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Lived Experiences of Congenital Heart Defect Diagnosis in Adulthood

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Walden University
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Abstract

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MA, Walden University, 2019

BS, University of Arkansas at Pine Bluff 2005

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Congenital heart defects (CHD) are reported by the Centers for Disease Control and Prevention as the most common type of birth defect and can affect more than 30,000 infants each year. However, CHDs diagnosed in adulthood are becoming a growing public health concern. When the defect is not diagnosed in infancy or childhood, adult individuals may experience an array of signs and symptoms leading to the diagnosis of a CHD. CHDs that are undiagnosed until an individual reaches adulthood can cause many health complications. The purpose of this phenomenological study was to describe the lived experiences of adults diagnosed with a CHD between ages 18 and 55 in the United States. The health belief model was the theoretical framework used to explore the lives of individuals diagnosed with a CHD as an adult. In-depth interviews were conducted with 10 individuals diagnosed in adulthood; data were video recorded, transcribed, and analyzed using thematic coding, stored in MAXQDA, and categorized for commonality. Results revealed themes that individuals with late diagnosis of a congenital heart defect experienced concerns regarding the diagnosis of their defect. Data derived from this study may be used to develop educational material to bring awareness of CHDs through various platforms. Recommended areas for further research include repeating the study with smaller research studies in clinical settings to help with the development of health education material and other research-related activities, by developing the knowledge and skill of health care professionals, and implementing procedures and protocols that could help identify, validate, and associate best practices through effective screenings based on patient concerns regarding their health.

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Table of Contents

List of Tables

Chapter 1: Introduction to the Study

Introduction

Congenital heart defects result when the heart or blood vessels near the heart do not develop normally before birth (American Heart Association [AHA], 2019). Congenital heart defects are considered the most common type of birth defect (Centers for Disease Control and Prevention [CDC], 2017) and can go undiagnosed well into adulthood. There is a difference between a congenital heart defect and congenital heart disease. A congenital heart defect results when the heart or blood vessels near the heart do not develop normally before birth. In the United States, more than 30,000 infants a year are affected at birth (CDC, 2017).

Congenital heart defects can range from minor to severe. They can include any of the following: aortic valve stenosis, atrial septal defect, coarctation of the aorta, complete atrioventricular canal, d-transposition of the great arteries, Ebstein's anomaly, l-transposition of the great arteries, patent ductus arteriosus, patent foramen ovale, pulmonary valve stenosis, single ventricle defects, tetralogy of fallot, total anomalous pulmonary venous connection, truncus arteriosus, or ventricular septal defect (AHA, 2019). The AHA (2019) reported "the word 'congenital' means existing at birth, and while the terms 'congenital heart defect' and 'congenital heart disease' are often used to indicate the same thing, a 'defect' is more accurate." A defect is a heart ailment, not a disease (AHA, 2019, para 1).

As discussed later in this chapter, adults diagnosed with a congenital heart defect in adulthood now constitute a growing patient population. A defect may be the primary

diagnosis without the physical presence of a disease. In this regard, there is currently a shortage of data specific to the diagnosis of congenital heart defects in adulthood and is the focus of my research. Bhatt (2015) found that in the United States, there is presently not a database of adults with congenital heart defects that provides systematically collected population prevalence data. Congenital heart defects diagnosed in adulthood can be presumed to be one of the less complicated forms of a congenital heart defect. According to Dr. Joseph Dearani "late complications and surveillance are essential with any patient diagnosed with adult congenital heart disease." (MFMER, 2020, 07:23). MFMER (2020) reported that in adulthood, arrhythmias are the most common complications with adult congenital heart defects, and they should be looked after to determine when they are going to become apparent so that appropriate medical therapy or interventional therapy can be advised. Because late complications can develop, understanding the knowledge level, lifestyle patterns, diet habits, and coping strategies of individuals diagnosed in adulthood can help bring more awareness to this now-growing population.

The way an individual perceives and manages their daily lives; how family, friends, and society treat them; and how the condition may impact their lives can be useful to preparing educational material for the public and for health care professionals. Previous research has shown that health care professionals need to be aware of this experience to assist and support patients and their families throughout the illness (Claessens et al., 2005). Only a few studies have been conducted that take into consideration the direct experiences of adult congenital heart disease patients, even

though these are crucial to adequately counsel patients and their families to promote quality of life (QoL; Claessens et al., 2005). Oster (2013) reported that implementation strategies are needed to help address gaps in scientific knowledge. In this phenomenological study, data were collected through interviews with individuals regarding their lived experiences, which led up to their diagnosis in adulthood. The information can be used to prepare educational material that will promote the need for early routine screenings and alerts for warning signs of heart complications and the need to be seen by a health care professional.

Background

Arth et al. (2017) addressed congenital heart defects as significant contributors to birth defect-related morbidity, mortality, and healthcare costs. Several state-based birth defects programs currently track congenital heart defects among newborns and young children. Still, the CDC (2019) reported that no tracking system exists to look at the growing population of older children and adults with heart defects. According to the CDC (2019), there have been measures to improve life expectancy for individuals diagnosed with a congenital heart defect at birth. Due to those measures, infants and children born with a congenital heart defect are living into adulthood. However, there is a growing population of individuals who are diagnosed with a less complicated heart defect, but a heart defect nonetheless, that may cause complications later in life. Jenkins and Honein (2018) addressed the broad impact congenital heart defects have at the population level. A public health approach is needed to address the challenges of these common critical

and costly conditions. Some patients may also suffer from psychosocial educational or behavioral issues as well.

Muenke et al. (2015) reported that survival rates have improved, and the number of adolescents and adults with heart defects has increased. Previous research conducted in North America suggests that more adults are living with heart defects than children, underscoring the need for appropriate services among this population. Oster et al. (2013) identified significant gaps in addressing the public health concerns related to the prevalence of congenital heart defects across the lifespan, risk factors for the development of congenital heart defects, long-term outcomes for persons with congenital heart defects, but no results linking to adult diagnoses. The study also showed limitations, lack of information beyond infancy, and variations in case definition, data sources, and ascertainment methodology (e.g., active versus passive ascertainment; Parker et al., 2010; Salemi et al., 2013). Since then, the medical community is beginning to realize the increasing public health burden and the impact of the aging congenital heart defect patient population. Oster et al. (2013) also addressed the many individuals with congenital heart defects who remain unaware of the long-term implications of their condition, the possible disease states, and the need for lifelong care.

The most reliable current evidence comes from the findings of Gilboa et al. (2016), who found that in 2010, there were 1.4 million adults in the United States living with congenital heart defects, and 160,000 having severe disease. Currently, there is not a national registry in the United States to help us understand the impact of congenital heart defects, but small steps have been taken, like the passage of the Congenital Heart Futures

Act in 2010. Krasuski and Bashore (2016) reported that “this act allowed the US Centers for Disease Control and Prevention to establish a pilot study of three US centers to begin tracking congenital heart defect prevalence in their respective states” (p. 111). The group has expanded and is using unique techniques to link administrative and medical data for greater insight into this growing population. Once data are fully collected, interpreted, and disseminated, a national registry can be developed for the United States. Until then, larger provincial and national records outside the United States will remain the most appropriate reference points.

Previous evidence has shown that not everyone has benefited from the health care system in the United States (Krasuski & Bashore, 2016). Diallo et al. (2018) reported there has been some “cross-sectional studies conducted in Canada and the Netherlands, which estimate a high proportion of young adults aged 18-22 years (47-60%) who did not receive the recommended follow-up care” (p.1635). Some potential contributors to this included the distance from specialized care centers, male gender, cost of care, cardiology visits outside university settings, and the lack of awareness or education of the issues among patients, families, and care providers. A unique contributor was known as the *fixed for life* syndrome, a 1960s misnomer coined by the medical community that assured patients of being surgically fixed for life (Diallo et al., 2018). In the United States, Chamberlain et al. (2015) reported that “healthcare system changes may help curtail this problem of follow-ups after diagnosis, but the United States is poorly equipped to handle the number of ACHD patients who need care” (p.110). Some parts of the United States have experienced dramatic and unexpected demographic changes over the past few

decades that provide additional unique challenges to the healthcare infrastructure, including an increase in cost.

Problem Statement

Congenital heart defects that are undiagnosed until an individual reaches adulthood can cause many health complications and can lead to increased hospital costs of more than 1.4 million dollars and require lifelong care from qualified specialists like cardiologists (Adult Congenital Heart Association [ACHA], 2017). Adults may be asymptomatic, which eventually leads to the detection of a lesion. Still, some lesions may escape detection until adulthood and become apparent because of a superimposed acquired heart condition or as a result of incidental findings (Bhatt, 2015). Gilboa et al. (2016) estimated the magnitude of the populations affected by congenital heart defects in 2010. The results showed that the prevalence for congenital heart defects ranged from 6 per 1,000 in adults, with more adults living with a congenital heart defect compared to children. Specifics for when they were diagnosed were not given.

There is information specific to living with congenital heart defects from childhood into adulthood available, but there is a lack of health education material for individuals who are diagnosed in adulthood. The aim of this study was to develop ways to educate the public on this growing public health concern by examining the lived experiences of individuals diagnosed in adulthood using a phenomenological approach. Data derived from this study may be used to develop educational material to bring awareness and to address the general public, public health professionals, physicians, schools, and individuals with congenital heart defects through various platforms.

Information obtained from lived experiences can one day be made available to the public through educational brochures and flyers.

Purpose of the Study

The purpose of this phenomenological study was to describe the lived experiences of adults diagnosed with a congenital heart defect from 18 to 55 years of age in the United States. In this qualitative study, I explored feedback from study participants regarding their lived experiences that led up to a diagnosis and their coping strategies to manage their condition after being diagnosed with a congenital heart defect. The gathered data will be made available for the development of educational material. The study may provide more evidence of the need for earlier and more routine screenings based on identified warning signs. Through education, the public and health care professionals can have more information about this rising health concern in adults, promote early and continuous screenings, encourage diet and lifestyle changes, the need to live a more active life to benefit their overall health, and the development of more innovative health education programs for this target population.

Research Questions

RQ1: What are the health-related lived experiences of adults leading to a diagnosis of congenital heart defects in adulthood?

RQ2: In describing their lived experiences after being diagnosed with a congenital heart defect, what are the coping strategies used by the participants to manage their condition?

RQ3: What are the health-related lived experiences of adults following a diagnosis and treatment of congenital heart defect in adulthood?

Theoretical Framework

The health belief model (HBM) developed in the 1950s by social psychologists Rosenstock, Hochbaum, and Kegels with the U.S. Public Health Service provided the theoretical framework for this study. The HBM explains why people in high-risk populations fail to participate in programs designed to detect or prevent disease (Boyle, 2017). The model is used to define the key factors that influence health behaviors as an individual's perceived threat to sickness or disease (perceived susceptibility), the belief of consequence (perceived severity), potential positive benefits of action (perceived benefits), perceived barriers to action, exposure to factors that prompt action (cues to action), and confidence in the ability to succeed (self-efficacy; Rural Health Information Hub, 2019). The HBM can be used to help design short- and long-term interventions for individuals with congenital heart defects.

In this phenomenology study, I employed the HBM as the theoretical framework. The HBM was used for this study to help guide the data collection and analysis process. In the 1950s, the HBM was created by Rosenstock, Hochbaum, and Kegels and was one of the first theories of health behavior. These authors described the constructs of perceived susceptibility, perceived severity, perceived benefits and threats, barriers, cues to action, and self-efficacy as factors that help determine human behavior (Rosenstock, 1974). Boyle (2017) addressed how the HBM was also used to explain why people, especially those in high-risk groups, fail to participate in programs designed to detect and

prevent disease. The model also has three components used to examine the perception of a threat to health, expectations of outcomes as it relates to a specific behavior, and self-efficacy or the conviction that someone can execute a behavior successfully to achieve the required outcome. Kisiangani et al. (2018) reported that the HBM has been effectively used to explore the lived experiences of individuals through early detection of breast cancer, being physically active when morbidly obese (Toft, 2015), and by managing Type 1 diabetes mellitus among African American youth (Strider, 2016).

For this study, the use of the HBM provided an understanding of how health concerns can be related to prevention, like improving screenings performed at birth or bringing awareness to symptoms that alert individuals of the need to go in for a checkup (Resnick & Siegel, 2013). This model was the most appropriate framework to use for this study because it provides an understanding of how individuals assess their health and focuses on their intentions to perform certain behaviors to improve their health. This is an important concept to the HBM. A person's intentions can be influenced by subjective norms. According to Boyle (2017, p. 81–82), if an individual sees the need to make a change is positive, their attitude toward the behavior changes. If they think that their loved one would agree to the change (a subjective norm), their motivation (intention) to change the behavior becomes higher, and they are more likely to make the change.

Nature of the Study

This qualitative research study includes a phenomenological approach to gain knowledge through descriptions of lived experiences of individuals diagnosed with congenital heart defects in adulthood. Rodriguez and Smith (2018) described

phenomenological research as residing in a naturalistic paradigm that asks the questions: “What is this experience like?”, “What does this experience mean?”, and “How does the lived world present itself to the participant or to me as the researcher?” (p. 96). The origins of phenomenology began with writings composed by Husserl. Phenomenology has been considered an international movement of researchers devoted to exhibiting the truth about an experience (Engelland, 2020). Husserl’s approach is now considered descriptive phenomenology, where the experiences are described, and researcher perceptions are set aside or bracketed to enter the lifeworld of the research participant without any presuppositions (Rodriguez & Smith, 2018).

According to Neubauer et al. (2019), Husserl rejected positivism’s absolute focus on objective observations of external reality and instead argued that phenomena as perceived by the individual’s consciousness should be the object of scientific study. Husserl contended that the focus should be on what is given directly to an individual’s intuition and that no assumptions should inform phenomenology’s inquiry; no philosophical or scientific theory, no deductive logic procedures, and no other empirical science or psychological speculations should inform the inquiry. The critical question of a phenomenological investigation for Husserl, rooted in an epistemological attitude, was: What is it for an individual to know or to be conscious of a phenomenon (Barua, 2007).

