." This woman decided to abort the pregnancy because of her young age and her severe type of CHD. She stated, "I remember contemplating I don't know if I can do it. You know I was young but then I knew I had the issue with my heart so I just wasn't sure."

Even if the unplanned pregnancy does not happen, the fear of the actuality can be overwhelming. Women chose to abort the unplanned pregnancy if they felt there was a large risk to themselves or the baby. One woman had to “call in and ask if I could use Plan B progesterone only.” When asked what prompted the call for the Plan B, the woman stated, “It was a safety precaution. I mean, just to be cautious. I didn’t use a condom or the condom had broken, or something.” Other women were adamant that if they did get pregnant accidentally they would abort the pregnancy. “When I got on birth control I asked them if I could even have an abortion because I think that it would be better to get rid of the unplanned pregnancy than go through dealing with the unplanned pregnancy and the cardiovascular stuff.” Yet, another woman stated, “I can say with certainty right now that I would definitely choose abortion over a risky heart complication for myself.”

Phase 2. Discovering childbearing options

The women in the study made a decision to explore childbearing options when they felt they were in a committed, stable relationship, either unmarried or married. “We ended up getting married, and so I went in to the cardiologist to get the A-OK to have kids.” These women had a desire to have children from an early age, and always wanted to have kids at some point in their lifetime. One woman stated, “When I was younger I thought I would have kids. I just never really put that thought away. I wanted to have a family.”

Gathering Information

When the women began to contemplate the idea of having children, they attempted to gather as much information as possible to discover all the childbearing options, and their pros and cons. The women made special appointments to discuss these topics. “I just made the appointment and they (physicians) were very excited and happy that I did that. They said a lot of patients will just go out and get pregnant, and then they are an after thought (laughter).” The healthcare provider was involved in the discussions with the woman and her significant other before a decision was made, to determine if pregnancy was a viable option. “I feel like my doctor was very open with me, and that he explained and was honest about possible complications.” Other times, the women were told pregnancy was not an option for them from the start. “I was just always told you can’t have kids. It was like period, end of story. It wasn’t something that was even up for discussion.” Some women were not told anything and were left with unanswered questions. “I thought I was always fine to have kids. Nobody ever told me I wasn’t. I want to know, can I carry a child? Is it gonna put me into heart failure again?” Some women had accidental pregnancies. “I saw a pediatric cardiologist. No one ever discussed having children with me. I was 19 when I got pregnant. Nobody ever told me I couldn’t get pregnant, I couldn’t have children, that it wasn’t good for my heart.”

Some women in the study had pregnancy discussions with their cardiologist starting when they were a teenager and continuing into adult life. “I was told at 14 that it would be really difficult to have children of my own, and probably not a good idea. That sealed it for my family planning and was consistently the message I heard as I grew up and into adulthood.” However, conversations with the health care provider changed over the years. “When I was still a teenager in high school it was that straight fear of if you get pregnant you’re going to die.” As the women got older, the conversations revolved around the risk involved with pregnancy. “It (pregnancy) might cause some of these other things to come up, because your body’s trying to support another life, and support you.” The women felt the doctor would be supportive of any decision they made, but the doctor advised against pregnancy. “He’s always been of the persuasion of, I’m not going to tell you not to do it. If it happens, we will be here for you, we’ll deal with it, but do everything in your power not to do it.”

Discussions with healthcare providers about pregnancy and childbirth included discovering the best time to have a child, or a “timeline,” depending on the woman’s functional ability and disease process. As the women were planning their life, the thought of having children needed to be considered earlier than expected. Some women were amazed to learn that they should have their kids earlier than planned.

I had mentioned [it] to my doctor the last time I saw her. She said well you're high risk, so late 20's/early 30's is really a good best time to have kids. I've just never planned on even being married until my late 20's/early 30's. It just never occurred to me that I needed to speed up my game plan just in case something happened to me. I felt so normal for most of my life that I didn't feel like I needed to factor this in.

One woman asked her cardiologist directly, "What's the time line? Is there a certain time I need to decide to get pregnant? And of course they did advise me the younger you are the better it would be."

Not only did the women gather information from their physicians, they also searched for information about family planning and pregnancy on their own through the Internet. "I got a lot of my information from my cardiologists and his team and then I just did my own research online, just looking at what I could find." The women wanted information about outcomes of mothers and children with similar diagnoses. The women were not encouraged by what they found.

I looked up studies, and I looked for outcomes of people who had diagnoses that were similar to mine and had had children, and I wasn't excited about the outcomes. What I have found is that not only is it a risk to your health, but there are not good outcomes for the child as well in terms of low birth weight, premature birth. Obviously, they're going to have less oxygen in utero because I have less oxygen. I knew it would be bad for my health, and I have worked really hard to keep myself healthy.

Women found that even though there are similarities with others that have CHD, each case is different and the research may not apply to them individually. "It's really hard to read about congenital heart disease, and family planning or contraception, just because each case is so different. So if you read one thing it's

more than likely not going to apply to you.” Other women found very little information, and preferred to not be a part of research about what pregnancy does to the CHD heart. “I really believe that the research just isn’t there. As selfish as it is, I don’t want to be part of that research and finding out what pregnancy does to the CHD heart.”

Pregnancy risk

Conversations with the cardiologist included a discussion of the increased risk associated with pregnancy. The conversations involved talking about the risk involved with delivery, the survival of the mother and child, and the potential to shorten her life span. “I actually just talked to my doctors today about what pregnancy entails. It’s going to be high risk, what kind of pregnancy, what kind of delivery would we prefer.” One woman stated, “My understanding is that it (pregnancy) would be risky for me. There would be a lot of planning. It would be dangerous to get through the pregnancy, and then after the pregnancy may shorten my life. Which I think that sounds very unappealing (laughter).”