Now works created by Husserl are illustrated by Martin Heidegger and others. Heidegger was a researcher who worked along Husserl at one point, but later disassociated and focused on understanding the experience, while Husserl focused on understanding beings or phenomena. Hermeneutic phenomenology originates from the

work of Heidegger and is also known as interpretive phenomenology. Hermeneutic phenomenology seeks to understand the deeper layers of human experience that lay obscured beneath surface awareness and how an individual's lifeworld or the world as they prereflectively experience it influences this experience (Bynum & Varpio, 2018). Hermeneutic phenomenology is also used to study individuals' narratives to understand what those individuals experience in their daily lives, in their lifeworlds (Neubauer et al., 2019). According to Heidegger (as cited in a study by van Mahen, 2017):

> During his early lectures of 1919 and 1920, Heidegger states that the manner and meaning of "lived experiences" is the primary question of phenomenology: The question about the manner of the possible having of lived experiences precedes every other question containing subject matter. Only from there and within the method is the fundamental constitution of what is to be apprehended determined. (p. 813).

Reiners (2012) reported that "Heidegger as the student of Husserl, rejected the theory of knowledge known as epistemology and adopted ontology, the science of being." (p.1). Heidegger developed interpretive phenomenology by extending hermeneutics, the philosophy of interpretation (Creswell, 1994). Heidegger broadened hermeneutics by studying the concept of being in the world rather than knowing the world. Heidegger (2013) gave a special twist to the primordiality of lived meaning with the notion of fading or the fading of meaningfulness, a transition into the stage and into the mode of nonprimordiality where the genuineness of the enactment and beforehand the renewal of the enactment are lacking. Van Mahen (2017) suggested if there is no

concealing, hiding, or fading of meaningfulness, then we would not need phenomenology because we would sense with perfect clarity the lived meanings of our everyday existence. From the types of phenomenological approaches previously studied, Moustakas (1994) addressed how descriptive hermeneutic phenomenology would be best used to bring to light and reflect upon the lived meaning of the experience. Husserl's phenomenological approach is most appropriate to explore the thoughts and perceptions related to their shared experiences.

For this study, a qualitative study with a hermeneutic phenomenology approach was conducted using the HBM. Interviews were conducted to allow study participants to share their personal experiences with being diagnosed with congenital heart defects as an adult. Boyle (2017) explained how the qualitative approach can be used to understand participants' experiences through their opinions and insights that can be derived from interviews. Qualitative analysis was most appropriate for this study due to its subjectivity and allowance for the variation of face-to-face, telephone, email, and video conference interviews, the use of surveys, and timeliness. Qualitative research can be categorized or ranked but not quantified as compared to a quantitative approach (Boyle, 2017). Qualitative research methods allow for the determination of the meaning, structure, and essence of the lived experience for the group of individuals diagnosed with congenital heart defects as adults. Bliss (2016) reported that this allows one to view the experience of obtaining data on the phenomenon. In this phenomenological approach, qualitative interviews were conducted with the use of video conferences, email, or telephone interviews. The qualitative interviews consisted of 10 participants and allowed for the

opportunity to ask open-ended questions to elicit the views and opinions from the participants (Creswell & Creswell, 2018). Patton (1990, p. 169) indicated that researchers should select information-rich cases from which they can learn a great deal about problems or the central importance to the purpose of the inquiry from the use of a purposeful sample.

Definitions

The aim of my study was to explore the lived experiences of individuals diagnosed with a congenital heart defect as an adult. Some of the common terms I used in my study are defined below:

Adult congenital heart defect: When there is the persistence of any structural abnormality present at birth that involves the heart and/or great vessels in adult life beyond 16 years of age (Mutluer & Çeliker, 2018).

Adult congenital heart disease: The most common birth heart defect encountered in the clinical setting, affecting 1% of live births (CDC, 2019).

Cardiovascular disease: A broad phrase for a set of different types of diseases affecting the heart and blood vessels (Thiriet, 2019).

Congenital heart defects: The most common form of birth defect; prevalence has been estimated at 7–9 per 1,000 births (CDC, 2019).

Congenital heart disease: One or more abnormalities in a heart's structure that an individual is born with (MFMER, 2020).

Coronary heart disease: A specific form of cardiovascular disease called coronary artery disease, a condition in which plaque builds up inside the coronary arteries. These arteries supply oxygen-rich blood to the heart muscle (AHA, 2014).

Quality of life (QoL): A multidimensional construct integrating an individual's subjective perceptions of physical, social, emotional, and cognitive functioning (Post, 2014).

Assumptions

The aim of this qualitative phenomenological research study was to explore the lived experiences of individuals diagnosed with congenital heart defects in adulthood. There are a few assumptions for this study. First, as the researcher, I assumed that I would be able to understand the participants in the study and that the participants would respond truthfully to the interview questions. Second, I assumed that all participants would offer unique information to the questions asked because of their lived experience of not receiving a diagnosis of a congenital heart defect until adulthood and would be honest about their experiences and honest during the explanation of their experiences. Third, I assumed that the instrument used for the semi-structured interviews would identify barriers and challenges of environmental, socioeconomic, and cultural factors and participants' perceptions of congenital heart defects based on their lived experiences. I also assumed that respondents participated of their own accord and answered the questions truthfully. Last, I assumed that I would be able to bracket my personal experiences and assumptions—that is, I was able to discover the lived experience of individuals diagnosed in adulthood without justifying their understandings based on my

experiences. Interviewing the participants provided information that aided in understanding the need for earlier heart screenings.

Scope and Delimitations

This qualitative phenomenological study was on the lived experiences of individuals diagnosed with congenital heart defects in adulthood. It did not include individuals who were diagnosed with a congenital heart defect from birth or throughout childhood. This study addressed the cost parameters associated with diagnosis and treatment of the heart defects after diagnosis. The study addressed the need for the development of health education material to bring awareness to this growing public health concern.

Limitations

The following limitations were identified, and measures were incorporated to mitigate the overall impact of the study. Study participants were individuals diagnosed with congenital heart defects over the age of 18. Findings may not be generalized to individuals born with a congenital heart defect in infancy and who are still living in adulthood. Potential barriers to conducting the study included the recruitment of enough participants due to time conflicts, ensuring confidentiality for the patient, and obtaining permission to conduct the study. Researcher bias was addressed in the how the questions were asked, and the types of questions asked were thoroughly reviewed. Potential obstacles could have occurred if the participants stated their beliefs on what they thought the researcher wanted to hear and may not have provided truthful responses during the interview. The method of addressing limitations included ensuring participant

confidentiality and providing a quiet and comfortable place to conduct interviews where the environment allowed participants not to feel intimidated or pressured. To address transferability, I provided clear and distinct descriptions of my data collection process, the recruitment and characteristics of the participants, and the location of the interviews.

Significance of the Study

In the United States, there is no prevalent data specifically to examine the demographics of individuals diagnosed with congenital heart defects as an adult. It remains unclear how many current patients were diagnosed as adults, what brought about the diagnosis, and how their lives have changed after diagnosis. Another area of concern is regarding pregnant women. Due to the unknown risk levels of congenital heart defects, if a woman becomes pregnant and has a congenital heart defect, she increases the risk of complications for her and the fetus (ACHA, 2017). This study allowed individuals diagnosed with congenital heart defects in adulthood the opportunity to share their lived experiences that led up to the diagnosis of the congenital heart defects. Through this phenomenological study using the HBM, participants were able to discuss and share their lived experiences, the type of congenital heart defect they were diagnosed with, the events that led up to that diagnosis, and the lifestyle changes they have had to make as a result of the diagnosis. Study results may bring more awareness to community members of the signs and symptoms of congenital heart defect and could provide a measure of how they can improve their quality of living. Results may be used to examine what individuals can do if they suspect a condition is present and encourage individuals to go to their doctor for a screening. Once diagnosed, individuals can take advantage of programs that

will benefit their transition of living with a congenital heart defect. Future health education materials and program materials developed from this study findings may serve as a guide to improve their QoL before symptoms worsen or before they develop into more complicated conditions secondary to their heart defect, such as heart disease (ACHA, 2017).

One of the more pressing concerns related to heart disease is the early detection of cardiovascular disease. Sizer and Whitney (2017) reported the root cause for cardiovascular disease is atherosclerosis, which is a common form of hardening of the arteries. Educational classes that target how cardiovascular disease develops could teach the importance of lower saturated fat consumption, lower sodium, and decreasing added sugar intake are beneficial components. Jackson et al. (2015) found that lack of knowledge results in the higher fat intake among adolescents and adults, and higher knowledge results in lower fat intake. Other components include education on the need for a diverse diet of fresh fruits and vegetables for phytochemical consumption, adequate-protein consumption, whole grains, and fiber intake, as well as adequate hydration, should be included in dietary changes.

This study is expected to create social change on a larger scale to combat the number-one cause of death in the United States, which is heart disease, with the use of ground theory (Chun Tie et al., 2019). Sizer and Whitney (2017) reported that "cardiovascular disease and strokes claim nearly one million lives per year, affecting more than 83 million people in the United States (pp. 399). Engelings et al. (2016) reported mortality results for adults with congenital heart disease are higher than for the

general population, and an analysis of the causes of death concluded that heart failure and sudden cardiac death were the number-one and number-two causes of death associated with adult congenital heart disease (pp. 31). Creating programs that encourage individuals to take advantage of preventive health measures that are covered with their insurance or to see their doctor for routine screenings can improve social change for this community. Through program development, individuals can participate in routine focus groups, health fairs, and nutrition education classes, including food demonstrations and physical fitness activities through their local health clinics and community service organizations.

Information gleaned from study results also may provide health care professionals with additional information to help implement patient-targeted health promotion techniques and to guide patient care and clinical measures to improve practice standards. Because congenital heart defects are typically diagnosed at birth or during pregnancy (AHA, 2017), study data could lead to more screenings in expectant mothers. Mayer (2017) reported that thorough screenings to prevent major health concerns later in life could potentially reduce the costs associated with the treatment of more severe complications. All individuals diagnosed with congenital heart defects will have to find a way to cope with their condition and find ways to continue to live life. The American Academy of Pediatrics (AAP, 2019) suggests assessing the impact of the timing of treatments and the distance to care as a barrier for treatment, which could require public health policy changes that would be needed to evaluate and define optimal care for congenital heart defects patients.

Summary

The overall outcome of this study is expected to promote social change in the community by encouraging individuals to access more routine screenings and to seek medical services to treat their condition before more complicated conditions arise. In Chapter 2, I provide a review of the literature to help address why adult congenital heart defects are becoming a growing concern and why understanding the signs and symptoms that can impact a person's life are important to the development of health education material regarding this growing health problem.

Chapter 2: Literature Review

Introduction

Congenital heart defects undiagnosed until adulthood can lead to increased hospital costs of more than 1.4 million dollars and require lifelong care from qualified specialists like cardiologists (ACHA, 2017). The purpose of this phenomenological study was to describe the lived experiences of adults diagnosed with congenital heart defects in adulthood from 18 to 55 years of age in the United States. In this qualitative study, I explored data collected from study participants regarding their lived experiences that led to a diagnosis and their coping strategies to manage their condition after being diagnosed with a congenital heart defect. Data derived from this study may be used to develop educational material to address the general public, public health professionals, physicians, schools, and individuals with congenital heart defects through various platforms. Information obtained from lived experiences can one day be made available to the public through educational brochures and flyers.

Bhatt et al. (2015) reported that the number of adults diagnosed with a congenital heart defect as an adult is on the rise. Mutluer and Çeliker (2018) reported that adult congenital heart disease exist when there is the persistence of any structural abnormality present at birth that involves the heart and/or great vessels in adult life beyond 16 years of age. This also increases the cost of healthcare for this population. Previous research has suggested the costs of inpatient care for adults with congenital heart defects appear to be increasing considerably (Briston et al., 2016). Also, Gilboa et al., (2016) suggested,

> approximately 2.4 million people were estimated to be living with a congenital heart defect in the United States in 2010; 1 million of those were children under the age of 18 years, and about 1.4 million were adults aged 18 years and older (para. 4)

The study also showed a total of 1,260,000 women and 1,163,000 men living with a congenital heart defect in the United States (Gilboa, 2016).

Liu et al. (2019) reported that, across the globe, having access to healthcare and diagnostic technologies is known to impact the birth prevalence rate of congenital heart disease. Other studies have shown marked heterogeneity between different regions, with a suggestion that congenital heart defect prevalence is rising globally. Liu et al. (2019) further suggested the degree to which this reflects differences due to environmental or genetic risk factors, as opposed to improved detection, is uncertain and the incidence rate for congenital heart defect is about 20% and can be attributed to genetic syndromes, teratogen exposure, or maternal diabetes, and the remaining 80% of cases account for the uncertainty of risk factors that contribute to the condition.

The CDC recently funded three pilot projects for surveillance of congenital heart defects to begin to address the prevalence of congenital heart defects in adults (Bhatt et al., 2015). The researchers also found that in the province of Quebec, Canada, there was a prevalence of 4.09 cases of congenital heart defect per 1,000 adults in 2000, with 9% of these people having diagnoses of a severe congenital heart defect. If this information is extrapolated to the United States, there would have been approximately 850,000 adults with congenital heart defect during this time.

In this qualitative study, I explored feedback from study participants regarding their health-related lived experiences, and the information may be used to develop educational material that encourages heart screenings and promotes healthy lifestyle behaviors. Through education, the public and health care professionals can have more information about this rising health concern in adults, promote early and continuous screenings, support innovative health education programs for this target population, and encourage diet and lifestyle changes and the need to live more active lives to benefit overall health. From the current literature, I found two studies on related topics from the past 10 years. However, only one of them (Gilboa et al., 2016) provided relevant information and diagnosis in adulthood, coping strategies, and educational material on this topic.

Literature Search Strategy

The literature search strategy included an in-depth search in the Walden University Library research databases. The databases included all EBSCO host databases, including Medline, SAGE Journals, and International Journals of Cardiology, and PubMed, as well as Google Scholar. Organizational websites were also examined, such as the CDC, Adult Congenital Heart Association, and the American Heart Association to locate articles related to adult congenital heart defects that focused on awareness, detection, and coping after diagnosis published between 2015 and 2019. International studies were included due to the limited research on the late diagnosis of congenital heart defects in adults in the United States.

The literature search provided full text articles published from 2004 to 2020. The most recent literature was searched and suggested there is a limitation of data on this topic and that more research should be done in the area; the diagnosis of congenital heart disease rather than a congenital heart defect without the presence of disease should be further explained. The search covered the most recent literature and included articles that are influential to research on this topic with the use of the phenomenological approach and the HBM. The key search terms and combinations of search terms for the literature review included: *congenital heart defect, late diagnosis, diagnosis in adulthood, adult congenital heart defect, coping with congenital heart defects, early detection for the congenital heart defect, congenital heart disease,* and *care for congenital heart defects*. Due to the limited data on the topic available, search terms were specific to congenital heart defects versus congenital heart disease.

Theoretical Foundations

A study published by Rollins et al. (2018) regarding the HBM described it as one of the first theories of health behavior created in the 1950s by Rosenstock, Hochbaum, and Kegels. Rollins et al. further explained the role of HBM is designed to help planners envision how the change would occur and the role interventions can play in helping to facilitate the change. Previous research suggested the use of this model provided an understanding of the health concerns that can be related to prevention, like the use of screenings as components for prevention. Rosenstock (1974) described the constructs of perceived susceptibility, perceived severity, perceived benefits and threats, barriers, cues to action, and self-efficacy as factors that help determine human behavior. The HBM was

also used to explain why people, especially those in high-risk groups, fail to participate in programs designed to detect and prevent disease (Boyle, 2017).

Boyle (2017) addressed the three components of the model that examined the perception of a threat to health, expectations of outcomes related to a specific behavior, and self-efficacy or the conviction that someone can execute a behavior successfully to achieve the required outcome. Previous research has shown that the HBM has been effectively used to explore the lived experiences of individuals through early detection of breast cancer (Kisiangani et al., 2018); when assessing being physically active when morbidly obese (Toft, 2015); and when arguing the management of Type 1 diabetes mellitus among African American youth (Strider, 2016). Becker (1974) reported the HBM model was extended to study people's responses to symptoms and their behaviors in response to a diagnosed illness. The HBM provided an understanding of how health concerns can be related to prevention, like improving screenings performed at birth or bringing awareness to symptoms that alert individuals they need to go in for a checkup. The HBM also provides an understanding of how individuals assess their health, focused on their intentions to perform certain behaviors to improve their health. The HBM can be used to look at many components that will help plan educational material for interventions. Glanz et al. (2015) addressed an individual's perceived susceptibility and perceived severity, perceived benefits and perceived barriers, cues to action, and self-efficacy as the major components.

According to Boyle (2017, pp. 81–83), if a client perceives they are at risk of contracting a disease and are concerned that having the disease carries serious

consequences, whether physical or social, they may be willing to make a change. This theory is of limited value for primary prevention efforts but can be effective when used with populations with nutrition-related risk factors, such as high cholesterol or diabetes, where diet change can be linked to tangible risk reduction. Boyle (2017) also noted that a nutrition assessment could include a client's perceived susceptibility and should pose questions like the following: Do you feel at risk for heart disease? Or how has the diagnosis of a congenital heart defect in adulthood affected your life? These questions focus on a client's perceived susceptibility and their perceptions of the severity of the risk. Boyle (2017) suggested that in the second component, the client perceives that a certain behavior will have benefits, but there may be some barriers to adopting the new behavior. The third component is self-efficacy, or the conviction that one can successfully execute the behavior required to produce the outcomes. Boyle (2017) also explained a person's intentions can be influenced by subjective norms. If an individual sees the need to make a change as positive, their attitude toward the behavior changes. If they think a loved one would agree to the change (a subjective norm), their motivation (intention) to change the behavior becomes higher, and they are more likely to make the change. The more severe they perceive the outcome to be (effects of congenital heart defects), the greater the chance they will be motivated to avoid the behavior (acknowledge symptoms and seek a screening).

Conceptual Framework

In this phenomenology study, I employed the HBM as the theoretical framework. The HBM was used for this study to help guide the data collection and analysis process.

In the 1950s, the HBM was created by Rosenstock, Hochbaum, and Kegels and was one of the first theories of health behavior. These authors described the constructs of perceived susceptibility, perceived severity, perceived benefits and threats, barriers, cues to action, and self-efficacy as factors that help determine human behavior (Rosenstock, 1974). The HBM was also used to explain why people, especially those in high-risk groups, fail to participate in programs designed to detect and prevent disease (Boyle, 2017). The model also has three components that can be used to examine the perception of a threat to health, expectations of outcomes as it relates to a specific behavior, and self-efficacy or the conviction that someone can execute a behavior successfully to achieve the required outcome (Boyle, 2017). HBM has been effectively used to explore the lived experiences of individuals through early detection of breast cancer (Kisiangani et al., 2018), being physically active when morbidly obese (Toft, 2015), and managing Type 1 diabetes mellitus among African American youth (Strider, 2016).

For this study, the HBM provided an understanding of how health concerns can be related to prevention, like improving screenings performed at birth or bringing awareness to symptoms that alert individuals they need to go in for a checkup (Resnick, & Siegel, 2013). This model is the most appropriate framework to use because it provides an understanding of how individuals assess their health, focused on their intentions to perform certain behaviors to improve their health. This is an essential concept with the HBM. Subjective norms can influence a person's intentions. According to Boyle (2017, pp. 81–82), if an individual sees the need to make a change as positive, their attitude toward the behavior changes. If they think that their loved one would agree to the change

(a subjective norm), their motivation (intention) changes the behavior becomes higher, and they are more likely to make the change.

The HBM provided an understanding of the health concerns that can be related to prevention, such as public health programs and educational materials that focuses on preventive methods like screenings. The connection of the HBM to educating community residents so that they understand that they are at risk for a health problem or disease is by looking at the fundamental principles of the model (Jones et al., 2015). The HBM illustrates that an individual's perceived risk of being affected by a particular health condition and the perceived severity of these effects impacts their decision making to change their behaviors (Glanz, Weimer, and Vinswanth, 2015). LaMorte (2018) reported

> the HBM is more descriptive than explanatory and does not suggest a strategy for changing health-related actions. In preventive health behaviors, early studies showed that perceived susceptibility, benefits, and barriers were consistently associated with the desired health behavior; perceived severity was less often associated with the desired health behavior. The individual constructs are useful, depending on the health outcome of interest. Still, for the most effective use of the model, it should be integrated with other models that account for the environmental context and suggest strategies for change (para 5).

The HBM is generally applied to settings that will motivate people to take charge of their lives and engage in positive health actions and avoid the negative health consequences as a critical motivational strategy (Rural Health Information Hub, 2019). Some examples of how this model is applied can be demonstrated in studies of individuals with HIV, heart

disease, and cancer. HIV is an adverse health consequence, and to avoid the consequences of contracting HIV, safe sex practices become a strong motivator (Kagee & Freeman, 2017). As it relates to heart disease, the perceived threat that heart failure can be a result of unhealthy diet practices can motivate individuals at risk to engage in a healthier diet and exercise choices (Shojaei et al., 2016). A study by Zare et al, (2016) which focused on prostate cancer prevention discussed how health education programs designed based on HBM could positively affect the prostate cancer preventive behaviors of individuals by improving their knowledge level and leaving positive effects on perceived susceptibility and severity as well as considering the perceived barriers, benefits, and health motivations.

Literature Review Related to Key Variables/Concepts

There is information specific to living with congenital heart defects from childhood into adulthood available in previous research studies, but there is a lack of health education material for individuals who are diagnosed in adulthood. Bhatt (2015) suggested that with minimal data and the lack of a database specific to adult congenital heart disease in the United States to provide systematically collected population prevalence data, more research is needed. Some of the research studies that are beneficial to my research provided a range of informative data that can be used in this qualitative study. An article by Irene Maher of the Tampa Bay Times (2017) looked at overcoming a congenital heart defect. It discusses an account of experiences that were shared with the editor and gives different accounts of experiences of individuals who deal with congenital heart defects with their young infants and the circumstances surrounding diagnosis. Some

defects caused no problems, while others have long-term ramifications. Therefore, bringing awareness to the concerns of late diagnosis is a key to encourage earlier screenings.

Researchers Carlsson and Mattsson (2018), explored the emotional and cognitive experiences, during the time of diagnosis and decision making, among males presented with a congenital heart defect in the fetus carried by their pregnant partner. The use of 12 expectant fathers was recruited through two tertiary referral centers for fetal cardiology in Sweden after they had been presented with a prenatal diagnosis of congenital heart defect in the fetus carried by their pregnant partner. The respondents were interviewed via telephone, and the interviews were analyzed using inductive qualitative content analysis. The results showed the effects of keeping the pregnancy or terminating the pregnancy, and their attitudes toward either decision. The results showed the importance of inclusive care and adequate follow-up routines for both expectant parents following a prenatal diagnosis. It looked at the initial emotional shock, the decisional processes, and depending on the decision the couple reached toward termination or continuation of the pregnancy. The study also focuses on the masculine perspective of dealing with the diagnosis of congenital heart defects and comforting and making decisions with the pregnant mother.

A study by Kronwitter et al. (2018), reviewed the psychosocial parameters that are missing from research and compared them to data that was collected 20 years ago. A slightly modified questionnaire was used to look at the difference between the two populations and predictors of psychosocial burdens for the more recent population was

reviewed. The results showed that there is more of a presence of more complex heart defects in the current population, as well as greater improvements in outcomes regarding school performance, employment, and sports. The author's research approach was qualitative and included survey administration. There are some limitations with the study in that it may have some selection bias due to the choosing of participants who may have a better education and access to adequate healthcare. The 20-year time gap can also be a limitation due to the difference between sociodemographic factors that can impact the results of the study. The article does fill a gap in the literature by viewing the missing parameters of the psychosocial parameters that affect an individual risk for congenital heart disease. The article can be applied to my study because it views conditions that can impact the health care and services for individuals diagnosed with a congenital heart defect.

A study by Engelings et al. (2016), viewed the deaths of individuals who were diagnosed with congenital heart defects as adults. The goal of the study was to analyze the causes of death in a nationwide contemporary cohort because the data was lacking. The study used a cohort of the German National Register for Congenital Heart Defects to screen patients over the age of 18, who died between January 2001 and January 2015. The data included cardiac diagnosis, symptoms, operations, interventions, comorbidities, and causes of death were analyzed. The leading causes of death were identified as heart failure and sudden cardiac death. The researcher's used a quantitative study to look at the data to compare causes of death over the course of 15 years. The gathered data helped them to determine the causes of death and other important data surrounding individuals

with congenital heart defects and possible causes of death. One limitation in this study was that researchers did not have access to the entire medical or surgical data of the patients, and despite frequent follow-ups with the patient's primary care physicians, it was difficult to obtain complete information regarding the cause of death for some patients. This study focuses on conditions that lead to heart disease or conditions of the heart leading to death, which relates to my study.

Determining which theoretical foundation will work best with my research topic and examines the lived experiences of individuals diagnosed with congenital heart defects as an adult was looked at in the following resources. The use of telephone interviews and video conferencing as a data analysis tool was beneficial to obtain information that will link to my research topic. A study by Alshenqeeti (2014), addressed ethical concerns and looked at the qualitative method of interviewing, and assessed the values and limitations of its use in research. The author discusses interview types and the differences between them and discusses the usefulness and shortcomings, validity, and reliability of using interviews as an instrument through critical evaluations. Musselwhite et al. (2007) identified the pros and cons of using telephone interviews as part of their research methods. Some of the benefits of using telephone interviews included using economic and human resources efficiently, minimizing disadvantages associated with in-person interviewing, developing positive relationships between researchers and participants, and improving the quality of data collection. Some cons to using telephone interviewing included maintaining participant involvement, maintaining clear communication, communicating with participants who offer extraneous information,

encountering participants with health concerns, and communicating with a third party. It is recommended by the authors that the Manual of Operations be used as a tool to assist researchers in meeting the requirements for successful interviewing.

A cross-sectional study by Harrison et al. (2011) investigated the barriers to medical, healthcare behaviors, and concerns regarding any medical, psychosocial, and lifestyle behaviors of adults with congenital heart disease. The study examined 123 adult patients and discusses some of the major concerns that they reported. The study included additional information regarding the barriers to care beyond financial and transportation challenges, education on when to seek medical attention, and not limiting reports to only individuals with congenital heart disease. The study also recommends the need for more patient center educational programs. A study by Claessens et al. (2005) aimed to explore the lived experiences of adults with congenital heart disease. It recognizes that this is a new and continuously growing population. The research is done through unstructured in-depth interviews performed with 12 patients between the ages of 25-40, who were diagnosed with a moderate or severe form of congenital heart defect. The study used the ground theory as a method of theoretical frameworks and resulted in a view of the central themes of the patient's experiences. The data were analyzed by transcribing the tape recordings. The overall results of the study showed that it was important for patients to feel normal as a big component of dealing with their defect.

Conclusion

Adult congenital heart defects are a growing health concern. Being able to develop educational material to address the concern is not only essential but is crucial to

providing guidance on life-changing conditions that can help people in different ways. By providing a clearer understanding of what congenital heart defects are and showing the need for more educational material on the subject can lead to early diagnosis, treatment, and management of the type of heart defect being treated, even if it is less severe. Providing educational material to health care providers can further enable them to provide information and build a trusting relationship with their patients. They can also refer their patients to other resources that will be beneficial for their health. Providing educational material to address the concerns of adult congenital heart defects are essential to understanding how the information will be assessed. This study focused on the benefits of the HBM and how it is used along with the phenomenological approach to understanding experiences associated with late diagnosis of congenital heart defects in adulthood. In Chapter 3, I describe the research design, sample recruitment, data collection, and analysis procedures that I used to capture the lived experiences of selected participants.

Chapter 3: Research Method

Introduction

The purpose of this study was to generate knowledge about personal accounts of the lives of individuals diagnosed with a congenital heart defect in adulthood and their ways of coping with it after diagnosis. This information can help to provide suggestive ways the health care community can use this information to create educational material for this population of people and for health care professionals and to find coping strategies after diagnosis for a better QoL. This phenomenological study aimed to reveal and interpret the lived experiences of individuals diagnosed with congenital heart defects in adulthood, who are between the ages of 18 and 55 years and live in the United States. This information may provide health care workers with many options for treatment and instructional ideas for individuals with a late diagnosis of congenital heart defects. This study may provide health providers with appropriate data for intervention in health education materials and proper counseling strategies.

The study can improve targeted outcomes and education to family members and caregivers when health care providers can provide tools that allow the families to cope with the diagnosis and provide a reference to evaluate signs and symptoms. Abuidhail et al. (2017) reported that data such as these can assist with the development of interventions and strategies that minimize the stress experienced by patients and that support the emotional capacity of patients dealing with a stressful situation. The data also may help families make better-informed choices on seeking healthcare earlier and obtaining diagnostic screenings. The study may answer questions as to where the gaps in

knowledge exist and how the scenarios are organized as opposed to risk factors for a crisis. For example, what is known about congenital heart defects? What impact does medical orientation have on the late diagnosis? What are the perceived factors or barriers to treatment and coping strategies?