The women with severe CHD were concerned with the risk associated with survival of themselves and the baby. “If you get pregnant there’s a lot more at risk because it’s not just the baby’s heart and the baby’s health, it would be your heart and your health as well.” The women commonly reported cyanosis with their type of severe CHD. One woman expressed her concern with her oxygen supply and her ability to support a pregnancy when she did not have

enough energy or oxygen to support her. “I didn't have my first open heart surgery until I was 13. I think the issue was is she even going to survive? I mean being, (sigh), being blue and not having enough energy and oxygen for myself...how was I gonna do it for two people?”

The women with severe CHD felt that they experienced a range of opinions from those that adamantly discouraged pregnancy, gently discouraged pregnancy, to those that would be supportive of any decision the women made. One woman decided to rely on her doctor to make the decision for her. “My doctor was going make that decision.” Other women experienced providers who tried to gently steer them toward a certain decision. “She doesn’t actively say, listen this is what would happen were you to choose to have kids or whatever. She uses tones where she slightly discourages it.” Another woman felt the doctor would be supportive of any decision she made. “They were willing to support me it seems like, but I could tell he was like, you know what, it’s a big risk. He would back me up regardless of what I did.” Other women reported an experience that was open and honest about the risks associated with their particular type of severe CHD.

He said if you decide to have children you are at a great risk. Your life’s at risk, and your baby’s life’s at risk. And when I heard that I’m like, you know what, I’m not even going to entertain this anymore. Because I don’t want to die over it and I don’t want to leave my husband with a child and be dead? I mean why do that?

Still other women felt that even with the input from the doctor it is ultimately a decision for the women and her significant other. “They can’t make that choice for you. If I were a doctor, who would I be to tell somebody you shouldn’t have kids? Especially if you are people of conceiving age.”

Planning for pregnancy

The women with CHD discovered they had to plan for pregnancy and childbirth. “We had to plan. It wasn’t just like a surprise.” Planning for pregnancy began before they stopped birth control, when they were just starting to think about having children. Their healthcare provider was very involved in the planning even before the women decided she wanted to get pregnant. “Once I got past 18, every time I went for my annual exam at the cardiology department, they would always say, ‘Are you thinking about having children? If you decide to get pregnant you need to let us know.’ That was always a comment.” Other women stated their healthcare provider wanted to discuss pregnancy before they even stopped their birth control. “It’s just not an option. We can’t get pregnant unless we planned it. They won’t let me get off of birth control until we talk about it because we need to be completely prepared and they need to be there before I conceive.”

“Backup plan”

Some of the women were unsure of their ability to carry their own children, or did not desire to carry their own children. “I’ve always wanted

children. I've always assumed that I wasn't going to carry them. I didn't know how I was gonna have them, but I knew I wasn't going to carry them because I didn't want to take the risk." These women chose adoption or surrogacy as "a backup plan." Other women discussed adoption and surrogacy as an alternative to pregnancy. "Well, we had discussed adoption, surrogacy. I just knew I wanted children, and so we thought about different ways we could do that without me having to be pregnant if that was going to be an issue."

The women decided to approach the subject of adoption and surrogacy with their healthcare provider and significant other. "We discussed potential adoption and surrogacy and that type of stuff because we just have to be open to options." The women discussed how these options are different from the "normal" or "typical" way of having children. "It would be different than the typical having a baby." The women added that it is a good thing to be able to have a different kind of experience from others. "It's not bad, it's just different. I love that there's ways for me to have kids, and ways for that part of life to be, in a sense, normal. Even though it's not a normal way to have kids, it's a normal thing to have kids."

One woman found out she could not carry another pregnancy after her first child and stated she was devastated by the news. She described how she and her husband went through a period of mourning and grief before accepting the inevitable and moving on. "We had mourned, we had grieved, and we had moved

passed not being able to have our own children.” She looks forward to adopting a child and feels she and her husband will “love the child like our own” and it would be “no different than having our own biological child.” Other women were glad they were told early that pregnancy would not be an option for them, and always thought of adoption as the choice for having children.

I sort of always had that idea that if I was a parent it would be through adoption. I have friends who found out when they were in their late 20's, and that was harder for them. But because I was told so early, I think it was just always the understanding I had as I grew up that if I did have kids it would be through adoption, it would not be through getting pregnant and carrying a child.

The women discussed the obstacles they had to overcome while attempting to adopt including the expense of adoption, and “being judged” for personal health issues, related to their CHD. “Adoption is so expensive and that’s the main thing. It can cost 40 to 50 thousand dollars. It’s a very expensive process.” The women discussed their thoughts on how hard it is for people to adopt because, in their mind, the agencies are very strict on the adoptive parents. The adoptive parents have to be healthy, and cannot have any health issues. The women felt as if they were “judged” because of their CHD. One woman stated, “Agencies are strict. And people have babies all day long that don’t want them, and don’t want to take care of them, and yet it’s so hard for people that can’t have children to adopt.” Another woman wanted to adopt but chose not to because she feared others judging her because of her health issues. “We were like, well

maybe we should adopt. But the thing with adoption is you have to be healthy; A its expensive, but B you can't have any health issues. And I just didn't want to be judged.

One woman described her experience with adoption as a “rollercoaster” ride. During the time she and her husband were attempting to adopt, she had cardiac surgery. She had asked that the birth mothers not be told of her health status, and the adoption agency did not honor her wishes. She felt that she was treated differently by the adoption agency because of her CHD.

Adoption is a roller coaster any way you look at it. We took several months off from presenting to birth mothers because I had just had the surgery. We did not want a birth mother to know, cause we did not want her to say, oh well, she is sickly. She can't take care of my child. I feel like they treated me differently because they shouldn't have told. And if I were a perfectly normal person, they wouldn't have said anything.

The women also discussed surrogacy as another “backup plan” to have children. “I really would not mind doing surrogacy. If that would be better for my heart, then I would do it in a drop of a hat.” Some women had potential surrogates, formally or informally, “lined up.” The women stated that the surrogates were friends and family members. One woman had her best friend as a potential surrogate. “I did have a surrogate lined up. Not contracted or anything, but my best friend had offered years ago that she would be a surrogate for us if we needed it.” Another woman had her cousin as a potential surrogate. “So, when I

got married my cousin said that she would carry kids for me. And so, we got that in our minds ever since.”

The women expressed emotional turmoil when considering surrogacy as an option for having children. The women described feelings of sadness and resignation about the expense and length of time involved in the process, with no guarantee for a child.

It’s sad that women have to spend insane amounts of money to go through the process of having a child. Obviously, nothing’s guaranteed, but this especially isn’t guaranteed. If it doesn’t work, then you do it all over again with more money. The process is long and I think it’s sad that this is what the process is.

Phase 3. Deciding if/when to have children

The women’s stories of family planning continued with the actual decision to have children or not. Conversations with all individuals involved were hard. “Those conversations are really hard.” One woman continued to vacillate on her decision. One day she would see children and remember that she liked them, and would think about having one of her own. Then the next day she would think the risk was too much and it would be “stupid” or “dumb” to have a child. “I think I’ve always gone back and forth. For the longest, I would think, why would you ever have a kid? That’s stupid. That’s dumb. I don’t want kids. But then sometimes I would think, I want a kid now.”

Some women always knew they wanted children. “I always knew I wanted to have kids. I knew I wanted to be a Mom someday. I didn’t know how

I was gonna have them but, I knew I wanted it to happen.” When these women thought of having children as a young girl, they dreamt of what the future would be including college, marriage, and names for children they had yet to conceive. “I’ve been picking out kids names since I was (giggles) a little girl. That was part of the process. You grow up, you go to college, you get married, and you have babies. So, that was always part of me.”

Emotional attachment to having children

Some women expressed an overwhelming urge and passion to be a mother, even with high-risk conditions. “I mean that’s the bottom line. Some women are so into wanting a baby and carrying a baby that it’s worth the risk for them.” Emotions surrounding having children ranged from determination, caution, and sadness. The women expressed all of these emotions during the interviews. One woman had defied all the odds as she was growing up, even walking when the doctors said she would not. She was proud that she had “proved them wrong,” and now she wanted to carry her own child, even if that meant going against the advice of her physician. “I want kids because it is my passion to be a mother. I was told when I was a little kid that I would never walk and I have proved them wrong. I walk. And you know they probably think she can’t have a kid, but I want one.”

The women expressed concerns about personal expectations and strong emotional ties to pregnancy that could influence family planning decisions. The

woman discussed how others do not understand the physical toll that having a baby causes, both during pregnancy and after. “I think people don’t realize you’re tired anyway. How tired are you going to be when you have to deal with your heart defect and being up all night with a crying baby? I think people just don’t think about that.” The women were concerned about other women with CHD that do not consider the future for themselves and the child. They just want to have a baby. “I think a lot of people are just thinking about wanting to have a baby, not how is my kid going to have to deal with me not being able to go to his functions because I’m in the hospital, or having the kid have to take care of a mom because mom’s too sick.”

Some women did not feel the urge to actually carry a child, but still wanted a child. “I guess I’ve never had that ‘I want to carry a child’ feeling. I’ve just never had that, so I don’t feel a separate loss or anything. I know a lot of women do.” However, sadness accompanied the thought of having to wait because the other options, adoption and surrogacy, are so expensive. If the women did not have to worry about finances, they would have already tried to get pregnant. “I guess my sadness comes from what the process is going to be like. If we didn’t have to do the whole surrogacy thing, we would have already tried to get pregnant, but because finances are involved, we are waiting.”

One woman was extremely overcome with heartache when she was told she could not have any more children after her first child. The news was

unexpected for her, as she and her spouse had been planning to have a large family. She had never been told that she couldn't have children until after the pregnancy, and the delivery caused life-threatening complications. "I mean, I always wanted, sigh, you know, I always wanted kids; a big family. I wanted four kids. So, to be told that I couldn't have any more kids was like somebody ripped my heart out."

The uncertainty of pregnancy

The uncertainty of an actual pregnancy and birth was scary to the women. "It's just kind of scary to have a kid." Women found the thought of pregnancy, childbearing, and life in the future intimidating due to unknown factors of how their heart would handle pregnancy and birthing. "I want them (children) and I'm scared because I don't know if my heart can handle pregnancy. My biggest fear is my heart." One woman asked her cardiologist how he thought her heart would handle pregnancy if she were to get pregnant. "His response was well, if you want to get pregnant, then I would say get pregnant, and we will figure it out as we go." For this woman her physician's response was upsetting and did not instill confidence. "I mean at that point I'm like well, it's a good thing I don't want to get pregnant, because I wouldn't feel too confident if that's what my doctor is saying."

Worries before pregnancy included the potential for a decrease in functional level, a shortened lifespan, and life threatening outcomes. Women

reported that their physicians explained that if their functional level was high before pregnancy there were not many issues post pregnancy. “He explained to me that your functional level before pregnancy, if it is high, usually you don’t have many issues.” Even with this reassurance, some women found the thought of a shortened lifespan unappealing and decided against pregnancy. “I’ve just nixed the idea of pregnancy to be honest. It wasn’t something I was ever crazy about anyway, because it shortens my lifespan. It’s like, how can my body support that.” The women found the uncertainty of survival and the potential to decrease their lifespan unnerving.

In my twenties, the messages got a bit scarier, like you may not survive pregnancy. If you did survive, that would not be the worst thing that would happen because it would shorten your life. To me, being a parent doesn’t mean having a kid and then dying five years later. I would want to make sure that I was there for a significant amount of that child’s life.

Still, other women discussed that pregnancy for others with CHD might be fine, but for them pregnancy could be life threatening. “I started thinking about everything involved with pregnancy when I was probably 15 or 16, cause that’s when my doctors started really talking to me about it. Where it might be bad for anybody, for me it could be life threatening.” .

While the women had worries about pregnancy and the effect it would have on their bodies, other women were confident in their ability to have children but were scared about complications for the baby, or during labor. “I worry about

having complications more on the baby side than on my side. It's more the baby that I'm concerned about." Another woman was concerned with labor. "So, actually carrying the child I wasn't worried about. It was only labor that we were concerned about." One woman had one successful uneventful pregnancy, delivered a healthy child, and decided that was enough. "We decided on one child. Everything went perfect and I just didn't want to tempt fate again."