Thakkar (2018) reported that with more than 1.4 million adults living with congenital heart disease in the United States, access to specialized, compassionate, high-quality, comprehensive care requires a shift toward more aggressive expansion of adult congenital heart disease care. According to Thakkar (2018), "this is especially important when we consider the sparse adult congenital heart disease provider representation in the vast majority of adult medical centers across the U.S." (para 2). Because the adult diagnosis of congenital heart defects is a growing health concern (ACHA, 2019), this study's findings may help toward building effective adult congenital heart disease programs to help with the management of adult congenital heart disease complexity matched with the cultivation of crucial resources and clinical services ranging from early detection to congenital cardiac surgery, and interventional cardiology to acquired heart disease while bridging partnerships with noncardiac specialists.

In Chapter 3, I describe the research design, sample recruitment, data collection, and analysis procedures that I used to capture the lived experiences of participants. I present a comprehensive description of the study design, the methods for selecting participants, data collection, and data analysis methods. I summarize the methodology and the procedures that I used to investigate the elements that led to the diagnosis of a congenital heart defect. I highlight the information regarding my position as the

researcher and its effect on the research study. I describe the relevance of the methodology to the purpose of the study, the participant information, and any ethical consideration with the phenomenological approach. Lastly, I discuss the complex phenomena of the lived experiences of individuals diagnosed in adulthood and the underlying reasons that led to the diagnosis.

Research Design and Rationale

Creswell (2018) reported that qualitative approaches to collecting data, analyzing, and interpreting the data, and writing the report differ from the traditional quantitative approach. In this study, I used a qualitative approach to examine the lived experiences of individuals diagnosed with a congenital heart defect in adulthood. This approach enabled me to investigate the external factors contributing to the diagnoses of congenital heart defects in adulthood. The external factors include the environment in which the participant lives, lifestyle habits, dietary habits, access to healthcare, income, and coping strategies after diagnosis. Chung Tie et al. (2019) reported "grounded theory is a well-known methodology used in both qualitative and quantitative data generation methods. Grounded theory sets out to discover or construct theory from data, systematically obtained and analyzed using comparative analysis" (p. 2). However, Creswell (2018) reported that phenomenology does not focus on an individual life but rather on a concept or phenomenon. I employed a phenomenological design for this study to align with my focus on capturing the lived experiences from the participants' perspectives for interpreting data (Patton, 2002).

Phenomenology was selected for this study because it allows the phenomenon as it naturally occurs to be implemented and to explore the lived experiences of the participants under investigation. Data were collected from the participants via video conference, email, or telephone conference to provide a better understanding of the phenomenon under study and answer the research questions.

RQ1: What are the health-related lived experiences of adults leading to a diagnosis of a congenital heart defect in adulthood?

RQ2: In describing their lived experiences after being diagnosed with a congenital heart defect, what are the coping strategies used by participants to manage their condition?

RQ3: What are the health-related lived experiences of adults following a diagnosis and treatment of a congenital heart defect in adulthood?

The phenomenological approach is appropriate for this study; this approach provided data from the personal perspectives to describe the experiences of patients with a late diagnosis of congenital heart defects and the coping strategies they used. Participants must have been diagnosed with a congenital heart defect between 18 and 55 years of age. Once chosen, participants were invited to describe their experiences with the late diagnosis of a congenital heart defect, give narratives of the significant life events, and explain further if there was a relationship between their overall health and this life event. Participants were asked to describe their coping strategies after diagnosis. The use of in-depth interviews is a data collection method used in qualitative research. In-depth interviews were used to gain knowledge through the description of lived

experiences and coping strategies to manage their condition after diagnosis. The aim of this study was to capture the health-related lived experiences of individuals diagnosed with a congenital heart defect in adulthood and to obtain descriptions from the participants' perspectives.

According to Patton (2002), the hermeneutic phenomenology approach offers a perspective for interpreting this kind of data. This methodology is suitable for the investigation of the phenomenon relevant to the lived experiences of the participants. Previous research shows this approach enables the researcher to use categories of knowledge consistent with the descriptive view of the participants' lived experiences (Heidegger, 1927/1962). The phenomenological methodology was also employed with success by Moustakas (1994), Giacomimi and Cook (2000), and Ironside et al. (2003). Matua & Van (2015) reported that hermeneutic phenomenology focuses on understanding the awareness of implications of the text, or the meaning of the expressions of words of the participants against the phenomena. I appraised texts of transcripts and the articulated descriptions of personal experiences and segregate themes (van Manen, 1997). Using this approach, I examined the text to expose any substance and to uncover any crude expressive, meaningful, and thematic meanings (van Manen, 1997). Once the themes had been selected, I decoded the narratives of their lived experiences. Matua & Van (2015) reported that with using hermeneutic interpretative phenomenology, the investigator and participants communicate, and the results are evaluated to provide conclusions. Van Manen (1990) reported that participants will communicate their understanding of themselves and their experiences that helped to fashion the meaning of

their experience. I served as the principal data compilation tool in a hermeneutic phenomenological study, to understand and to be aware of the implications of the texts, namely the meaning and expression of words of the participants against the background of the phenomena (Matua and Van, 2015).

Role of the Researcher

A researcher has many responsibilities when conducting a study (Creswell, 2007). Apart from recruiting and selecting participants, researchers must be competent and knowledgeable enough to implement the appropriate instrument, conduct interviews, organize, and store the data, analyze data collected, and prepare reports for best results. Groenewald (2004) suggests that a researcher applying phenomenology is concerned with the lived experiences of the people involved, or those who were involved with the issue that is being researched. Starks and Trinidad (2007) reports the researcher's objective is to ask probing questions to encourage the study participant to elaborate on the details of the issue at hand, to achieve clarity, and to stay close to the lived experience. My professional skills and education provided me with the knowledge of working with individuals diagnosed in adulthood. I have served as a site supervisor and team leader for a large community nutrition program for eight years and currently work in collegiate education and community program development for over five years. Previous research suggests that there is a need to ensure the researcher has a privileged position balanced with the responsibility to both the participant and the research method (Hay-Smith et al., 2016). Researchers must also follow a code of ethics to ensure that the participants do not feel judged or uncomfortable when they are being interviewed.

Bracketing My Perspective

My perspective includes my experience coming to understand and implement evidence to practice as an individual diagnosed late in adulthood. My personal details help to frame my background as the researcher.

Researcher's Context

I was diagnosed with a congenital heart defect at 35 years old. My experience in health care started almost 20 years ago when I pursued a career as a registered nurse, and eventually, a registered dietitian. In 2005, I began to pursue my career to become a Registered Dietitian Nutritionist. After completing my dietetic internship, I became a Nutritionist for the Women, Infant, Children's (WIC) program, where I worked for eight years before moving into my current position teaching on a collegiate level. Working at WIC, I taught others about the benefits of eating healthy and being physically active. One year before diagnosis, I began to experience shortness of breath when physically active and was referred to a cardiologist, but the in-office costs were too expensive. Therefore, I could not get the required echo and stress test completed.

I continued to monitor the condition, and a year later, as I began to train for the MS 150, which is a 150-mile bike ride across Texas, the symptoms became more pronounced. When I was on level ground, there were no symptoms. When I went uphill or up a flight of stairs, I became short of breath. This led me to return to my primary doctor, who insisted that I have an echo and stress test, but this time referred me to a different cardiologist who performed the echo and stress test. I was diagnosed with Ventricular Septical Defect (VSD). My professional skills and education include the

knowledge of working with families and children for eight years, teaching nutrition education classes in the community for eight years, teaching nutrition courses at a university for the last six years, and teaching nutrition courses at a university and nutrition education classes in the community. The researcher's role and responsibility for this study included designing the study, creating open-ended interview questions and guidelines, conducting the interviews, collecting the data, and conducting the data analysis and interpretation. Further as the researcher was the primary instrument for data collection, interpretation, and analysis controlling for bias was paramount.

Researcher Bias

Blair et al. (2011) suggest that researcher biases can undermine the quality of the study. For the current study, researcher bias was addressed beginning with self-awareness of the personal interest driving desire to conduct the study. My interest in this study came from past experiences of personally being diagnosed at age 35 with a congenital heart defect after having breathing problems while training for a marathon. The participants were not exposed to the details of my personal life. The use of consistent documentation throughout the study was used to enhance the quality of the study and to control for unintended bias. Researchers are encouraged to consider how biases may affect the quality of their study and to use documentation as a way to remain aware of potential implications of bias. Actions and reactions, as the study was conducted, were consistently documented, and addressed throughout the study. Blaire et al. (2011) reported that biases do exist in research studies, and that it is important to have an ethical framework to deal with ethical issues.

As noted above, interest in the current study came from personal life experiences and the lack of available information to address the topic. Researching the topic of congenital heart defects yielded information only on the different types of heart defects and the levels of severity. There is a lack of data reflecting signs and symptoms that could pose a need for health care screenings. The signs and symptoms may not be the same as those identified with more complex heart conditions and can be inadvertently overlooked. There is also more of a reference to congenital heart disease versus congenital heart defect, as they are stated to mean the same thing. Addressing the difference between the terms can be beneficial to promote the benefits of earlier screenings.

Researchers Dorfler and Stierand (2020), reported that bracketing can be conceptualized as the researcher's attempt to hold in abeyance their pre-understandings and assumptions to attain experiences before making sense of them. The themes that emerged from the study represented the fundamentals of my prior understanding of the phenomenon and my involvement with the phenomenon. This bracketed my prejudices, and I avoided justifying the meaning of the data that supported personal deductions regarding the phenomenon. I also created an account of their experiences during the data collection to offer the experience that helped to form perceptions related to their experiences as the researcher. I ensured that my position was balanced with the responsibility to both the participant and the research methods.

Methodology

Participant Selection

The phenomenological study involved identifying and locating participants who have experienced or are experiencing a phenomenon that is being explored (Rudestam and Newton, 2015). Purposeful sampling was used to identify participants in the study. This approach does not need underlying theories or a set number of participants. Bernard (2002) suggests that this method allows the researcher to find people who can and are willing to provide the information by virtue of knowledge or experience This study recruited 10 participants. Many phenomenological studies contain a small number of participants, typically 10 or less (Rudestam and Newton, 2015). The participants for this study were recruited from social media groups on Facebook due to the growing concerns of the COVID-19 pandemic. These groups included the Congenital Heart Defects & Heterotaxy Syndrome Info and Support Group, Adults with Congenital Heart Defects, Congenital Heart Defect Awareness, and Living with Congenital Heart Disease. Due to the widespread of the pandemic, obtaining face-to-face interviews was not permissible due to restrictions mandated by the CDC Guidelines and social distance recommendations (CDC, 2020). According to the CDC (2020),

> the "Coronavirus Disease 2019 (COVID-19) global pandemic has forced public health to reassess its approach to providing care while keeping staff and patients safe. The guidance has the following objectives: 1) minimizing the risk of exposure, illness, and spread of disease among staff conducting public health emergency response operations and essential public health functions; 2)

> minimizing the risk of exposure, illness, and spread of disease among members of the public at public health facilities; and 3) preserving essential functions and mission capabilities of the state, territorial, local, and tribal health departments" (para 1).

Procedures for Recruitment, Participation

Participants were informed about the study by flyers that were created and posted to the following Facebook groups; the Congenital Heart Defects & Heterotaxy Syndrome Info and Support Group, Adults with Congenital Heart Defects, Congenital Heart Defect Awareness, and Living with Congenital Heart Disease. The potential participants who met the study criteria and who were interested in the study were instructed to contact me using the e-mail address provided on the flyer. The inclusion criteria for this research included the following: adults aged 18 and 55 years diagnosed with a congenital heart defect as an adult. The exclusion criteria included adults aged 18 and 55 years diagnosed with a congenital heart defect at birth or during childhood, and who are less than the specified age requirement.

Instrumentation

The instrument that was used to collect data for this research study was the Consent Form (Appendix B) and Interview Protocol (Appendix C). The instruments were customized and reviewed before the implementation to make the necessary revisions. Member checking was implemented during the interview process with the study participants for validity and appropriateness. The Interview Protocol focused on questions about each of the issues related to this research study to help me facilitate the

interview process. All the study participants were presented the same questions, in the same order, and given equal opportunity, time, and duration to respond to the questions during the 45 min interview session. The instrument was self-designed and tested before administering the study to ensure that it is formatted correctly, and understandable. The questions aligned with the phenomena under the study.

The interviews were administered mainly via video conference. The participants provided their informed consent before the interview took place to ensure understanding of the scope and purpose of the study, to be informed on how the information would be used, and to ensure their confidentiality was protected. I provided an overview of the study and explained the informed consent upon meeting with the participants. The interviews were video recorded to enhance the researcher's accuracy of the participant's responses. After the interviews were concluded, participants received a follow up email to verify the information. Historical legal data was not used as a data source.

Data Collection Method

The phenomenological methodology includes identifying the lived experience through the literature review of the phenomenon and by conducting an observational investigation through data collection and bracketing of the researcher's knowledge (van Manen, 1997). Individuals who responded to the social media posts and were interested in participating were instructed to contact the researcher to go over the inclusion criteria before scheduling the interview. Considering the pandemic, interviews were conducted virtually via Zoom (video conferencing), email, or telephone conferences. An appointment was scheduled with the 10 participants who responded to the flyer and filled

out the Consent Form; however, if the individual did not meet the prescreening criteria, they were not scheduled for an appointment.

Qualified participants were required to participate in the interview session, which lasted approximately 45 minutes at a scheduled time via video conference. Upon meeting with the participants, I provided an overview of the study and explained the informed consent form. The participants were asked to sign the informed consent form before the start of the interviews in order to further explain and provide an understanding of the scope and purpose of the study, how their information would be used, and how their confidentiality would be protected. A researcher-developed instrument of interview questions was used to interview the participants. If needed, participants were contacted for follow-up questions. Participants were also debriefed on the findings of the study via the method that the interview was conducted after the conclusion of the study. The data was kept secure by encryption. No names or obvious identifiers were used when storing the data. The data will be kept for a period of at least 5 years, as required by the university.