Passing on CHD

The women were not only concerned with pregnancy and labor, but also with passing the disorder on to their children. "We did talk about having genetic testing. I need to know what I'm working with, right?" The women's biggest concern "was having a child whose going to have a heart defect" because CHD can come "out of nowhere." Even though genetic testing is available to determine if a woman is a carrier for CHD, some of the women did not take the opportunity to discover if they had the gene. These women continued to express concern about passing CHD to their children. "I'm worried about possibly passing some sort of CHD to my child." The women that did have the genetic testing completed, continued to express concerns about having a child with CHD even after tests results were negative for the gene. "I was tested for 22q deletion chromosome and I don't have it. I read research that suggests that if somebody has a congenital heart defect they are more likely to have a child that would have, not the same defect, but a congenital heart defect."

A few of the women were pregnant when they found out about genetic testing for congenital heart disease. Some women knew about the testing when they were pregnant but did not have it done. “When we found out we were pregnant, we didn’t do any of the tests. For us it wouldn’t have made a difference.” Other women had the testing completed. “They did genetic testing for fragile X and some other things. Basically we have a 50/50 chance of each child, or a 1 in 4 chance of each child, being born with a heart condition.” One woman had multiple family members with CHD and was curious about a genetic link for her children. “I think it’d be interesting do to more genetic testing on myself and my children. I’ve had two healthy kids, but my sister has the same defect as I do, and she had one child who has a defect.”

Finally, the thought of unintentionally harming the unborn child was frightening. “That was probably the most frightening. I thought, you know, what have I done? What if I give this child this horrible thing?” The women felt more clarity with defined risk values for a genetic link was needed. “I wish it was clear that there’s a possibility that it is hereditary so if you have a child you have whatever times percentage more likely that you may have a child with the same type of a defect or a similar defect.”

Influences on the decision: family/spouse/others

Women identified multiple influences on their family planning decisions. These social, familial, and spousal influences would incite personal questions

such as, “Why do I have to be somebody that wants to have babies?” and “Is this a bad idea?” The women felt that choosing to have children was a personal decision that took time to contemplate and discuss with loved ones. However, at times loved ones and others inserted opinions that were unwanted and not requested. “What confounds me is how much people feel like they are able to have an opinion about your reproductive life (laughter). It just seems like a very intrusive thing that people have opinions about what you should be doing (laughter).” These unwanted opinions made some women rethink their decision repeatedly.

Everybody who thinks that they should have a say is like, oh, you are going to regret it if you don’t have kids. There are times when I question, ‘Is this a bad idea? Am I going to be that person that regrets that I did not have kids?’

Cultural expectations to have children made women feel their family did not understand their situation. “There is a lot of cultural expectation. One time I asked my parents, ‘Hey ya’ll know I can’t have kids right?’ I think my Mom is in denial because she just, kind of, wrote it off.”

The women described their mother and spouse as highly influential when making family planning decisions. The women relied on their mom for advice and care from an early age, and therefore the mother’s opinion about family planning was significant. The woman’s spouse or significant other’s opinion was considered more reliable than the physician’s opinion at times. “I think my

decision comes more from what I decided along with my husband and Mom's input. I'm giving that more credibility than even what my physicians are saying." Discussions about having children between the women and their significant other began early. If the women were in a relationship, they discussed having children with their significant other while they were dating.

My husband and I discussed it before we got married. I wanted to tell him I couldn't have kids. And he said, 'I love you for you and if that means we don't have kids then we don't have kids.' Why would we want to have a kid and if something were to happen to me he'd have to raise it by himself. He said, 'I don't want to have a kid that doesn't have a mom.'

Other influences on decision making included the women's physician and participating in counseling. When women discussed the risks of pregnancy and birth with their physicians, they felt an underlying sense of partiality as to which decision they should choose. Some women felt their doctors thought they were weird if they didn't want to have a baby. "I think that the sense I get from doctors I speak to is if you are a woman, then you have to have a baby. If you don't want to have a baby that's weird." Other women felt that their doctor found it startling if they do not want children, which made the women wonder if they had made the right choice. "I think that as much as people try and keep their biases to themselves, its always been clear that people are just doing that double-take when you say, no I am not interested in that." Other women participated in counseling to help with decision-making. "If I didn't have as strong of a support system for

my family, I probably would not be in the place I am. My husband and I are both in counseling and that helps a lot too.”

Phase 4. Pregnancy

After gathering information, discussing the situation with loved ones, and contemplating the consequences of pregnancy, some women with CHD decide to get pregnant. Women described their pregnancy experiences as normal, terrifying, and traumatic. One woman was used to being different and having to be careful, and described her pregnancy experience as normal. “I guess I’m just used to being a little different and having to be more careful but I always had a feeling, an internal feeling, that everything would turn out OK. If I wasn’t meant to have children then I would not have them.”

Women were surprised at how much the pregnancy affected their heart. “I don’t guess I really realized how much it would affect my heart.” Some women learned of potential issues after they became pregnant, and were terrified of the consequences of pregnancy on their heart. “All these things can happen and I just didn’t know. It’s terrifying. It’s scary. I was in tears a lot.” Some women stated their doctors “scared the hell” out of them so much that all they could think about was “I’m gonna die and my baby’s gonna die.” One woman’s cardiologist suggested she have surgery soon after her baby was born. “My cardiologist, during my pregnancy, specifically said these words, ‘After we get that parasite out

of you we will discuss surgery.’ I haven’t been back.” At these times, the women would hope that “whatever it is that you do, that everything is going to be OK.”

Some women with CHD who go through a pregnancy call it traumatic. “It was a very traumatic experience really.” For example, if it was an unexpected pregnancy with several cardiovascular problems, the entire experience is negative. “I had a lot of problems with her (daughter). This was before they realized how bad my heart really was. I passed out over and over again.” After their first child, some were told they should not have any more children. “It was devastating.”

Even if the women felt adequately prepared for any health issue, they continued to worry about similar potential complications as before pregnancy. “I did, of course, worry. I am human.” The women continued to worry about loss of function after pregnancy, and if their heart could handle pregnancy.

What I mainly worried about is my loss of function. I don’t really have any restrictions on my activities. I’m not on oxygen. I worried that I would get pregnant, have a baby, and then that would change. I wouldn’t be able to do as much as I do now. That would be even worse having a small child. I didn’t worry so much about dying, or something major happening, but just that I would have a change in the way that I function afterwards.

Other women decided not to worry especially if they felt the pregnancy was going well. “Once I became pregnant everything went so smooth, there was really no reason to worry.”

A surrogacy story

Only one woman experienced a successful surrogacy and birth of twins. She and her husband decided on surrogacy because her chances of heart failure after pregnancy were high. The woman discussed how she tried to push through her emotions, but realized she was grieving not being able to have her own children. She went through depression during that time in her life, and had to find help to sort out her emotions. “I was trying to push through it without grieving, and then I realized I’ve got to deal with that. I went through therapy, because it was hard to accept that I wouldn’t get to have that experience.”

She and her husband decided against adoption because they wanted to have children that were genetically their own. They decided on gestational surrogacy.

I didn’t want to do adoption and my husband was on the same page. That may sound crude, but I felt like I had the ability to carry taken away from me. So, at least I wanted a chance to try to have some that were genetically my own and my husband.

She and her husband found a surrogate through word of mouth. “My husband and I reviewed it (the profile) and ended up meeting with her and she became our surrogate. We got a contract drawn up with a lawyer.”

The woman described the process as long and arduous. Each retrieval of eggs and transfer of embryos was nerve wracking. She and her husband would pray for success, and cry when a transfer failed. After several unsuccessful

transfers, finally a viable pregnancy of twins was achieved. The surrogate pregnancy was generally smooth and the woman was able to watch her children being born. “I got to watch my daughters be born. I may not have gotten to have them in my body and experience the first movement which she would text me about, but I got to be there.” Her twins are thriving, growing, and asking the normal questions kids ask about how they got here. She and her husband are open about their experience to the children and anyone who inquires.

Phase 5. Feelings about family planning decisions

The family planning story continued as the women discussed how they worry about what the future will bring for them, physically and emotionally, if they decide to get pregnant or if they already had children. The women continued to describe themselves and their family planning experience as different from other women. Ultimately, the women described being comfortable with their decision regarding family planning. Even when they re-visited one of the other phases, they generally returned to the same conclusion.

Worrying about the future

The women described future physical and emotional worries similar to the concerns they expressed before and during pregnancy. The women continued to worry about the potential for a decrease in physical functioning and a shortened lifespan after childbirth. The women wished their functional level to stay the same. “That’s my concern for the future. I just don’t want to lose the capacity

that I'm at now. I just want to stay where I am. I don't want it to get worse."

The women expressed worry about other women with CHD who might not think about how pregnancy will affect their future health. "Some people just want to have a kid so bad they ignore the bad side, and just look at the good side. They see a person had a baby and they're fine, but they don't see how they're doing five years down the road." Other women worried about how the potential for future surgeries might affect their children. Taking care of children while going through cardiac surgery would be difficult. "If I would need bigger surgery like a transplant, I feel that is too hard. That seems like raising a child in that context would be really, really, be difficult."

The biggest worry voiced by the women in the study was that they would die and not be there for their children. The women repeatedly discussed their fear of something happening to them where they would not present to watch the child grow up. "I worry about of course dying and not being here for them when they grow up. That's probably my biggest one." If the women were not afraid of death, they were afraid that something would happen where they would not be available for their children. "That's probably the biggest fear. Being told that my heart is getting weaker. When is that time going to come when I can't run around, play with them, and do things with them the way another mother could?"

Even with these worries, the women decided to make the most of the situation. They decided to make the best of the time they have with their families

while they are healthy. “I hope and pray that I maintain what I’m doing now for many years. I don’t know what’s going to happen. I have to keep reminding myself to take one day at a time. Whatever is supposed to be will be.”

Being different/being normal

The women described themselves as different from other women.

Feelings of loneliness accompanied the feeling of being different because they did not know anyone else that had CHD, or any similar disorder. For one woman, loneliness occurred before and during pregnancy, and after the birth of her child. She felt frustrated that people did not understand her situation.

I’m the only person I know that has a heart defect, much less the one that I have, which is kind of rare. So, it does feel lonely. I always try to just be as normal as I can be. But it was different during pregnancy not being able to feel like I knew someone that was also high risk and having all these extra appointments all these extra concerns. And I feel like people did not really understand that.

The women reflected on being different, stating that if they did not have CHD having children would be easy. “The fact that I have CHD is an extra barrier. If I were normal it wouldn’t be as hard to have kids.” The women discussed if they did not have CHD they could announce their pregnancy with a surprise, the “normal” way. “I’d get to do it like everybody else and go surprise I’m pregnant. It would have been nice if I didn’t have CHD to deal with. I can be normal and put those cute announcements on Facebook. I mean I miss that.” The

women felt that for them, because of all the planning involved with a pregnancy, this type of announcement was not possible.

The women described the differences between their pregnancy and their friends without CHD who had “normal” pregnancies. The women couldn’t have the same carefree attitude as their friends because of their CHD. The women felt their friend’s pregnancies were a lot less stressful and worrisome

I didn’t have the same carefree attitude that my friends who have had children had. They kind of just decided they wanted children and had their baby. It was totally happy. Just the normal fears and worries about delivery and having a new baby. Not the kind of level that I had.

The women continued to discuss how their friends with “normal” pregnancies did not have the added stress of going to all the special doctor appointments. “They didn’t have to worry about the stress involved with going to those doctors. It is the most stressful thing. It’s your heart. It’s not like it’s a foot or a limb or anything else, it’s a thing that functions your entire body.”