Qualitative Data Analysis Plan

Unit of Analysis

The unit of analysis constitutes the smallest unit from which information can be collected in the study. According to Patton (2002), individual people, groups, and organizations can be the unit of analysis. Therefore, the primary focus of data collection is on what is happening with the phenomenon in a setting and how it affects the individuals in the setting. I collected data from adults aged 18 and 55 years who were

diagnosed with a congenital heart defect in adulthood. These adults are the units of analysis for this study.

Data Analysis

The interviews were scheduled at a time convenient for participants. The demographic data of each participant was collected. The interview questions were open-ended and prepared in advance and took no longer than one hour to complete. All interviews were video recorded to enhance researcher accuracy of the participants' responses, and notations of interview dates, locations, and time duration with the participants' approval were kept. The documents used were Microsoft Word, Microsoft Excel, and MAXQDA software. As a result of the interviews, any emerging themes and questions were coded, analyzed, and summarized for data analysis.

Thematic analysis is a qualitative research method that provides core skills for conducting many other forms of qualitative analysis (Braun and Clarke, 2006). It can be widely used across a range of epistemologies and research questions (Nowell et al., 207). It is a method for identifying, analyzing, organizing, describing, and reporting themes found within a data set (Braun and Clarke, 2006). A rigorous thematic analysis approach can produce trustworthy and insightful findings, and it can provide a rich and detailed, yet complex account of the data (Braun and Clarke, 2006). Van Manen (1997) suggested three methods that are involved in thematic analysis that were used in this study. These included taking a holist approach, discriminatory approach, and sentence-by-sentence analysis. This process was continued until saturation was reached. Saturation was used to ensure that adequate and quality data are collected to support the study (Walker, 2012).

Researchers Hennink et al. (2017) identified two different approaches to saturation and drew out the parameters that influenced saturation in each approach to guide sample size estimates for qualitative studies. Saturation would be determined when the same responses come from participants, or by the researcher's judgment and experience (Patton, 2002; Van Rijnsoever, 2017), or when no new information has been obtained after interviewing all participants (Van Rijnsoever, 2017). Saturation was achieved after completing eight interviews, but I continued until with all scheduled interviews.

All information obtained from the study participants was kept confidential. All copies of personal data and information pertaining to each participant were secured in a locked cabinet, and all electronic documents were secured through encryption and the use of protected hard drive software. After five years, all data will be destroyed, and all electronic files will be deleted after the required five-year period of data retention as specified by Walden University. The data will be erased from the hard drive instead of deleted so that it cannot be duplicated later. As a security measure, I assigned each participant a pseudonym that was known only to me. Participants were not disclosed any other participant information, and all data was kept confidential. I am the only one with knowledge of security.

Data Management

Starks and Trinidad (2007) reported that in qualitative analysis, the researcher is considered the instrument for analysis. Creswell (2003) reported that the objective of data analysis is to make sense of the textual data. Verbal statements and the actions of participants in this study were analyzed for meaningful interpretation using several

approaches for monitoring, documenting, and evaluating the analytical process. The analytical methods that I have chosen helped in understanding the thoughts and feelings of the participants as they provided their lived experiences, and their coping strategies, and how they could be affected by the environment, socioeconomic status, and cultural values.

Maxwell (2005) stated, “that a categorizing strategy in qualitative research is coding.” (p.465). With there being several steps in the coding process, being able to describe, classify, and interpret the data from the interview was necessary. I used Microsoft Word’s transcribe feature to transcribe the data. I used Excel to help develop the codes and themes from the transcribed data, and I used MAXQDA software, a qualitative data analysis software, to determine if the same or similar codes and themes emerged. If any discrepant cases were found, I followed-up with the participant to verify and clarify information before proceeding.

Evidence of Trustworthiness

Providing accurate representation of the findings was fundamental to qualitative research as the researcher was involved in every phase of the investigation procedure; research strategizing, interviewing, transcribing the data, data analysis, and preparing the findings of the study (Sanjari et al., 2014). To accurately represent the conclusion of the study there was a need to ensure that trustworthiness or credibility, transferability, dependability, confirmability, inter- and intra-coder reliability, and ethical procedures were followed.

Credibility

One of the critical criteria addressed by researchers is one of internal validity, in which they seek to ensure that their study measures what it is intended to measure (Shenton, 2004). Lincoln and Guba argued that ensuring credibility is one of the most important factors in establishing trustworthiness (Shenton, 2004). Credibility can deal with several issues that must be addressed by the researcher. Previous research by Shenton (2004) showed that some of these can include: the adoption of research methods that are well established both in a qualitative investigation and information science, the development of an early familiarity with the culture before the first data collection begins, random sampling of individuals to serve as informants, and triangulation to name a few. To ensure credibility, I chose an appropriate well-recognized research method; I researched peer-reviewed articles on adult congenital heart disease to develop early familiarity with the participating organization.

Transferability

Shenton (2004) suggested showing transferability would allow comparisons to be made; a provision of background data can be used. Researchers can give suggestions about transferability, but it is the reader's decision whether the findings are transferable to another context. To address transferability, I provided clear and distinct descriptions of my data collection process, the recruitment and characteristics of the participants, and the location of the interviews.

Dependability

Shenton (2004) reported that dependability in qualitative research refers to the reliability or repeatability of the findings within a study. I increased dependability in the study by ensuring that the same interview questions were asked of all participants, and I used direct quotes to provide more insight into their lived experiences.

Confirmability

According to Shenton (2004), confirmability is the qualitative investigator's comparable concern to objectivity, allowing the findings to be linked back to the participant data rather than to an individual researcher's set of assumptions. Koch (2006) reported that "a study's trustworthiness may be established if a reader is

able to audit the events, influences and actions of the researcher". (p. 15). Shenton (2004) acknowledged that audit trails allow an observer to trace the course of the research in a step-by-step process via the decisions that were made and the way the procedures were described.

Inter- and Intra-coder Reliability

Van den Hoonaard (2008) reports that inter- and intra-coder reliability are two processes related to the analysis of written materials. Intercorder reliability involves at least two researchers who code the data independently, and intracoder reliability involves one researcher who codes in a consistent manner. In this study, I used an intercoder reliability test and a colleague with no knowledge of the research method or questions coded the data for reliability in the coding process.

Ethical Procedures

I am a health care professional and member of the Academy of Nutrition and Dietetics. There is a code of ethics that I have voluntarily adopted as a nutrition and dietetics practitioner to ensure that I follow all ethical procedures as a practitioner to the public. To ensure that each of the participant's interests is protected, I obtained approval from the Walden IRB before conducting the study. I requested and obtained IRB approval from Walden University's Institutional Review Board on April 26, 2021 (approval number 04-26-21-0674961). According to Emanuel et al., (2000), "one of the key principles of ethical research is that the benefits and risks of research should be distributed fairly" (para 3), and that participants who devote their time toward engaging in research activities and place themselves at risk deserve to receive some benefits in return (Resnick, 2015). Participants in this study received a $15 Amazon Gift Card. This incentive was for the participant's time and effort, and to increase participation efforts.

In this study, I explored the participant's understanding of their lived experience and how they recognized factors that led to a diagnosis in adulthood. I prepared questions in advance to collect the participants' views to address the research questions of the study. The in-depth interviews provided the opportunity to gather information from individuals with a late diagnosis. This study focused on environmental and social-cultural aspects that led to a late diagnosis of congenital heart defects in adulthood. Due to these facts, one of the primary objectives of this study was to ascertain that the participants in the study were treated with fairness and protected against any discrimination.

I also obtained informed consent to ensure that the research was ethically conducted for each study participant (Groenewald, 2004). The informed consent agreement was developed through the recommended items that were established so that the participants understood the purpose of the study and the obligations of the research study. I provided a copy of the signed consent to the participant and retained a copy for myself. Participation was voluntary, and each participant could request to end the interview at any time. Member-checking techniques were used to address the research questions and the credibility of data collected and aided in probing any unclear responses that were provided by the participants. Probing offered a clear understanding and a way to obtain valuable information about the collected data.

Summary

In Chapter 3, I have presented a detailed explanation of the methodological procedure that was used in this study. I applied a phenomenological design using in-depth interviews to collect data of lived health-related experiences of adults aged 18 and 55 years diagnosed with a congenital heart defect in adulthood. The purpose of this qualitative study was to describe the lived experiences of adults diagnosed with congenital heart defect in adulthood from age 18 and 55 years of age in the United States. This chapter also included the participant's informed consent process, and how they could withdraw from the study. An explanation of ways to ensure trustworthiness, the method of data collection, and the analysis and interpretation of the data were presented in this chapter. The role of the researcher was discussed with emphasis on protecting

human participants in research according to the requirements of the Walden University Institutional Review Board. Chapter 4 will present the results of the study analysis.

Chapter 4: Results

Introduction

The purpose of my study was to describe the lived experiences of individuals diagnosed with a congenital heart defect as an adult between ages 18 and 55 in the United States. For this study, data were collected through interviews with 10 individuals who were diagnosed between ages 29 and 55; these data were then analyzed. This chapter is divided into several sections. In the first sections, I present information regarding the setting, demographics, and data collection. In the following section, I discuss the data analysis. Finally, I discuss study results, evidence of trustworthiness, and a summary. The research questions of this study were:

RQ1: What are the health-related lived experiences of adults leading to a diagnosis of a congenital heart defect in adulthood?

RQ2: In describing their lived experiences after being diagnosed with a congenital heart defect, what are the coping strategies used by the participants to manage their condition?

RQ3: What are the health-related lived experiences of adults following a diagnosis and treatment of a congenital heart defect in adulthood?

Setting

Once a participant showed interest to participate, I confirmed that they met the participation criterion of a diagnosis of a congenital heart defect as an adult versus in childhood. Then, I sent them an email containing the consent to participate. Once participants reviewed the form and consented to participate in the study, I sent a follow-

up email for them to schedule their interview session in a secure encrypted link. I arranged a secure Zoom link for the interview according to the participant's availability. I conducted all interviews in private conference rooms to avoid interruptions and to record the interviews. All interviews lasted between 25 and 45 minutes. Once interviews began, I spent time with the participants to establish rapport and to ensure the participants felt comfortable moving forward. All interviews were recorded via Zoom, saved, and then transcribed via Microsoft Word, and resaved under a new pseudonym.

Demographics

In this section, I focus on the background information of the participants. All participants involved in the study were diagnosed with some form of congenital heart defect between ages 29 and 55. The total number of participants for the study was 10, and all were women from different educational and ethnic backgrounds. I have assigned pseudonyms to all participants to protect their confidentiality (Table 1). Of the 10 participants, two (20%) participants had associate degrees, two (20%) had bachelor's degrees, three (30%) had master's degrees, and three (30%) had a different degree: Ph.D. (10%), PA (10%), or trade (10%). Table 1 shows the age ranges of the participants. The average age was 38.7 years, with a median age of 36.5 years. The average age at diagnosis was 34.3 years with a median age of 31.5 years. More than half (70%) of the participants had children, with a total number of nine children among participants. Many of the participants want children, want more children, or expressed being afraid of the risks due to their heart defect. The average household size was 2.8 people. The ethnic backgrounds of the participants were Caucasian (70%), Cuban American (10%), Slovak

(10%), and Indian (10%). The types of defects detected ranged from less severe to more severe. The less severe forms were atrial septal defects (60%), followed by more serious defects like CCTGA or LTGA (10%), scimitar syndrome (10%), pulmonic valve stenosis (10%), and a large left main coronary artery fistula (10%), as noted in Table 1.

Table 1

The Purposive Sample

Pseudonym	Current age	Age at diagnosis	Race/ethnicity	Type of defect
Brandy	41	32	Caucasian	CCTGA or LTGA
Asa	31	29	Caucasian	Scimitar syndrome
Lauren	37	37	Caucasian	Pulmonic valve stenosis
Kaci	36	31	Slovak	ASD
Augusta	34	30	Caucasian	ASD
Eloise	60	55	Cuban	Large left main coronary artery fistula
Kim	33	33	Caucasian	ASD
Ashley	38	37	Indian	ASD
Shannon	45	30	Caucasian	ASD
Aleah	32	29	Caucasian	ASD

Data Collection

The phenomenological methodology used helped me to identify the lived experiences of the participants through the literature review of the phenomenon and by conducting an observational investigation through data collection and bracketing of my knowledge (van Manen, 1997). I performed this by bracketing my experiences during data collection (van Manen, 1997). The qualitative findings evolved from three kinds of data collection: in-depth, open-ended interviews; direct observation; and written documents (Patton, 2002). A total of 30 participants responded to my flyer seeking participants; 15 out of the 30 met the requirements for participating in the study and 12

consented to participate. All participants scheduled their interview to officially agree to participate in the study, but only 10 kept their appointments. Due to the COVID-19 pandemic, interviews were conducted virtually via Zoom (video conferencing) and email follow ups. Face-to-face interviews were not allowed due to CDC (2020) recommendations for social distancing and avoidance of in-person contact during the COVID-19 pandemic.

Data collection took place from May 12, 2021, to August 8, 2021, for the 10 participants who volunteered to participate in the study. Table 1 describes this purposive sample. The data collection was conducted through semi-structured in-depth interviews to help enhance the participation of the participants to allow them to freely express their lived experiences. The collection of data followed techniques required by a phenomenological inquiry. Specifically, each participant provided audiotaped interviews, recorded observations, and reflexive notes. The reflexive notes recorded my feelings, insights, and thoughts. The final requirements in phenomenology support the research process with transcription of the interviews, coding, analysis, and discussion of the data.

During the data collection process, the identified participants were invited to participate in the study. They were informed that they must consent to participate in the study and agree to a video-recorded interview in which they would be asked questions about their lived experiences and their insights and recollections of what led to their diagnosis of a congenital heart defect. Participants who agreed were sent, via encrypted email, the informed consent form to participate in the study. Once participants consented to participate by responding to the email and confirmed their participation in the study,

the participants were asked to schedule their interview meeting via Zoom. Twelve of the 30 potential participants scheduled their appointments, but only 10 kept their appointments.

On the date of the interview, after formal introduction, I reviewed the purpose of the study and informed the interviewee the meeting would be recorded. Once the participant agreed, the interview began. I used a prepared semi-structured interview with open-ended questions, as noted earlier (see Appendix C). The interview questions were formulated to guide the participants in describing their lived experiences after being diagnosed with a congenital heart defect in adulthood. Participants were allowed to discuss any related comments regarding the topic at the end of the interview process. Once all interviews were completed, they were transcribed over a 1-week period. I emailed all participants a copy of their transcribed interview and asked them to confirm the accuracy of the transcript or clarify their responses. Three participants formally replied confirming they had received their transcript via e-mail, one replied with a verbal telephone call, and one replied via text message indicating they received their e-mailed transcript and that it was accurate. I received a response from a total of five participants. The remaining five participants did not respond.

Throughout the process of interviewing, I kept a reflective journal to take notes of my thoughts and feelings for each participant during the interview for bracketing purposes. The personal log was used to record the reflexive notes of my experiences and reflections on the study. The recorded notes were written during and directly after each interview while it was still fresh in my mind. I recorded the participant’s appearance and

nonverbal cues, reactions to questions, and my impressions of how the interview progressed.

Data Analysis

The interviews were recorded via Zoom meetings and saved for transcription later. Once all interviews were completed, all interviews were transcribed, and participants were provided a pseudonym. Next, transcripts were uploaded using Microsoft Word, Excel, and MAXQDA software, however, I found it difficult to develop the themes from the software. I switched to Excel, which allowed me to better organize the participant data based on each interview question, as well as bracket the data into columns. The analysis of data was conducted after the transcription by reading, reviewing, writing, rewriting and clarification of content by the interviewee. Thus, the data analysis process included phenomenological reflection and phenomenological writing, which are recommended by van Manen (1997), and allowed for the uncovering of the participant's lived experiences.

Phenomenological Reflections

Thematic analysis was conducted to determine the existential themes. The phenomenological reflection along with phenomenological writing begins with the data collection process. Interpretations and descriptions of the findings evolved as the themes emerged from the analysis, and the reflexive notes and shared feelings derived from the participant's responses.

Conducting Thematic Analysis

Van Manen (1997) used three methods in thematic analysis. These include taking a holist approach, discriminatory approach, and sentence-by-sentence analysis. To begin, all transcripts were interpreted in their entirety to gain a holistic understanding of what the participant experienced. Second, using the discriminatory approach, I reviewed all transcripts again and highlighted texts, expressions, and opinions that gave meaning to the phenomenon of study. Lastly, I read the transcripts line-by-line again, this time concentrating on the implications hidden in the text. To understand the expressions of the participants, the interviews were coded under the four lifeworld existential of van Manen (1997) which are lived space (spatiality), lived body (corporeality), lived time (temporality), lived other (relationality) (Krumwiede and Krumwiede, 2012). I recognized important responses from the transcripts of the participants and classified them under thematic headings.

After I completed the thematic analysis of all the participants' transcripts, many themes and categories emerged from the analysis. Subsequently, I analyzed the themes and identified relationships based on my understanding from the literature. The clustering resulted in the creation of themes and subthemes of the lived experiences of women diagnosed with a congenital heart defect as an adult. Next, I interpreted the data by reviewing all transcripts again, now using the themes that evolved as headings and sub-headings and reassembled participants' significant narrations listed under these thematic headings (Table 2). Interpretation of the findings was undertaken by reading, reviewing, writing, rewriting, and interpreting the meanings, then reviewing the literature, and then

reflecting and reassessing the themes to capture the fundamental nature of the experiences of the participants.

Table 2

Themes and Subthemes of Women Diagnosed with a Congenital Heart Defect as an Adult

Themes	Subthemes
Concerns regarding diagnosis of defect	Feeling anxiety
Initial thoughts and feelings during onset of symptoms	Symptoms experienced Reactions to diagnosis Impact of financial cost of treatment
Diagnosis acceptance and coping mechanisms	Strategies used Connecting with others Feeling validated
Postdiagnosis recommendations for self and others	Being aware Being proactive Seeking answers Share experiences and trusting doctors

Identification of Emergent Themes

Once all transcripts were analyzed, I compared all themes and subthemes. During the comparison, I made a note of similar associations, combined them, and compared them to my reflexive notes while maintaining each participant's signature phrases. I created a list of themes through comparison and from interpretations that emerged. They were added to the file that created a list of themes from the comparisons. To help with naming the themes, I captured the essence of the participants' meaning from their stories and how they expressed their feelings. Their thoughts and feelings helped me to name the themes (Table 2) and helped with the emergence of subthemes from those themes, which added truthfulness to aid in a phenomenological depiction of the phenomenon of the study (van Manen, 1997).

Interpreting Lived Experiences

Once the themes had emerged, I began writing with the help of the reflexive journals to create a coordinated view of the participant's lived experiences. As themes emerged, I started summarizing each participant's experience with the help of the personal logs and reflexive notes in Excel. Next, I notated each experience to help me to realize the essence of participants' experiences. After review, it was necessary to preserve the participants' experience by including quotes of their responses. I bracketed the data to include the accurate responses of the participants to help back the interpretation of the data. The themes were described in words with the intent of highlighting the participants' understanding and plans while moving forward. No discrepant cases were identified in the study.

Evidence of Trustworthiness

The study used a qualitative phenomenological research approach to meet the purpose of the research study. Data was collected using a semi-structured interview process that allowed participants to share their lived experiences with a late diagnosis of a congenital heart defect. The validity of the data was established by the participants' perceptions of their confirmed existence of the phenomenon in their lived experience. Several techniques may be necessary to build consistency or trustworthiness in research. The research dictated several techniques to support credibility as follows: dependability, confirmability, transferability, member checking, and triangulation (Shenton, 2004; Koch, 2006).

Dependability is based on clear and accurate documentation of the researcher throughout the research process. The actions required to support credibility are taken by maintaining an audit trail via encrypted email correspondence, and reflexive journaling. To confirm that the sources are authentic or to establish confirmability the data had to be verified for accuracy and observations of the data collected to detect and correct discrepancies. Rosip and Hall (2004) suggested reviewing information from verbal and nonverbal cues to establish the accuracy of data.

Transferability enables the replication of a research study. The actions used to support transferability were taken by recording an audit trail and keeping a reflexive journal. According to Band-Winterstein et al. (2014) reflection and reflexive practice are critical, introspective analytic processes that lead to a deeper understanding of experiences. Reflection entails looking back on experiences to make sense of the past, reflexivity entails reflection on social or intersubjective processes (Berger, 2015). How a researcher shapes how the data was created, and how they reached their findings can be done with reflexive journaling.

To help with accuracy, member checking provides valuable information and allows participants the opportunity to review the information they provided to the researcher. This provides an opportunity to review the transcripts for clarity, identify misquotes, misunderstandings, and misinterpretations. The use of triangulation helps researchers identify distorted or possibly tainted information from participants due to deception, personal or cultural issues, or issues of social acceptability (Carter et al., 2014). The action for triangulation helps with conformability and requires that

researchers compare the same data from multiple sources to establish trustworthiness. Actions taken for triangulation in this study were comparing the same information given amongst interviewees, reflexive notes, and follow-up interviews after participants reviewed the transcripts. Credibility was achieved through documenting interactions with participants during the interviews, analyzing the data repeatedly, and paying attention to the texts, and member checking with the participants.

Results

The purpose of my study was to explore the lived experiences of individuals diagnosed with a congenital heart defect as an adult. Although there is established knowledge on congenital heart defects and it is referred to as congenital heart disease in the literature, it is limited with regards to the lived experiences of individuals who were diagnosed in late adulthood (Bhatt et al., 2015). There were three primary research questions for this study:

RQ1: What are the health-related lived experiences of adults leading to a diagnosis of congenital heart defects in adulthood?

RQ2: In describing their lived experiences after being diagnosed with a congenital heart defect, what are the coping strategies used by the participants to manage their condition?

RQ3: What are the health-related lived experiences of adults following a diagnosis and treatment of a congenital heart defect in adulthood?

Four themes resulted from interviews with the 10 participants in the research study. The participants expressed their experiences which led to the careful evaluation of

the themes that emerged from their stories. This also helped to understand their experiences regarding the phenomenon of the study. The patterns or themes that developed from the thematic analysis were combined or categorized together to give further meaning. The following four themes emerged: (a) concerns regarding diagnosis of defect, (b) initial thoughts and feelings during onset of symptoms, (c) diagnosis acceptance and coping mechanisms, and (d) postdiagnosis recommendations for self and others.

I categorized the themes based on questions developed for the interview guide and common themes brought up by the participants during the interviews to best explore the lived experiences of individuals with a late diagnosis of a congenital heart defect. The codes offered an approach to break down the interviews for interpretation.

Theme 1: Concerns Regarding Diagnosis of Defect

Participants shared the type of defect they were diagnosed with, how they were diagnosed, and at what age they were diagnosed. Participants were diagnosed between the ages of 29 and 55. The types of defects identified from participants included ASD, CCTGA or LTGA, Scimitar syndrome, and pulmonic valve stenosis. All the participants discussed the concerns they had regarding the diagnosis of their defect. Examples include all the following:

Asa said,

> I started having chest pain, shortness of breath, and it's kind of continued, for a couple of months. It started to get worse, and I really attributed it to anxiety at first. And then one night it was just so bad. My husband said you've got to go to

> the ER like something is not right. And so, I went in fully expecting, you know, hey, you're having anxiety. You're going to be sent home with like a Xanax or something and they ended up doing, blood work. My D-Dimer was elevated. I think a couple of the other labs were a little bit off. They ended up doing this CT with contrast and determined that I had this congenital defect called "scimitar syndrome, and it's very rare.

The D-dimer test is a test used to detect if person has a blood disorder. It looks for D-dimer in blood. D-dimer is a small piece of a protein fragment that is made when a blood clot dissolves in your body (Medline Plus, 2021).

Augusta stated:

> In 2017, I was going to make a life decision to join the military and I went to go to my cardiologist to prove my heart murmur wasn't going to affect me, and during the bubble study they found the hole. It was an atrial septal defect.

Ashley shared:

> Until the age of 37, I had no symptoms that I thought were heart related. Last year, I had UTI (urinary tract infection). I had to have antibiotics for that so the moment I had these antibiotics that led to a trigger in my heart rate. I had to go to the ER and that was the time when a lot of tests were done, and that led to my detection of the ASD.

Eloise shared:

> At 42 I had Vitak, which is ventricular tachycardia and ended up in the ER with a heart rate of like 280, and they had to use the paddles. And so, I was put up with a

cardiologist after that, and they put me on some medication and fast forward I started having atrial fibrillation, still with the same cardiologist. They had run echocardiograms and he thought I had a defect, but he thought it was a really benign one that was just causing some agitation to the left ventricle. So, I continued on thinking I just had atrial fib.

Eloise continued:

> The summer before it was diagnosed, I was having a lot of atrial fib and having some syncope, which is some passing out; feeling like I was fainting and things like that. So, my doctor recommended me to get checked again. For some reason he recommended that I get checked by a pediatric cardiologist at Miller Children Hospital.

The doctor recommended this because he felt there was something they were not picking up.

Eloise continues:

> So I went to this guy, and he took all my lab tests. He ran an echo. He did some other tests and he said I need to send you to Cedars Sinai you; I think you have something that's pretty serious. So, I went to Cedars Sinai, and they did a heart MRI and a bunch of other tests, and on the heart MRI I have something called, I had, Large left main coronary artery fistula. So basically, with my heart, my blood was being shunted around the regular path into my pulmonary artery and my circumvent artery, and they were very, very large.

This is a rare condition where one in 14 million people have this diagnosis, and her doctor had only closed one. Eloise became very emotional as she recanted her experience.

Kaci shared:

> It was really a coincidence. I was changing jobs and they required some kind of a medical check. My GP (general practitioner) was just listening with a stethoscope and heard it and sent me for more testing and it was an ASD.

Kim stated:

> The day after Christmas (2020), I started showing COVID like symptoms, and despite four COVID tests and then covid antibody tests. I was negative for all of those and continued having difficulty breathing, and decreased appetite, and my pulmonologist said we should do a CT and then echo. They did a bubble study, and from there I had more diagnostics that eventually gave me my official diagnosis of an ASD.

Lauren shared:

> During my pregnancy in 2019, I had an increase in blood pressure which was attributed to maternal hypertension, but it never really went away after pregnancy. I ended up in a different primary doctor because I was kind of getting the runaround because my blood pressure wasn't consistently high. It was kind of floating around a little bit like it would be normal some days and then other days it would be ridiculously high. I was trying to get my blood pressure back under control, and it was related to a pulmonary stenosis.

Brandy reported:

> In 2007, my feet had been swollen for several months, so I just went to the regular family doctor. I just wanted fluid pills, so I could see my ankles again. During the exam, my doctor heard a murmur when he listened to my heart. They did an X ray, an ultrasound, and TEE. They thought I had a mass in one of my valves Which at the time they thought I had a mass in my, I forget they thought I had a mass in one of my valves. I was referred to a regular cardiologist who determined I had leaking mitral valve regurgitation.

Some participants like Eloise and Shannon recanted very vivid and emotional experiences. Mainly due to their final diagnosis not being identified for several years, they had to endure an array of symptoms in the process ranging from heart palpitations, anxiety, and syncope. Having doctors to listen to their concerns was different for everyone.

Shannon shared:

> I had about five episodes of syncope (of passing out) unexplained. Well, I tried to explain it away. I was told by a doctor that and I'm a "young emotional woman" and I passed out because I'm emotional. Essentially, after five episodes of passing out over about a year maybe a year and a half, a friend of mine told me that it just it did not seem to add up and I need to go to see her internist who then, turned me on to a cardiologist. I felt as though I was not being listened to, so I went to this new primary care physician.

Shannon continued:

> She sent me for an echocardiogram, and like the next evening at 10:30 on her own house phone, she called me saying I had a major defect and it had to be repaired straight away, so that was about Christmas time of 2006. It really was just finding the right doctor who was willing to get to the bottom of all those passing out episodes.

After listening to the participants share their concerns regarding the diagnosis of their defect, it was clear that congenital heart defects affect people in various ways and can be present even when there are no obvious symptoms present. Most of the participants had to have open heart surgery to repair the damaged areas, while others were able to have a non-invasive procedure to correct the defect. The type of defect and severity of it also affected how the individuals reacted to the next steps and treatment efforts.

Theme 2: Initial Thoughts and Feelings During Onset of Symptoms

Each participant was asked to share the symptoms they felt leading up to their diagnosis, and their initial thoughts when they were diagnosed with the defect. All participants shared their feelings during the onset of symptoms, and reactions after they were diagnosed. Some examples include participants like Asa:

Asa reported:

> I started having chest pain, shortness of breath for a couple of months. It started to get worse, and I attributed it to anxiety. After diagnosis I kind of lost my mind and I spiraled really until my surgery. I was very afraid. I've got a daughter and I was so afraid that something was going to happen to me during surgery and then I was going to die and

leave my daughter, and so I kind of lost my mind. I was binge drinking a lot, and I completely stopped caring about what I ate.