The women described jealousy, envy, and resentment of other women that were able to have children easily, the “normal” way. “I’m never going to experience a pregnancy with my own body. It is a lot of jealousy and envy.” One woman felt aggravation and resentment toward her sister in law’s third pregnancy. “It’s aggravating when my husbands’ sister is having her third baby and it’s like, really? Sometimes I think, Bitch.” Other women described sadness about their situation that included going through depression. “I was very sad that I couldn’t

have children. I had a lot of time to deal with it, but... at times I would go through depression where I would be really upset.” The women would feel guilty about having these feelings, especially when they felt they should be happy for the other woman. “If somebody else got pregnant around me, like somebody in my family was having a baby I would be happy for them, but I would be sad for myself. It was a very selfish, selfish thing.”

The feelings of being different, and resentment about having a different experience having children, did not ever completely go away. The women continued to express sadness and resentment around others who were pregnant. “Still today, I still have problems. If somebody constantly has babies over, and over, and over, and over, again, I have feelings of resentment toward the mom. I don’t think they realize how precious children are.” The women continued to explain that those feelings returned if they felt that another mom was ungrateful for her children.

Somebody I know had a 7 year old and adopted. Then turned around and got pregnant, and she complained the whole time. That kind of stuff springs up those old feelings because I constantly think if I was able to have another child I would go through it all again. I think some people don’t realize what it’s like not to be able to have kids.

The women continued to describe how people say things that are hurtful and bring back those feelings of sadness. “A lot of people say foolish things. After my

surgery, people would say, ‘Oh well, now that your heart’s fixed, can’t you have kids?’ Not realizing that I can’t.”

Even with the longing to be normal, some women accepted their disorder and found a positive aspect about having CHD and family planning to consider. One woman decided that having CHD was “good” because she would have children in a unique way, different from everyone else. She decided to embrace the fact that she was different. “Sometimes I think it might be good that I do have CHD. Cause then I do get a chance to do it differently and experience something that not everybody gets to.”

Being comfortable with decision

When reflecting on their decision, the women felt that they had made the right family planning decision even if others close to them thought they would change their mind. The women felt that family and physicians thought they would change their family planning decision later, when they were in a stable relationship, either married or unmarried. “I know that they saw people who were in their late twenties that came in and said, ‘I don’t care what the risks are I want to do that.’ I think that they were worried that I might suddenly think that.” The women, however, were influenced by other women’s high-risk pregnancy experiences. The women would watch friends go through pregnancies with life threatening consequences, and were happy that they would never feel the need to have a child. “A lot of cardiologists were saying, ‘Well you don’t know how

you're going to feel when you're married.' And I watched my friend go through it, and I said I'm never going to feel that way."

The women recognized a balance between their comfort level with the family planning decision they made and knowledge of their specific disease. The women felt empowered and self-reliant when they were given information about CHD and family planning options. "I feel more empowered understanding and knowing what my choices are." Some women felt more self-reliant because they had been educated from an early age about their disease.

My doctor wanted me to know what would happen. I'm truly blessed that they were so forthcoming with everything, and they really coached me to be an adult and learn to deal with things, so that when I'm in the world on my own, I don't need to rely on anybody else.

At the end of the interviews, the women were comfortable with their family planning decision for now. Some woman realized why it was so hard for them to be around kids, and the reason they had made a certain decision about family planning. "I just think my life experiences have shaped what I think of kids. I realized why I don't like to hear kids crying. It reminds me of being in the hospital, and hearing kids cry. It's too hard for me to be around them." Some women experienced relief that a decision was made. "I wasn't upset. I didn't mourn it. It was like a light switch went off and that was it. I wasn't going to do it." Now that a decision was made, they could move on and think about other things. "I am glad that I've already made this decision so I don't have to think

about things that would compromise my health in order to be in a fulfilling relationship. I feel secure knowing that is a closed book at this point.” Other women felt that it was probably not in God’s plan for them to have kids. “I just look at it like well, that’s God’s plan then.”

Chapter 5

Discussion

The purpose of this qualitative narrative study was to describe the personal stories of adults with CHD and their family planning decisions. The study questions were: how do adults with CHD make family planning decisions, what information do adults with CHD obtain to make family planning decisions, and what information do they still need? The interviews revealed that family planning occurs in phases beginning with contraceptive decisions and continuing through discovering childbearing options, deciding if/when to have children, pregnancy, and feelings about family planning decisions. Women with CHD obtain information from the healthcare provider, family, friends, and the Internet. Even with the information these women obtain, they continue to want more. For women with CHD, strong feelings of fear and worry occur when making a decision during all phases of family planning. The women described concerns regarding family planning issues that were consistent with the literature including contraception, communication between the adult with CHD and physicians, passing CHD on to children, pregnancy, and childbirth (Horner et al., 2000; Reid, et al., 2008).

Choosing a contraception option for the woman with CHD is difficult. The need for contraception can be medically induced or due to life circumstance such as becoming sexually active or marriage. While some women in the study

received contraception counseling, others received little to none. These findings are consistent with the literature that describes a lack of counseling for women with CHD (Kovacs et al., 2008; Sable et al., 2011). As a result, the women were fearful that the contraception they chose might be potentially harmful to them, depending on their type of CHD. Open honest conversations between the obstetrician, cardiologist, and the woman are important to facilitate an informed decision regarding contraception and prevention of an unplanned pregnancy. Similarly, communication between the cardiologist, gynecologist, and the women during the other phases of the family planning process is important.

Family planning is an emotional topic for the adult with CHD (Horner et al., 2000; Sable et al., 2011). Women with CHD experience many influences on their family planning decisions. These social and familial influences can cause frustration and worry about making the right decision. If women with CHD decide differently than those close to them, they feel regret and question their decision. All of the women in this study felt a desire to have children whether their type of CHD was mild, moderate, or severe. This finding is consistent with the literature that the desire to have children is not dependent on the severity of CHD (Morissens et al., 2013).