Augusta reported, “I had heart palpitations and was short of breath all the time.” After finding out about the defect, she also stated “I was in shock, and I was kind of numb after a while.” Ashley shared that since her diagnosis was discovered as a result of her taking antibiotics for a UTI which caused the abnormal heart rate, prior to that “I used to have palpitations, and they use to worry me.” However, during her diagnosis Ashley was 2 months pregnant, and due to the defect and timing of diagnosis she had to have an abortion in order to have the surgery to repair her heart. She shared, “In February 2021, I had conceived, I went through an induced abortion, and that took a toll on my health.” She had to have the surgery, and four months later she developed COVID after her closure.

Eloise shared, “I had shortness of breath, atrial fibrillation, and ventricular tachycardia a couple of times where my arrhythmia needed to be reversed’. She also shared “I was scared”. Kaci expressed, “I was really very tired”. After finding out about her condition her first thoughts were “OK, now I have a heart disease and what are we going to do about it.”

Kim shared:

> I did have a respiratory illness that really threw me for a loop for about two and a half months. After that I continued to have decreased energy, difficulty breathing and just overall exhaustion that I didn’t have before. I first thought it was COVID.

Lauren stated, “I would have episodes where it felt like my heart was racing and I felt like I was going to pass out”. She also shared that since she had these episodes since she was teenager “I didn’t really think too much of it. I thought it was just, normal.”

Brandy shared:

Initially early on in 2007, it was really just the swollen ankles which I still have today. Now, as the years have gone on, I notice that I have a lot more shortness of breath. I’m a lot more tired, and those symptoms have just kind of progressed over the years. I just felt like I was going to age quicker than I wanted to. Shannon shared, “I had about five episodes of syncope (of passing out) unexplained”. “It was a shock to me.” While others had a very different experience like

Aleah:

> I was 12 weeks pregnant with my second child when I first experienced heart palpitations which is not uncommon in pregnant women. I knew all along something wasn’t right, but when a doctor tells you your symptoms are normal, and you’re fine it’s hard to get answers. I had no symptoms with my first pregnancy. I had extremely high blood pressure in my first pregnancy warranting me to be on bedrest, but nothing to red flag the defect. The only symptom I had was heart palpitations during my second pregnancy. I want to say I was shocked to learn it was related to the defect, but honestly I was just so tired of trying to make people believe there was actually something wrong with me. If I’d listened to my OB doctor, I would have never had it checked out, and I am so thankful I pushed for further investigation.

After participants recanted their initial thoughts and responses to learning about their congenital heart defect diagnosis, their feelings during the onset of symptoms, some also shared the financial impact the incurred with the costs for treatment of their conditions.

Kim shared:

> We are fortunate enough to have really good health insurance. We met our out-of-pocket deductible and that was $6,000. When we got the bill or the EOB (explanation of benefits), just from the hospital for my heart surgery it would have been $94,000.

Brandy shared:

> Yeah, I mean just the average echo now is $7000 for just the echo and ultrasound. Luckily, I've always had decent insurance. I would say just my annual visit to do the Echo and EKG and visit with doctor is$ 9-$10,000. The MRI I had done, was $8-$10,000. It's expensive if you don't have insurance. I can see where you might be put in a real bond.

Shannon shared:

> I've had like 14 months of being out of work for the second heart surgery. I got about 60% of my salary, but for the first I just got disability, which in New York, is like $150 a week. Like I don't really understand how someone could live on that little amount, if I calculated all of it, it's been between $20,000-$30,000. I've lost between that in co-pays. I was on Coumadin. So that was like $50,000 a

week. Just to have the surgery we had to pay $6000 out of pocket plus I was out of work for 10 weeks.

Some participants had insurance through their employer, their spouse's employer, or as part of their local government. All participants shared feelings of uncertainty after their diagnosis. Most of the initial thoughts and feelings centered around trying to understand what was happening to them, their heart, the type of defect they are diagnosed with, how it would affect their day-to-day life, and fear of the unknown; fearing that their symptoms would get worse, fear of not knowing what to expect, how it would change their family dynamics; or not being there for their family or their children. Some were fearful that they would not be able to have more children in the future.

Theme 3: Diagnosis Acceptance and Coping Mechanisms

After hearing about how the participants learned about their diagnosis, the symptoms that led to their diagnosis and their initial thoughts and feelings after diagnosis, I was looking forward to hearing about the coping strategies they used to help manage their condition, their symptoms, and their family dynamics. The most common strategies shared were wanting to connect with others who also had the same condition and feeling validated after previously being told by doctors that nothing was wrong. Some coping strategies shared include:

"I'm exercising that helps a lot. I do some journaling when things get bad, and things get very stressful, so it doesn't freak me out" (Eloise). To connect with others, some examples shared by participants include: "Once I realized everything was fine then I kind of reverted back to a normal way of thinking and acting and coping, but it was a

really rough summer (Asa). “Once I realized everything was fine then I kind of reverted back to a normal way of thinking, acting, and coping” (Asa). Asa talks about how she found herself again after the surgery when she realized that she was going to be okay, but it was a really rough summer. She talked about how she thought about her being there for her daughter and began changing her ways of coping with the news of the surgery. She stopped drinking and went back to her previous ways of coping which included exercising.

Brandy shared, “I stop and take some deep breaths when I feel the heart palpitations or anxiety happening.” Kim shared, “Doing things like finding Facebook groups with other people who have been through it helps me. I like to read through their stories and connect with them.” Kim also adds regarding the type of surgery she had,

> I understand that as far as heart surgery goes, mine was minimal and I’m so appreciative for that. I truly AM, but that doesn’t mean that my experience is any less valid. So, I’m wanting to read as well with hearing other people’s stories I know I’m not alone, so finding Facebook groups is really helpful.

Taking notes and journaling are two coping methods used by Eloise and Kaci. Kaci shared, “I try to make sure to note my questions so that when I can get those answers from the specialist, I can be sure to articulate all of the questions that I have and all of the concerns that I have going forward.” Kaci also shared,

> For me, it was really helpful of the group on Facebook group, where I also saw your so your post, because it really was helpful for me to read and talk to people who have the same condition like me.

To connect with others was one of the most common strategies shared, for example Augusta shared “I’m part of a support group on Facebook.” Kim also shared that “doing things like finding Facebook groups with other people who have been through it.” Lauren shared “I try to make sure to make notes of my questions so that when I talk to the specialist, I can be sure to articulate all of the questions that I have and all of the concerns that I have going forward.”

Shannon shared, “We have an adult congenital heart defect support group run out of Columbia Presbyterian. I went to several of their meetings, and that was helpful to sort of gain an understanding of other people through talking about it.” Shannon shared that since she works on a cardiac unit “I had a lot of support from talking to the doctors and the nurses. I also see a therapist now.”

Eloise also admitted to seeing a therapist to help her to manage the PTSD that she has experienced from the two major surgeries she’s had as a result to her defect, surviving the earthquake that occurred while she was in the hospital recovering from one of the surgeries, and from catching COVID. She reports, “I see a therapist when I need help.” Some of the participants also voiced that humid or hot weather plays a role in their heart palpitations. Aleah shared, “I avoid being outside in hot weather mainly. When the palpitations would hit me, I would just try to remain calm until they passed.”

Other strategies included feeling validated that they have an answer to attach to what they were feeling because they knew something was wrong but felt like no one believed them. A few examples include:

"I was told by a doctor that I'm a quote "young emotional woman" and I passed out because I'm emotional" (Shannon).

Aleah recalls:

> I KNEW all along something wasn't right, but when a DOCTOR tells you your symptoms are normal, and you're fine it's hard to get answers. I want to say I was shocked, but honestly I was just so tired of trying to make people believe there was actually something wrong with me. If I'd listened to my OB doctor, I'd never had it checked out and in so thankful I pushed for further investigation.

Theme 4: Postdiagnosis Recommendations for Self and Others

At the conclusion of all interviews, I asked each participant if there was anything they would like for people to know about their condition, and if they would like to share additional information regarding their experience that would be helpful for the study. Participants shared post diagnosis recommendations for themselves and for others who may be experiencing some of the same symptoms and problems. Common responses included being aware of what is happening, being proactive when you feel something is wrong, continuing to seek answers until someone listens to you, and sharing your experiences with others.

Ashley shared "I would like for more people to be aware that you know you can totally be walking around and then one day to start developing symptoms." Ashley stated, "You should get yourself checked for your heart before things get out of control." Eloise shared, "I think asking questions when you don't feel well, don't put it underneath the rug. Keep asking questions." Kim shared, "People need to know that your experience is

no less valuable or valid than someone else's experience. Just because it's not as serious. Experiences are experiences. They're all going to be different." Lauren also shares the same sentiment when she shares, "Tell people about the condition, because most people would have never assumed that I had a defect given the fact that I've lived a completely normal life."

Brandy adds:

> If you have swollen extremities or you have a lot of shortness of breath Just go get it looked at because it may be nothing or maybe something. Like I couldn't let mine go for years and never knew even still today, I guess I could have but. You know, I'm glad I think people want to just put off and put off because they don't want to go to the doctor. No, be proactive. I mean it's better to catch it early and start treating it then let it go on years and years and then you find out your heart is turned into crap. Now you need surgery.

Lauren shared:

> Just telling people about the condition because most people would have never assumed given the fact that I've lived a completely normal life, so just like sharing the news that like hey, I have this heart condition that might require treatment, I don't know what that looks like. I don't know what you know what that means.

Shannon shared, "I think the importance of a screening for adults not only like their cholesterol levels, but also the heart structurally to be sure, you know, everything is OK with the heart." Aleah adds "People need to realize that congenital heart defects

being found in adults is common. More common than anyone realizes and if you remotely think something is wrong don't stop until you find a doctor who will listen."

Summary

During the interviews and analysis of audio-recordings, transcriptions, and handwritten notes, I was able to further explore the lived experiences of 10 women diagnosed with a congenital heart defect as an adult. Table 1 provides insight to the purposive sample, and Table 2 highlights the emergent themes and subthemes for each of the research questions. The four themes that were identified were the concerns regarding diagnosis of defect, initial thoughts, and feelings during onset of symptoms, diagnosis acceptance and coping mechanisms, and post diagnosis recommendations for self and others. Several factors led to the diagnosis of congenital heart defects in late adulthood for the 10 women who participated in this study. I presented information in this chapter that detailed participant recruitment procedures, data collection, storage of data, data analysis, evidence of trustworthiness, and the results of the study. The data collected from the semi-structured interviews revealed four emerging themes from interviews: 1) concerns regarding diagnosis of defect 2) initial thoughts and feelings during onset of symptoms 3) diagnosis acceptance and coping mechanisms, and 4) post diagnosis recommendations for self and others. Each theme resulted from the data collected during the interviews that produced a rich description from the 10 participants who were diagnosed with various forms of congenital heart defects in late adulthood, which led to the summary of my research questions.

Summary of Research Question 1

RQ1: What are the health-related lived experiences of adults leading to a diagnosis of congenital heart defects in adulthood? This research question was addressed by all four themes. The themes captured the recollections of their lived experiences, concerns regarding diagnosis of their defect, their initial thoughts, and feelings during onset of symptoms, diagnosis acceptance and coping mechanisms, and post diagnosis recommendations for self and others. Participants wanted to share in relation to the current effects the condition had on their lives.

Summary of Research Question 2

RQ2: In describing their lived experiences after being diagnosed with a congenital heart defect, what are the coping strategies used by the participants to manage their condition? Several subthemes emerged from the themes in this research question and are addressed by theme three. The participants had a range of experiences when learning how to live with their condition after diagnosis. All participants had different experiences of adjusting after diagnosis. Many expressed feelings of anxiety, fear of the unknown, relief of knowing why they had been feeling the way they had for months or maybe even years. One lost her way and began engaging in unhealthful behaviors, and two wished their doctors had listened to their feelings about their health before their diagnosis. Two participants expressed that they did not have time to cope after diagnosis due to the need to have emergency surgeries. All participants expressed that connecting with others was an effective way to cope with their condition. Support from family, friends, doctors, therapy, and social media groups helped them to cope after diagnosis. Others expressed

engaging in physical activity and changing their eating habits helped them to stay focus and not become too stressed. If they did feel symptoms arise, many participants shared how they would take deep breaths to calm down until the symptoms subsided.

Summary of Research Question 3

RQ3: What are the health-related lived experiences of adults following a diagnosis of congenital heart defect in adulthood and treatment? This question was answered specifically by theme two, initial thoughts and feelings during onset of symptomology, because it portrayed participants' recollections of how they felt after diagnosis or post-surgery. If they did not have surgery some were required to take medications to manage their condition. Some participants expressed that they would have to be on certain medications like aspirin and blood thinners the rest of their lives or would have to continue to have ablations the rest of their lives.

I learned from the interviews that individuals diagnosed with a congenital heart defect in late adulthood experienced various levels of emotions from the start of symptoms until diagnosed. In some cases, symptoms were controlled while others continue to struggle with the notion of knowing they will need to continuously have surgeries or procedures done on their heart. The fear of the treatment no longer working remains for some participants, and not knowing if they will be able to have children in the future. This creates uncertainty for some in relation to how they live their lives moving forward and how to find ways to cope. With controlled symptoms, participants shared fear or uncertainty of the treatment no longer working, and the fear that their illness could worsen. All participants were impacted by the effects of the diagnosis at

various levels. It impacted their families, their ability to work, and for some has been a huge financial strain.

After accepting their diagnosis, developing coping mechanisms were shared including being aware of what's happening with your body, being proactive, seeking help, and sharing the experiences with others. Many participants engaged in physical activity, began eating healthier, sought information from the internet, and reached out to join online support groups or participated in therapy sessions. Other participants expressed having a hard time trusting doctors, because the doctors told them nothing was wrong, even when they tried to explain that there was something "off" with them. The additional information shared by participants that included their post diagnosis recommendations for themselves and others was important to share to bring awareness for others who may not be diagnosed with a congenital heart defect. Suggestions are for healthcare providers to treat each patient individually based on their needs, improve the plan of care by listening to the patient's concerns more, and following up with the patient more until a diagnosis has been reached.