Events that trigger thoughts about childbearing include life situations such as feeling pressure from family, and being in a committed, stable relationship, either unmarried or married. For women with CHD, pregnancy and childbirth can

be a life-threatening choice. They are scared of the risks associated with pregnancy and childbirth, and they want to make an informed decision about family planning. These women search for information about childbearing related to their type of CHD from their healthcare provider, family, friends, and the Internet. Family planning discussions with the healthcare provider should begin early (Canobbio 2004). These findings are consistent with literature describing a need for early and accurate family planning counseling for women with CHD (Canobbio et al., 2005; Freeman & Foley, 2008; Sable et al., 2011; Stout & Otto, 2007; Uebing, Steer, Yentis & Gatzoulis, 2006).

Planning for pregnancy is a large part of the family planning process. While women with CHD are emotionally attached to the thought of having children, they have concerns regarding physical functioning, during pregnancy and after childbirth. This finding is consistent with the literature describing specific concerns of women with CHD regarding personal health during pregnancy and childbirth (Reid et al., 2008). Planning for pregnancy begins before the woman stops birth control. The woman, her significant other, and her cardiologist will carefully plan the details of a safe pregnancy including medication alterations, timing of the pregnancy, and which physician specialists to include in her care. Conversations with the cardiologist can be comfortable and helpful to overcome any fears. This finding is consistent with the literature that

describes a need for a collaborative approach to family planning for the adult with CHD (Kovacs et al., 2008).

Women with CHD are not only afraid for their personal health, but also afraid of passing CHD on to their children. Some women have genetic testing before a pregnancy to discover if they can pass the disorder on to their children. Some women might decide differently about family planning if they know more about their personal genetic history. This finding is consistent with the literature that women and men with CHD report anxiety and fear related to passing CHD on to their children (Horner et al., 2000; Reid, et al., 2008).

Women with CHD, whether they decide to have children or not, all have similar worries about the future. For the women who decided to have children, they worried before, during, and after pregnancy. These worries centered on the potential for a decrease in physical functioning and whether they would live long enough to see their children grow up. For the women who decided not to have children, they worried about a decrease in physical functioning should they choose to have children in the future. All of the women were afraid of losing physical function for any reason. This finding is consistent with the literature describing concerns regarding personal health during and after pregnancy and childbirth (Ngu, Hay, & Menahem 2014).

Surprisingly, some women discussed their absolute conviction to carry a child regardless of the risk involved, while other women wanted to be sterilized

early in life in order to “move on” with their lives. When the women were unsure of their ability to carry children, or did not desire to carry their own children, they chose to either not have any children, to adopt, or to have a surrogate carry their children for them. This “backup plan” is an important and viable option of family planning for women with CHD. These women were still very emotionally attached to the thought of having children, yet they were fearful of how the pregnancy and childbirth process would affect their physical functioning. Both adoption and surrogacy processes are expensive and time consuming and the woman can experience issues of being treated differently by adoption agencies because of her CHD.

Another surprising finding was that some women felt as if they were the intermediary or “stuck in the middle” between their cardiologist and obstetrician. The literature describes a need for a collaborative approach to family planning (Kovacs et al., 2008). Most of the women described feeling like a messenger between healthcare providers, and did not experience a collaborative approach to care. Several participants described situations where the providers did not communicate with one another. This gap in care caused confusion, anxiety, and fear regarding family planning decisions. The women described a need for increased communication between the patient, cardiologist, and obstetrician.

Implications for Healthcare

Having children is an emotional personal decision that a woman with CHD makes with careful consideration of the information she receives from her healthcare providers and influences from outside sources. The woman is scared to make the wrong decision but is emotionally attached to the thought of having children. This study found three main needs of women with CHD when making family planning decisions: early communication, accurate and reliable information, and support.

As the adult with the CHD population continues to age, more specialized care will be needed. This population wants more information regarding the risks of family planning in relation to their particular CHD. Conversations with healthcare providers about the desire to have children are important when discovering childbearing options for women with CHD. They want information early, during adolescence, in order to make informed decisions regarding contraception and family planning, pregnancy, and childbearing. These findings are consistent with the literature describing family planning issues are not addressed consistently with this population (Sable et al., 2011).

The health care provider is obligated to know and understand the needs of the CHD adult population. This population needs to have cardiologists and obstetricians that are specially trained for them and their family planning issues.

When healthcare providers are trained specifically for CHD, they will be able to impart accurate and reliable information to the adult with CHD.

Healthcare providers should adopt a more collaborative approach to care of the adult with CHD. Consistent communication between the cardiologist and obstetrician will help decrease any anxiety and fear related to family planning decisions. Collaborative care can include in person and online support groups that specialize in family planning issues of the adult with CHD. In this way, a more synergistic environment will enable the adult with CHD to feel supported and reassured in family planning.

Framework

Sister Calista Roy's theory of adaptation, Roy Adaptation Model (RAM), guided this study. According to Roy, the purpose of nursing is to understand people in order to maximize health and living to the individuals full potential, and promote adaptation (Roy, 2009, 2011). The underlying assumptions associated with the theory, and the RAM's focus on the individual experience guided the development of the interview schedule.

The interview schedule focused on discussing the family planning experience of the adult with CHD. Interview questions were developed using the major concepts of stimuli, coping mechanisms, adaptive modes, and output behaviors in the RAM. Findings from this study, suggest that the stimuli, or circumstances and influences that determine family planning, was wanting

children. The coping mechanism used for the study, was the cognator subsystem. This subsystem stores, relates, and responds to the stimuli through perceptual and information processing, learning, judgment and emotion. Having children is an emotional decision, however the women in the study chose to gather information and learn more about options for family planning, in order to make a family planning decision.

Adaptation is the use of conscious awareness and choice to respond and integrate to environmental changes (Roy, 2009). The woman with CHD must be consciously aware of any information regarding family planning in order to choose an option and adapt to any changes in health condition. The adaptive mode concepts of role function and self-concept identity were included in the study. Role function, as a part of adaptation, is concerned with how one feels they are expected to behave in society. The self-concept identity mode of adaptation includes beliefs about the physical and personal self and self-ideal. The women in the study, considered their familial and societal role, and any personal self and self-ideal beliefs when making a family planning decision. These women had concerns with how their personal self and self-ideal fit into social, familial, and spousal expectations. The output behavior of the family planning decision, was an ineffective response or an adaptive response. An ineffective family planning decision could potentially threaten survival. An

adaptive family planning decision would promote the health and integrity of the women with CHD.