The information gained from the interviews has provided insight to understanding the lived experiences of the individuals diagnosed with a congenital heart defect as an adult and how they found out about their defect, the symptoms they felt leading to the diagnosis, accepting the diagnosis, and developing coping mechanisms to manage their condition, as well as post diagnosis recommendations they believe to be beneficial for themselves and for others. The interpretation of the findings will be presented in chapter 5. Chapter 5 will answer the research questions as it relates to the essence of the

experiences of the participants. The chapter will also discuss the results of the study within its theoretical framework. I will report the limitations of the study, study implications, the impact on social change, and recommendations based on the study results.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative study was to explore lived experiences of individuals diagnosed with a heart defect as an adult between ages 18 and 55. The prevalence rate is expected to continue to grow exponentially as more patients survive early interventions and adult patients with congenital heart defect live longer (Gilboa, 2016). Although there is an expansive amount of literature on congenital heart defects and their reference to congenital heart disease (Bhatt, 2015), the literature is limited on the lived experiences in adulthood, thus exposing a gap in the literature. The gap in knowledge is a result of not enough health education material to educate the public on signs and symptoms that could be related to an undiagnosed heart defect. The lived experiences of individuals diagnosed in late adulthood could create an opportunity to develop healthcare information to bring awareness to this growing health concern. The knowledge of the lived experiences and viewpoints of individuals willing to share their experiences is critical for developing effective education strategies or methods that would help individuals and families to decide to go in for routine medical checkups and screenings for heart defects.

There is minimal data and no database specific to adult congenital heart defects in the United States to provide systematically collected population prevalence data (Bhatt, 2015). Thus, more research is needed beyond this study assessing the lived experiences of individuals diagnosed in adulthood. A total of four themes emerged from the participant interviews and subthemes were developed. The findings revealed that

participants experienced some of the same symptoms, shared similar experiences and treatment parameters, and shared some of the same goals after diagnosis. This chapter contains the interpretation of the findings, discussion of the limitations of the study, recommendations for future research, and discussion of the implications of this study. In conducting the study, I sought to answer the following research questions:

RQ1: What are the health-related lived experiences of adults leading to a diagnosis of congenital heart defects in adulthood?

RQ2: In describing their lived experiences after being diagnosed with a congenital heart defect, what are the coping strategies used by the participants to manage their condition?

RQ3: What are the health-related lived experiences of adults following a diagnosis and treatment of congenital heart defect in adulthood?

Interpretation of the Findings

The following themes emerged from the analysis of the data from the individuals diagnosed with a congenital heart defect as an adult: (a) concerns leading to diagnosis, (b) initial thoughts and feelings during onset of symptomology, (c) diagnosis acceptance and coping mechanisms, and (d) postdiagnosis recommendations for self and others. There were several emerging subthemes from the interviews: (a) feeling anxiety, (b) symptoms experienced, (c) reactions to diagnosis, (d) impact of financial cost of treatment, (e) strategies used, (f) connecting with others, (g) feeling validated, (h) being aware, (i) being proactive, (j) seeking answers, and (k) sharing experiences. I will interpret the findings using the literature review as the lens of the examination.

Theme 1: Concerns Regarding Diagnosis of Defect

Participants expressed the events that led to their diagnosis, which led to defining what type of heart defect they were living with their entire lives. After diagnosis, they expressed feelings of anxiety and stress not only to them but to their loved ones as well. Many of the participants expressed fears about finding out about their condition later in life, the effect it had on their family, and how they are coping. These uncertainties can affect a person's QoL. According to Moons et al. (2005), "QoL was defined as the degree of overall life satisfaction that is positively or negatively influenced by individuals' perception of certain aspects of life important to them, including matters both related and unrelated to health" (pp. 941).

The first theme that emerged from the interview data showcased participants' beliefs on what led to their diagnosis and their concerns regarding the diagnosis, the type of congenital heart defects, and how it would impact their lives. One subtheme emerged from the first theme (feeling anxiety) and captured what the participants experienced that led to their diagnosis and the concerns they felt after learning about the type of defect they had. This theme shed light on the types of defects participants were diagnosed with in relation to severity of the defect and required treatments. Their perception of their condition and current day-to-day activities were essential to how they moved forward with their new diagnosis.

Theme 2: Initial Thoughts and Feelings During Onset of Symptomology

Participants disclosed the symptoms that led to their diagnosis and their initial thoughts and feelings during the onset of their symptoms. Many of the participants shared

some of the same symptoms: heart palpitations, anxiety, swelling in the extremities, fear, being in shock, fatigue, shortness of breath, and lightheadedness. Public health focuses on the health of the population rather than the health of an individual; thus, public health efforts are typically prevention activities targeting a population to reduce morbidity and mortality on a population level (Oster et al., 2013). Participants searched for answers to relieve their anxieties, to reach a sense of comfort, and to provide a sense of solidity through Facebook groups, therapy sessions, and family support. Participants indicated that having a better understanding of their condition helped them to make better decisions on how to manage and live with their condition, plan for future treatments and surgeries, and share with others information about their condition.

Theme 3: Diagnosis Acceptance and Coping Mechanisms

The participants shared their lived experiences and how they managed their condition after surgery, the coping mechanisms they used, the lifestyle changes they had to make, and their connections with their doctors. The most common strategies shared were connecting with others and feeling validated after previously being told by doctors that nothing was wrong. Some participants had a gut feeling something was wrong and they could not get answers to their questions. Some encountered many of the same conditions for months or maybe even years before their final diagnosis revealed a heart defect. Others felt as if they were healthy, had no problems that they assumed would be severe until the diagnosis was made. Some conditions were less severe yet required a noninvasive procedure or immediate surgery. Others were severe and required open heart surgery and many follow-up procedures. Participants depended on a connection with their

healthcare providers to feel secure in their treatment parameters and to feel as if their feelings regarding their condition were addressed. A long lapse in medical care may result in adverse outcomes because adult congenital heart defects must be monitored frequently for the development of complications from structural heart defects (Williams, 2015). Their acceptance of their diagnosis and feeling secure in the treatment plans helped the participants to develop a coping mechanism that would address the fears and uncertainties that felt related to their specific heart defect.

Theme 4: Postdiagnosis Recommendations for Self and Others

Feeling comforted and having support after diagnosis was important to all participants. All participants realized the value of their lives and being present for their loved ones. They learned to live with the effects of their diagnosis and wanted to share additional information with others who may have been diagnosed with heart defects or others who may also be undiagnosed. Each participant's story, diagnosis, and treatment parameters create an experience in time. As participants described the intense, life-altering experiences, their waiting periods for surgery, and healing and recovery, they needed support from all around. Because congenital heart defects are associated with lifelong comorbidity and health services use, there has been a need for repeated surgical interventions (Ionescu-Ittu, 2010). Participants need support from their spouses, children, nursing staff, doctor, and other healthcare professionals to recover and effectively manage their condition. Over time, participants developed a stronger need to have a positive attitude toward their condition and an appreciation for the lives of those closest to them. The experience caused the participants to prioritize the people and things most

important to them to feel comforted in the presence of others, a connection with individuals in Facebook groups, and a better connection with their healthcare providers.

The participants provided postdiagnosis recommendations and stressed the need to be more aware of what is happening with their bodies and being more proactive when they feel things are off. Ignoring the warning signs and the symptoms could lead to the condition worsening. They stressed the importance of seeking answers when there are continuous feelings that something is not right or if symptoms continue to happen without further explanation. Participants also acknowledged the importance to share their experience with others. All participants expressed how being a part of social support groups really helped them to feel confident in living with their condition, finding the help they needed, and obtaining more information about their specific heart condition.

Comparison to the Health Belief Model

I used the HBM as the theoretical framework to guide the data collection and analysis process. The HBM was also used to explain why people, especially those in high-risk groups, fail to participate in programs designed to detect and prevent disease (Boyle, 2017). The model has three components that examine the perception of a threat to health, expectations of outcomes as it relates to a specific behavior and self-efficacy or the conviction that someone can execute a behavior successfully to achieve the required outcome (Boyle, 2017). For this study, the use of HBM provided an understanding of how health concerns can be related to prevention, like improving screenings performed at birth, or bringing awareness to symptoms that alert individuals that they need to go in for a check-up (Resnick and Siegel, 2013). This model is the most appropriate framework to

use because it provides an understanding of how individuals assess their health, and it focuses on their intentions to perform certain behaviors to improve their health. The HBM is more descriptive than explanatory and does not suggest a strategy for changing health-related actions (LaMorte, 2018). The HBM is generally applied to settings that will motivate people to take charge of their lives and engage in positive health actions and avoid the negative health consequences as a critical motivational strategy which was illustrated in the participant's responses.

Limitations of the Study

The participants of the study included 10 individuals diagnosed with a congenital heart defect between the ages of 18 and 55. I used a systematic sampling method that supported the selection of participants who volunteered for the study and met the inclusion criteria. In addition, I employed member checking when collecting data, developed semi-structured interviews with predetermined questions, and maintained an accurate audit trail and documentation throughout the study. As I was diagnosed with a congenital heart defect as an adult, the research study was susceptive to investigator bias. I used the process of bracketing to reduce researcher bias. Van Mahen (1990) states that "a phenomenological study aims to present the current understanding of a phenomenon to increase knowledge, inspire additional investigation, support individual consideration, and present insights for other research." (p. 135).

Recommendations

In this study I aimed to educate the public on this growing public health concern by examining the lived experiences of individuals diagnosed in adulthood, using a

phenomenological approach. Data derived from this study may be used to develop educational material to bring awareness to the general public, public health professionals, physicians, schools, and individuals with congenital heart defects through various platforms. Information obtained from lived experiences could one day be made available to the public through educational brochures, and flyers. A hermeneutic interpretative phenomenological approach was used to uncover the phenomena. This approach was a means to seek, explore and understand the individual experiences of existence and expose the underlying extracts related to this understanding (van Manen, 1990). I will present the recommendations of the study under three headings: health care practices and diagnostic testing, congenital heart defect education material, and congenital heart defect research.

Health Care Practices and Diagnostic Testing

It is necessary to develop the knowledge and skill of health care professionals to facilitate the efficient translation of evidence to patient care. The clinical setting must have procedures and protocols that could help identify, validate, and associate best practices through effective screenings based on patient concerns regarding their health. A patient's concerns regarding their health and well-being must be heard and validated by all health care professionals. Further testing is also important to capture the defects and to provide adequate treatment of the condition. Echocardiography in older adults with congenital heart defect should be interpreted by physicians with expertise in both congenital and acquired heart disease. They should take full advantage of all specialized techniques, and technologies available for adults, and they should include both the

anatomic diagnosis and quantitative assessment of chambers, valves, and great vessels in a format accessible to physicians caring for adults (Bhatt, 2015).

Congenital Heart Defect Education

There is a need to provide health education material that brings awareness to the signs and symptoms that individuals may experience that could indicate a need for further health screenings in adulthood. Health educators can assist with information that health care professionals would be able to share with patients and their families due to the lived experiences explained by individuals of this study. This information will allow healthcare professionals to provide necessary services to patients, and to encourage rapid diagnosis and treatment of underlying conditions. Obtaining participants' lived experiences in this study is one way to start gathering information that pertains to conditions that lead to their diagnosis. Nevertheless, a focus on this topic indicates a need for further research.

Congenital Heart Defect Research

There is a scarcity of research studies conducted on the topic of congenital heart defect diagnosis in adulthood. Continuous examination of the topic through smaller research studies in clinical settings could help with the development of health education materials and other research-related activities. Information gained from this study and follow-up studies could help with initiating a database in the United States to track congenital heart defect diagnosis in adulthood.

Implications

The findings of the study are indicative of various implications for further research, health education, and advances in clinical practice. The results of this study are

important to bring awareness to this growing public health concern. The knowledge regarding congenital heart diagnosis as an adult was limited including the awareness of theories of evidence translation, frameworks, tools, and steps in translation. Educational programs that focus on evidence-based knowledge and skill development are necessary to promote social change and should be tested through further research studies.

Conclusions

My aim in this phenomenological study was to explore the perceptions and lived experiences of individuals diagnosed with a congenital heart defect as an adult between the ages of 18-55. This study was an attempt to reveal and interpret the nature of the experiences the participants underwent before and after diagnosis, and the coping strategies they utilized to manage their condition. The positive social change implication of this study is the recommendation to leaders in health care, educators, and researchers to recognize the need to create health education material to bring awareness to this growing population. Organizations must include current theories and frameworks to cultivate a culture and foundation to provide appropriate patient care for this population.

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Appendix A: Recruitment Flyer

PAID RESEARCH PARTICIPATION

- Would you like to earn a $15 Amazon Gift Card by participating in a research study on congenital heart defects?
- There is a need to improve the quality of health for congenital heart defects diagnosed in adulthood. Many studies and statistics have shown congenital heart defects, also called “congenital heart disease” as a growing population amongst adults. This study is seeking 10-15 adults between the ages of 18 -55 years old, who were diagnosed with a congenital heart defect as an adult, not at birth, and who are willing to participate in an interview session to share their experiences related to their diagnosis.
- An appointment will be scheduled with the first 10-15 participants who respond to the flyer to fill out the Consent Form; however, if the individual does not meet the prescreening criteria, he/she will not be scheduled for an appointment. Qualified participants will be required to complete a survey questionnaire that may take approximately 5 minutes to complete and participate in the interview session, which will last 45-60 minutes at a scheduled time via video conference, email, telephone or face-to-face. If you are interested and would like further information, please contact Jacklyn Sanders at 281-770-4407 or Jacklyn.sanders@waldenu.edu.

Appendix B: Interview Protocol

Interview Protocol for Perceived Coping Strategies Contributing to Congenital Heart Defect Diagnosis in Adulthood

Interviewee: _____

Location: _____

Date: _____ Begin Time: _____ End Time: _____

Part I

This phenomenological study will assess and understand the variables of the lived experiences leading to the diagnosis of a congenital heart defect and the copying strategies utilized after diagnosis. Secondly, study participants will explain in detail their personal experiences as it relates to their living conditions, financial status, and way of thinking that together may have influenced or contributed to their CHD diagnosis.

Part II. Questions:

Cultural Beliefs and Values

1) Could you give me a brief history of what led to the diagnosis of a congenital heart defect?
2) What were your first thoughts and reactions when you began to experience symptoms? What were the symptoms?
3) What are your thoughts about your future health and wellbeing?
4) How does your CHD affect your everyday life now?
5) What are strategies that you use to work through them?
   What do you think people need to know about your condition?