Future Research

CHD adults are living longer into adulthood. Current research focuses on adults with CHD and their physical aspects and risks associated with contraception, pregnancy, and childbirth. This study described the personal narrative of adults with CHD and their family planning decisions. The findings from the study support the need for more research regarding family planning and information communicated to the adult with CHD, and the effects of pregnancy on the adult with CHD. These individuals are emotionally attached to having a child, even though they are afraid of passing CHD on to their offspring and of the potential to have a decrease in physical functioning after pregnancy and childbirth.

Future qualitative studies need to be conducted that focus more intensely on the emotional aspects of family planning, including the significant other's point of view. Support groups, in person and online, that focus on family planning need to be implemented and studied for their outcomes with the CHD adult population. Future experimental studies can incorporate the effect of in person and online support groups on family planning decisions. Longitudinal studies need to be conducted that focus on the physical effects of pregnancy on cardiovascular function, and the woman's life span after pregnancy and childbirth.

A longitudinal study of this manner could discover needed information to help alleviate the fear of a decrease in physical functioning after pregnancy and childbirth. These studies could guide development of interventions to educate health care providers on how to counsel women with CHD regarding birth control, pregnancy and adoption/surrogacy.

Conclusion

Family planning is an ongoing process that is difficult for adults with CHD. Adults with CHD desire more information regarding family planning issues during each phase of the family planning process. Women with CHD must be aware of their condition to make an informed choice during any phase of family planning and adapt to any changes in their condition. In general, the woman with CHD wants to have children if it is possible, and if she will not have many physical limitations or decrease in functional ability after childbirth.

The women in the study expressed a desire for early communication, accurate and reliable information and support for their personal family planning decision. These women will consider family, physician, and social influences, and will seek to understand the pros and cons of a decision before they choose their family planning option. These women behave purposefully in all phases of family planning and will seek information regarding family planning from their healthcare provider, other woman with similar conditions, and the Internet. After the women discover their options, discuss the options with their provider, family,

and significant other, they will make a decision. Some women decide to carry the child themselves, others decide on adoption or surrogacy, and others decide on abortion.

Managing care with the inclusion of a holistic viewpoint for this growing population is increasingly important (Gilboa et al., 2010; Verheugt et al., 2010). To maximize the health of the adult with CHD, family planning should be incorporated in to primary care. Greater understanding of adult experiences with family planning will be useful in future educational efforts for the adult with CHD and their healthcare providers.

Appendix A
Percent Change in Annual
CHD Mortality Rates
1999-2006

	% change
Overall	-24.1
Males	-20.5
Females	-27.6
Hispanic	-28.3
Non-Hispanic White	-25.7
Non-Hispanic Black	-15.6
Other Non- Hispanic	-14.8

Appendix B
Overall Mortality Related to CHD
in all Ages by Race-Ethnicity
1999-2006

	Rate
Non-Hispanic White	1.76
Non-Hispanic Black	2.19
Hispanic	1.53
Other Non-Hispanic	1.27

Appendix C
CHD Interview Schedule

Aim: to explore the decision making experience of the adult with CHD regarding family planning

Informed consent script to be stated at the beginning of the interview:

Thank you for taking the time to share with me your experiences with CHD. The purpose of this interview is to discuss your family planning conversations with any individual, either in healthcare or from any organization, and the family planning decisions you made. There are no right or wrong answers to any of the questions and you may skip any question you do not want to answer. You may stop the interview at any time should you become uncomfortable without any penalty. I encourage you to share what you want to share, as I am interested in learning from you. Potential benefits involved with the study are that sharing your individual story of family planning with others in the CHD community and with health care providers may benefit others like you by increasing awareness of the needs of adults with CHD. The risks associated with the study include the loss of time involved with speaking over the telephone and the potential emotional distress involved with discussing an emotional subject. The interviews will last between 20 minutes to one and a half hours, and will be concluded when you or I feel there is nothing more to discuss or you become uncomfortable and wish to stop the interview. This interview will be audio-recorded and immediately transcribed by me using no identifiers, including personal, physician, or hospital names, included in the transcript to maintain your confidentiality. Transcripts will be numbered according to the order the interview was completed. Electronic transcripts will be kept in a locked password encrypted computer for five years after completion of the study. I

will store tapes and printed transcripts in a locked safe in a locked office, and they will be destroyed five years after completion of the study.

Interview questions:

(To establish age, gender, and type of CHD)

How old are you?

What state do you live in?

Are you male or female?

What ethnic group do you most relate to?

What is the name of your CHD diagnosis?

When were you first diagnosed? (age)

1. Tell me about your immediate family, who you live with, or who you are close to.
2. What are your thoughts about having children?
3. Did you ever think about having children of your own?
4. Are you currently in a relationship? Are you single at this time?
5. At what age did you start thinking about having children?
6. Where you ever told anything about having a family of your own or getting pregnant?
7. Where did you get information about family planning or pregnancy?
8. Tell me about your experience discussing family planning issues with a health care provider/counselor/organization.

9. How do you think your decisions with family planning would be different if you did not have CHD?
10. What kind of worries, if any, do you have about having children? Did or do those worries impact your decision?
11. What would have been beneficial to know in the past about having children that you know now but did not know then?
12. Do you feel that CHD is a permanent problem? If so how do you see the future? Physically, Emotionally
13. Is there anything else you would like to discuss? Anything you feel we did not talk about enough?
14. Do you have insurance? Private or other?

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Biographical Information

Kathryn Osteen began her career as a cardiac critical care RN in 1994 after she graduated from Baylor University with her Bachelor of Science in Nursing. She graduated with her Masters in Nursing in 1997 from Baylor University and continued to work as a cardiac critical care RN. Kathryn became interested in adults with congenital heart disease after working with individuals in the cardiac critical care unit. In 2002, she became a faculty member for Baylor University. Kathryn plans to continue to explore research for this population of growing individuals.